Autism: The Potential Within

The PLAY Project Approach
To Helping Young Children with Autism
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by
Richard Solomon MD
Dedications

To my wife Linda, my love of 44 years, and to my amazing children Onna and Gabe without whose love and encouragement I could not have pursued the mission of serving the children.

To the families and children who have taught me so much about the human spirit and the potential within each one of us.
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Foreword
by
Lisa Grettko

When I was a senior in high school in 1972 I took a course in Early Childhood Development and, in class, we watched an old black-and-white movie that depicted a mother trying to feed her autistic son. The child in the movie was a beautiful three year old, but he did not speak and he refused to look at his mother (much less eat the food she offered.) The movie’s narrator explained that the child was autistic and concluded that he would require institutionalization.

In 1994 when I was pregnant with our first child, I visited a local bookstore and flipped through a newly published child care book which described (in alphabetical order) the ailments that can afflict children. As I looked through the illnesses that began with the letter “A”, I noticed that there had been no development in the treatment of autism because, like the movie I had seen in 1972, this newly-published book stated that autistic children do not recover and require institutionalization. I counted our blessings when our first child hit each developmental milestone on time.

Our second child was born in 1998 and his first symptoms surfaced when he was very young. While feeding him a bottle one night, I realized that he wasn’t looking at me. Instead, while in my left arm he was focused on the horizontal blinds to my right. So, I put down the bottle to “switch” him to my right arm. As his face came close to mine in this process, he averted his eyes. In this new position he focused on the light in the ceiling, because the horizontal blinds were now behind his head. After a few minutes, I put down the bottle and switched him into my left arm once again and, as before, he averted his eyes. In that moment, I realized that our son’s gaze aversion was the same as that little boy’s in the movie I had seen in 1972.

Our wonderful pediatrician was at a loss as to how to help our young son improve. He mentioned that speech therapy, occupational therapy and physical therapy might help, but questioned their efficacy because our son was still too young to sit still or focus his attention for a significant length of time. A nearby therapy clinic tested him and recommended that we immediately start speech therapy, occupational therapy, physical therapy and sensory integrative therapy. After nine months of intensive therapies, our son couldn’t utter a word and hadn’t made much progress. The therapy clinic suggested that we make an appointment with Dr. Solomon—an autism specialist.

I met Dr. Solomon in February, 2001, when our son was a beautiful 2½ year old with bright red curls and dark eyes that darted around the room and never made contact with my own. He was vacant and aloof. After observing our son intently, Dr. Solomon confirmed that he was, indeed, on the autism spectrum. Although my husband and I had strongly suspected autism for more than two years by that point, my heart stopped when Dr. Solomon confirmed our worst fears. In the next breath, however, Dr. Solomon offered words of encouragement when he said that our child was relatively easy to engage and was a good candidate for the PLAY Project.

Dr. Solomon’s explanation of the PLAY Project was like a beacon of hope in a very dark and scary wilderness. Unlike those books that offered no hope whatsoever, Dr. Solomon unfolded a veritable roadmap of how to help our child. When he told me that the PLAY Project required twenty hours of play-based therapy every week, out of sheer despair I replied that I was prepared to do it 24 hours a day, 7 days a week if it would help our child make progress!
Christy Pratt was our PLAY Project Consultant and her first monthly home visit was in May, 2001. At that point, our son's chronological age was 2 years, 8 months, but (years later) Christy told me that his functional developmental level was that of a nine month old. Each month she recorded video of my husband and me playing with our son and she took the video back to Dr. Solomon, who reviewed the video and called (or e-mailed) with explicit instructions on how we should play with our child in the next month to promote his progress to the next developmental level.

We were the nineteenth family in the PLAY Project, which was then a new program at the University of Michigan. Although it was considered an experimental therapy in 2001, the play-based nature of the therapies made sense to my husband and me. At first, it was difficult to figure out how to “follow the child’s lead” in order to implement the play strategies that Dr. Solomon recommended. Once we got the hang of it, however, we found the PLAY Project strategies to be creative, liberating, and fun! Often, my husband and I would craft new ways to implement the PLAY Project therapies. For example, I created the “Happy/Sad Face Game” to help our son communicate his emotions before he could speak. (Fear was, by far, his most frequent emotion at that time.) My husband created the “Swing While Naming his Body Parts Game” to help extend our son’s engagement time while teaching him the parts of his body.

Our child made progress and, after several months in the PLAY Project, he finally spoke a word—“Ahkee”. Although nobody knew what it meant at the time, our son was suddenly very expressive in his frequent (almost perseverative) use of this single word. He began speaking in earnest a year later, just before his fourth birthday. Shortly thereafter, when I asked him what “Ahkee” meant, he grabbed my face in his little hands, looked me in the eyes and joyfully replied “Mommy! Ahkee is Mommy!”

Our family participated in the PLAY Project for three years. Dr. Solomon’s monthly instructions to us after he reviewed our son’s video clips were insightful, enthusiastic, and reassuring; he always seemed to know what was going on in our child’s mind, and what stage of his development was coming next.

Although the PLAY Project is designed for young children, as our son grew older we often used the “template” of PLAY Project strategies to teach many of the things that typical children seem to know instinctively or learn naturally, such as imagination, flexibility, focus, empathy, and humor. Today, our son is seventeen and he speaks and interacts like a typical junior in high school. His grades are pretty good, and he is a happy, well-adjusted, and remarkably empathetic young man, with a wonderful sense of humor.

The parents of autistic youngsters experience sheer panic when they realize the enormity of their child’s diagnosis: the sting of hearing the word “autism” in connection with your child never goes away. However, the PLAY Project is a beacon of hope in a wilderness of despair for the families of autistic children, and for the children themselves. I shudder to think what would have become of our son and the rest of our family without Dr. Solomon and the PLAY Project.

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Acknowledgements

My office visits with thousands of families and children with autism spectrum disorders over the last 25 years gave me the motivation to put their lives and experiences into book form. So first I acknowledge ‘my’ families and ‘my’ children who have taught me so much about the human spirit, the potential within each one of us to grieve and cope, to be overwhelmed and still overcome, to grow and develop and laugh and have fun together and love despite the challenges.

Next, I owe a debt of gratitude to Stanley Greenspan MD, Serena Weider PhD, and Ricki Robinson MD, MPH, who have been my mentors and colleagues and inspired me to offer a developmental, individualized, and relationship-based (DIR) approach to my families and children with ASD. For decades now, as a society, we have been focusing on how to change the behavior of children with ASD from the ‘outside in’ using the ABA (Applied Behavior Analysis), Skinnerian, behaviorist approaches which are the most commonly offered services in the U.S. Though Stanley died in 2010 his foundational work on the importance of the child’s feeling life and functional emotional development is continuing to enter the mainstream. Serena Weider drew the map that all of us now follow to help children with ASD become more symbolic and imaginative. And Ricki Robinson was my model of what it means to be the complete pediatrician for children with autism spectrum disorders. Stanley, Serena, and Ricki taught me to stand for an approach that honors the child’s unique potential to grow from within. I could not have written this book without their guidance and inspiration.

Though the story and characters in this book are drawn from my clinical experience, the PLAY Project approach, which the Grant family implements as Jacob’s intensive intervention, is now an evidence-based model founded on rigorous research*. Jim Lyddy introduced me to the possibility of getting a federal research grant back in 2007. Perri Zimmerman, research manager extraordinaire, successfully managed all the details of the NIH grant from 2009-2012. Ron Maio DO, helped me prepare the research manuscript and gave fundamental advice on methodology. My research colleagues at Michigan State University’s Community Evaluation and Research Collaborative, Laurie Van Egeren PhD, and Melissa Quon-Huber PhD, rigorously evaluated the program, and finally my friend and colleague Jerry Mahoney PhD, Professor at the Mandel School of Applied Social Sciences at Case Western Reserve in Ohio, not only allowed us to use his outcome measures, but gave astute advice and guidance throughout the research process. Without good research, even wonderful clinical models, are often overlooked in this era of evidence-based practices.

My beloved wife of 44 years, Linda, supported me and gave me the space to write this book for hours on end and over long weekend days and through many months. She read the chapters and gave me her honest opinion as only a wife can and she made the book better. My darling daughter and work colleague, Onna, was a constant source of support, encouragement, and also critical reviews and suggestions. I am the father of two adult children and grandfather of four, all of whom live in Ann Arbor where I live and have my practice. I am so grateful to all of them for understanding that ‘papa’ has been busy writing his book and will play with them a lot more when he’s done.

Finally, a number of others have really come through for me to help bring this book to fruition. A big thanks to Frank Murphy who did the final editing, Nick Vetter who helped with a number of the
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Autism: The Potential Within
The PLAY Project Approach to Helping Young Children with Autism
Introduction & Overview

Children with autism want to keep the world the same. This tendency toward repetition and isolation too often deprives them of the opportunity to develop to their full potential. Through intensive early intervention, however, many children with autism can gain the language and social skills necessary to become highly functional in society if their families and the professionals who work with them know how to find the potential within each child.

Over the last twenty-five years, as a developmental and behavioral pediatrician, I have followed thousands of young (ages 14 months until about six years old) and older children with Autism Spectrum Disorders (ASD) and learned from them the developmental progression that would help them get better. Many of these children made dramatic gains in their development and most made substantial progress when they received appropriate, individualized, and relationship-based interventions early in life. As a pediatrician, I am trained to listen closely to parents' chief complaints and give guidance that is scientifically sound, professionally caring, and, above all, practical. In this book, I am giving professional advice with the highest possible personal standard: what I would do for my child if he or she had autism.

During office visits, I frequently record the discussions I have with families. This book summarizes those discussions in a series of 'office visits' with the Grant family (a composite of many families) whose son, Jacob (a composite of many children with autism), is initially diagnosed with autism. The book follows Jacob and his family along the path from the time of diagnosis until Jacob goes to kindergarten. Along the way, I collaborate with the Grant family on the most practical ways to help Jacob grow developmentally, emotionally, and socially. It is my hope that any family will be able to identify with Jacob and his family and discover their place on 'the path' that will lead them to the next level of their child's potential.

- **In the first section: What to Do First?** I address everything families need to consider when they first get the diagnosis, including essential information on ASDs, the most valuable websites and resources, and the best types of interventions.
- **In the second section: The PLAY Project Approach** I present my play-based, developmental approach to ASD. Every parent wants to have a better relationship with his or her child. The PLAY Project is a parent-implemented, home-based model that promotes playful interactions between the parents and their child in a way that helps the child improve his or her functional development (See Glossary) and gives parents the joy of being their child's best play partner. I follow Jacob from the beginning of intensive intervention until he goes to school.
- **In the third section: Daily Hassles** I discuss methods for using 'misbehavior' as a way of helping children with autism mature and learn appropriate behavior and social skills. I present 'parenting protocols' that will help parents know what to do for the most common difficult situations (i.e., tantrums in public, sibling squabbles, toilet training delays, picky eating, etc.). I also discuss whether medication would be helpful for Jacob's behavioral and emotional difficulties.
- **At the end of each ‘visit’** I provide a handy summary of key points, a brief list of good resources & websites, and a preview of the coming chapter.
From my experience, I have learned that parents want three fundamental things for their child: First, they want to have a close, loving, and satisfying relationship with their child. Second, they desperately want their child to make progress in development, language, behavior, and social skills so that, third, their child can survive and thrive in a difficult world. I believe that, in combination with other therapies and school, playful interaction is the key to helping parents get what they want for themselves and their child with autism, and it is also what all children need—a social foundation built around what they love. What I tell parents all the time is: “When you do what the child loves, the child will love being with you.” This love of people leads to social engagement, and it is EQ (emotional intelligence), not IQ alone, that is the better predictor of success in this difficult world especially for children with ASD.

The other major lesson I’ve learned is that families need hope. I have seen so many children get better from their autism that I can offer real hope. Hope is what holds your hand through grief and allows you to come to acceptance. Acceptance is what allows you to see your child for exactly who they are. And, as I often say to parents, “When you accept your child for exactly who they are, that is the best and fastest way to help them reach their full potential!”

To sum up: Most children with ASD, if given early, intensive intervention have the potential to become quite functional in society. Autistic disorders occur on a spectrum of severity; while some children with ASD can move up and even off the spectrum, most will steadily grow developmentally, emotionally, and socially despite their autistic condition. I am not denying the difficulty that parents face in helping their child. Nor am I denying the grief that parents experience. But I am not giving false hope either. Not only can I personally testify to the wonderful progress that most children with autism can make when they receive early, intensive intervention, there is a growing body of scientific literature (including our own—See Appendix B) that supports my clinical observations.

So, welcome to my office. I invite you to listen in as I accompany the Grant family on their path to discovering how to help their son, Jacob, reach his full potential.
Prologue
The Origins of the PLAY Project
(for Charles)

Before I introduce you to the Grant family in the next chapter, let me tell you how I first came to understand how children with autism look at the world.

Pebble Creek
Back in the 1970's before I went to medical school, I worked for two years as a ‘mental health worker’ at a special education public school for children. This school, with the cute little name of Pebble Creek, had the worst behaved children in all of Ann Arbor, many of whom had autism. There I met 10-year-old Charles. Charles was smart, verbal, and had high functioning autism with terrible aggressive behaviors, including screaming, hitting, swearing, and even vomiting on purpose.

Charles, among his other endearing traits, had a strange walk. He would take a step forward and then rock backward on his back leg, his arms slightly bent up flapping a little with each rocking step. He looked as if he was some awkward bird trying to take off. He walked with this 'rocking step' all the time, which marked him as eccentric whenever we went out publicly. It was also very slow going, walking with Charles. Come on Charles, you’re taking forever.

Finally, one day, after months of working (and walking) with him I asked him: “Charles, why do you walk this way?” To my surprise, he had an answer. “I’m undoing,” he said matter-of-factly as if I should have known. “Undoing?” “Yes. First I take a step forward and then... I undo it by taking a step backward.” I got it. He wasn’t rocking backward; he was stepping backward.

In this way, at least in his own mind, Charles never had to take a step forward in life. In this way, he could keep the world the same, which is the theme song of all children with autism. I've never forgotten what Charles taught me, but I didn't truly understand the nature of autism and why children with autism needed to keep the world the same until I went through my medical training—including pediatric residency and developmental and behavioral pediatrics fellowship—and subsequently followed hundreds of children with autism in my clinical practices in Pittsburgh and Michigan.

Medical Training
After Pebble Creek, I went to Michigan State University’s medical school (where I learned almost nothing about autism) and pediatric residency (where I learned a little about autism). Then, during my fellowship in developmental and behavioral pediatrics, I was exposed to the work of Stanley Greenspan MD, a nationally recognized child psychiatrist and expert on autism. Greenspan’s Developmental, Individual differences, and Relationship based (DIR) model and his play-based methods were consistent with those I had been using at Pebble Creek. I wanted to learn more about the DIR theory.

Through my fellowship, I came to know Stanley Greenspan personally and studied DIR extensively. However, it wasn’t until 1989, when I move to Pittsburgh for a job as the medical director of Developmental and Behavioral Pediatrics at Allegheny General Hospital, that I had an opportunity to apply the DIR approach to children with autism.
In 1990, several parents from the greater Pittsburgh area who had young children (ages 2-7) with autism asked me to help them develop services for their children. Because of state Medicaid law in Pennsylvania, all children diagnosed with Autism Spectrum Disorders (ASD), regardless of parental income, could receive as much intervention as the physician ordered—commonly between 20-40 hours per week—FREE to the families! I was shocked at the services I could provide with just the stroke of my pen.

Over the next ten years, I helped deliver intensive and comprehensive services to hundreds of children with autism in the greater Pittsburgh area using various approaches (See Section 2: Introduction - PLAY Project and/or ABA). I also trained hundreds of professionals in the developmental, play-based approach that I called, for the first time, the PLAY Project. In 1998, I was honored to receive the ‘Professional of the Year’ award from the Pennsylvania State Association for Retarded Citizens (ARC) for my work with young children with autism and their families.

In 2000, I returned back home to Michigan to direct the University of Michigan program in developmental and behavioral pediatrics. I was excited to apply what I had learned in Pennsylvania to my work in Michigan. I assumed I would be able to prescribe intensive intervention—40 hours per week of intensive, one-on-one intervention, delivered in the home by trained personnel, free to the parents—only to discover that there was no Medicaid reimbursement for the intensive treatment of young children with autism in Michigan! In fact, like most states in the U.S., there were (and continue to be) very few intensive and comprehensive services of any kind readily available in Michigan.

The main lesson I learned in Pennsylvania was that children with autism had so much potential to improve if only they could get intensive intervention early in life (18 months to 6 years old), when they are able to make major improvements in their language and social skills, given the right opportunities. We were, in effect, saving the developmental lives of these young children with autism.

So, in desperation to provide intensive services for the families in Michigan I decided to bypass the lack of public services and go directly to the families. Every parent wants to have a better connection and closer relationship with their child and even a single working parent spends 45 waking hours with their child every week. So I re-designed the PLAY Project into a Home Consultant Program where parents are taught by professionals to provide intensive intervention at home.

As we began to coach parents in the PLAY Project Home Consultation model, we learned that many parents were at a loss as to how to connect with their own child. As I said to Julie and Jim Grant when they were about to leave my office after their first visit: “The most important thing I can tell you is don’t let Jacob play alone for long periods of time. Don’t let him spend hours watching TV or playing with the same toys over and over again even if he seems happy playing alone.”

But Julie said to me: “You’re telling me not to leave Jacob alone, but I don’t even know how to engage him yet.” From the time they first noticed delays, Jim and Julie tried to engage Jacob. All he
did was ignore them, turn his back on them, or move away. Julie felt rejected and discouraged which many parents experience when this happens. I can’t even interact with my own child. Jim became frustrated when Jacob wouldn’t listen to even basic commands to stop doing something dangerous or aggressive. He won’t listen to a thing I say. The Grants felt lost because their Jacob was lost to the world. I reassured them that, with persistence, we would get Jacob engaged; that it was the neurologic tendency of children with autism to keep the world the same—even if that meant not engaging with their own parents. We just had to find the way in.

**The Neurologic Comfort Zone & Brain Plasticity**

Thanks to my initial experiences with Charles at Pebble Creek and my subsequent study of brain research related to autism, I came to understand why the child with autism wants to keep the world the same. It turns out that the neurons (the brain cells) of the child with autism are either disorganized or under-connected or both, like a net that can’t capture the complexity of the world. The world feels overwhelming and chaotic, so the child retreats and feels safe in sameness, control, and repetition.

I call this the child’s *Neurologic Comfort Zone* (NCZ) defined as *what the child will do when you let him/her do whatever he/she wants to do*. Often this shows up as repetitive behaviors or interests and can range from over-focusing on visual objects and toys like watching doors opening and closing or watching trains that are lined up, to fixating on books or even topics like dinosaurs or planets. To stay in their Comfort Zone, children with moderately severe autism often block out sounds, especially language, and won’t even turn to their names to the point where many parents worry about their child’s hearing. These avoidance reactions are unconscious and not on purpose. It’s the under-connected brain of autism that causes absorption into a world of sensations and locks children into their Comfort Zones. If you leave these children alone, their experiences will be further limited, which in turn further stunts their potential. It’s a vicious downward developmental spiral.

**Saving Grace: Neuronal Plasticity.** Luckily, the brains of most children with autism have a developmental capacity to make more and better brain connections if they get intensive intervention. This capacity is called ‘neuronal plasticity’ and it’s the saving grace of autism. Engaging interactions with people literally causes the brain to make stronger and better connections as the child begins to form a more complex picture of the world. It all depends on *engagement*.

*Engagement!* And there are many points of engagement where the child and the real world meet. We just have to take advantage of it. When I was at Pebble Creek, in 1977, I wrote a poem called *Puppet Shop* about how to break into the children’s Comfort Zone, into their self-isolation:

**Puppet Shop**

We found him
in an old toy box
on the back porch
of our shop
his soul
stiff
like a puppet’s body
his eyes
like a memory
of the last puppet show.

But he is only like
a puppet.

Somewhere
his world opens—
the eye of a kaleidoscope—
into ours.

Then we begin the task
of handing him back
the strings
one
by
one.

So, I dedicate this prologue to Charles, who first helped me understand how children with autism look at the world. By understanding the need of children with autism to keep the world the same, we can better enter into their world—‘the eye of a kaleidoscope’—in a way that is both fun and functional, in a way that will help them reach their full potential. As I say to parents just starting out: When you’re having fun and the child is having fun with you, you’re doing the PLAY Project right!

Now, let me introduce you to Jim and Julie Grant, who came to my office seeking a diagnosis for their 2½ year old son Jacob, who was initially quite stuck in his Neurologic Comfort Zone. . . .
Section One
What to Do First:
Initial Diagnosis and Recommendations
For Jacob and His Family
Chapter 1
Visit 1: Part 1
“Jacob has autism.”

*The Diagnosis*

After nearly two hours of evaluating Jacob (age 2 years 8 months), I was certain that he had autism (See Appendix A: Jacob’s Initial Evaluation). I had carefully questioned his mom and dad, Jim and Julie Grant (not their real names), about Jacob’s language, social skills, and interests, as well as the family’s genetic history and Jacob’s past medical history.

I had observed Jacob and his younger brother, 15-month-old Charlie, playing in my office and noticed that the brothers hardly interacted unless Charlie went after Jacob’s trains. Then, Jacob would become anxious then angry then aggressively push Charlie away. I couldn’t recall Jacob seeking his parents to play even once through the visit. He went to them occasionally to pull them by the hand to leave, but when he was told ‘Not yet,’ he returned to playing with the trains alone, head down, without referencing anyone. He put the various Thomas the Tank Engine trains on the wooden figure-8 track, pushed them around and around, and flapped his hands in excitement.

Here is an edited version of the recorded evaluation I made with Jacob’s family as we neared the end of our visit.

**Dr. Rick:** “Okay, let me summarize what I’m hearing you say. Jacob has a couple of dozen words that he uses inconsistently at the age of nearly three. This represents a *language delay*, but I like the fact that he understands when you announce routines like ‘time to eat’ or ‘time to take a bath’ and he is beginning to understand when you tell him to stop when he’s doing something you don’t want him to do.”

**Dad:** “If he wants to.”

**Mom:** “Otherwise, he’ll ignore you totally. We were worried about his hearing.”

**Dr. Rick:** “When it comes to his social interaction, he mostly goes into a corner in the daycare and plays with toys alone and doesn’t play with his peers. I also notice that he doesn’t interact much with his brother. And he hardly referenced you to play with him today, which you say is pretty typical for him. So, he has problems with *social engagement and interaction*.

“Also, he loves cars, trains and trucks and watches how the wheels move. He lines his trains up. He opens and closes doors a lot. And he’s a big fan of ‘Baby Einstein’ videos. So, he has *dominating and repetitive interests*.”

**Mom:** “And he’d watch those videos all day long if you let him.”

**Dad:** “Which we don’t.”

**Dr. Rick:** “Finally, he has several *sensory issues*. He puts his hands over his ears when he gets upset, and when he gets upset, he can stay upset for a long time. Loud, chaotic, noisy environments bother him. He does a little toe walking and flaps his hands in excitement. He is very visual and loves to look at lined up objects. And he is not a great eater because he only likes food that’s smooth.

“I’m so sorry to say this, but I’m afraid Jacob has autism. It’s a *mild* form of autism, but I feel quite certain that he has it.”
I stop talking to give the diagnosis time to sink in. Julie's face clouds up and tears form. I offer a tissue. Jim's hand reaches over to hold his wife's hand; his eyes go down, and his face loses all expression.

**Dr. Rick:** “I'm sorry.”

**Mom:** “I knew it.”

**Dad:** “We've been waiting to hear this for a long time now.”

**Mom:** “It’s just hard to hear.”

**Dr. Rick:** “No parent wants to hear that anything is wrong with their precious child. . .”

*The Path to Diagnosis.* Jacob’s parents came to my developmental and behavioral pediatric practice after a series of frustrating events. When they first suspected that something was wrong with Jacob’s development at 18 months, they rushed to the Internet where they found an overwhelming amount of information that led them to believe that children could be cured of their autism through the use of special diets, vitamin shots, and other ‘biomedical’ therapies (See Chapter 4 - Diet, Biomedical Treatments, Immunizations and Autism).

Then, they went to their primary care doctor who, sadly, told them that boys tend to develop more slowly than girls and to ‘wait and see’ how his development goes over the next six months (See Resources & Websites: AAP Recommendations). And the grandparents on Jim's side of the family said that even Jim developed language later than his sister, so not to worry.

By the time Jacob was two and still not talking, the Grants became desperate to find help. Eventually (and sadly from my perspective), after almost a year of worrying about Jacob's lack of language, they heard about my practice from an acquaintance. Their story is not unusual at all. Far too many children are not getting diagnosed until age four even though parents are worried by 18 months and autism can be diagnosed by 14 months! At least the Grants brought Jacob in before the age of three.

**Accurate Information.** In this first visit with Jacob and his family, I feel the need to cover the first essentials: What is autism and how I came to my diagnosis, and where the parents can find accurate information about autism. I make sure I give the Grants time to talk about their reaction to the diagnosis (See Chapter 2: After the Diagnosis: Grief, Guilt, Hope and Action), and then we discuss intervention options.

The Grants are recovering from the initial shock of my diagnosis. The tears are drying and Jim and Julie just look drained. I like to record our discussion because I know that for the rest of the visit, the Grants wouldn't be listening to much of what I had to say but to their own grief.

**Dr. Rick:** “Do you mind if I continue recording our discussion? This way you'll have a document of important information.”

**Dad:** “That’s fine, that’s fine. So what do we do?”

**Dr. Rick:** “The bad news is that Jacob has autism; the good news is that with proper intervention I think he could do very well.”

**Mom:** “I'm so upset.”
Dr. Rick: (trying to be hopeful): “Listen, mom. Jacob has some language before age three. He has no unusual physical findings. He seems smart. I'm optimistic. Let me give you a little overview of what autism is and what we have to do next to get Jacob on the upward path.”

Dad: “Sounds good.”

Dr. Rick: “The first thing I want you to know is that this is not your fault.”

Mom (tearing up again): “That's a big relief. I was worried I had done something wrong.”

Dr. Rick: “No. This is not due to parenting or what you ate or did during pregnancy. And, mom, you told me everything went well during Jacob's birth. So there is nothing medical that caused Jacob's problems.”

Dad: “So what did cause this?”

**Autism is Primarily a Genetic Condition**

Autism is thought to be primarily a genetic condition (though see other contributors below) that causes poor nerve connections in the brain. There are more dozens of autism genes and solid scientific evidence has found that the relatives of children with autism have some of the traits of autism, like mild language delays or being socially shy or being very precise and analytic (See Resources & Websites: AGRE). When I take family histories and look at the 'family tree', I very frequently find certain jobs over-represented including engineers, computer technicians, mechanics, tool-and-die workers, accountants, and other 'left-brained', linear thinkers. Other common traits found in relatives of children with autism include: obsessive-compulsive tendencies, language delays, and relatives who are 'collectors', those who were 'odd' socially, and those who never succeeded in the workplace.

Importantly, if a family has one child with autism, there is a much higher chance that a second child will have it especially if the next child is a boy. The risk of the next child having autism is about 20% for a boy and 5% for a girl. In identical twins, the chances are about 70% that both twins would have autism but even in fraternal twins the odds are about 35%. That autism is at least in part a genetic disorder is not in question. Over 500 articles on the genetics of autism were published this year alone (See Resources & Websites: AGRE).

Mom: “What about Charlie? Could he have it?”

Dr. Rick: “I've also been watching Charlie today and he seems to be doing great. His language is good; he's looking at us all the time. If he worries you at all though, let me know. But, dad, when I was asking you about your family tree, you mentioned that your uncle, who was a tool-and-die worker, was not very social at family gatherings.”

Dad: “Odd as a three dollar bill.”

Mom: “I'm very perfectionistic myself and Jim, he's an IT consultant.”

Dad: I have to be very precise in my work.

Dr. Rick: “I've noticed that when smart, detailed oriented people marry, the odds of having a child with autism go up.”

*The Under-connected Brain.* Autism genes cause the brain of the child with autism to be ‘under-connected’ (See Resources & Websites: Autism and The Brain; See also References & Scientific Note). I tell parents that their child's brain is like a net that is too loose and can't capture the complexity of the world. Typical children with typical brains seek novelty; children with autism seek 'to keep the world the same' which sadly keeps them in their own world. This is why they do the same things over and over. I call this tendency to keep the world the same the child's 'Neurologic Comfort Zone' (See Glossary). Repetition makes a chaotic world predictable. It makes the children less anxious and overwhelmed.
Dad: “Then autism is a brain condition that makes it hard for our kids to connect so they stay disconnected.”

Dr. Rick: “Well said, dad. Kids on the spectrum have a hard time with anything that’s too complex. What are our most complex functions? Language and social skills. And these are the main deficits in autism. The job of intervention is to tighten that ‘neurological net’ so the child can make more sense of the world, gain language and be social.”

Why is Autism Increasing So Much?

Dr. Rick: “In short, on the basis of brain science, children with autism have difficulties with the two most complex human abilities, namely, language and social skills. They want to keep the world the same, which leads to repetitive and dominating behaviors and interests. These three characteristics—delays in language, delays in social skills and dominating interests—define the diagnosis of autism.”

(See Resources & Websites: DSM 5 Diagnosis of Autism).

Dad: “Well, I was reading in the newspaper just yesterday that autism is becoming an epidemic. What I don’t understand is if autism is genetic as you say, then how come it keeps increasing so much. I never heard about an epidemic of Down Syndrome.”

Dr. Rick: “Very astute, dad. The people who study population trends in autism have concluded that this increase cannot be due to genetics alone. While most experts agree that part of the increase in autism is due to diagnosing children earlier and diagnosing milder cases, something else is going on. In fact, as of 2015 we’re at 1 in 68 children. And with boys four times more likely than girls to get autism, we’re at 1 in every 42 boys!”

Mom: “Why is that?”

Dr. Rick: “Males are more linear in their thinking. It may have to do with testosterone. No one knows for sure. I just say that ‘women are the superior species’.” (We all have a good laugh at that.)

Dad: “But why the big increases? I’m seeing road signs that say ‘By the time you get to work, a child will be diagnosed with autism’.”

Environmental Factors & Autism

Dr. Rick: “I don’t want to take up too much of our time now, but the continuing increase in autism also appears to be due to environmental factors like prematurity and exposure to toxins while the baby is in the womb.” (See List below).

Mom: “Toxins in the womb?”

Dr. Rick: “Studies on cord blood show that all mothers tested had hundreds of neurotoxins like dioxins, PCPs, fire-retardants, and especially pesticide residues in their amniotic fluid. The amounts were small but even small amounts may affect the baby’s brain connections. Another recent study showed that if a parent’s occupation exposed the fetus to toxins their child had a larger chance of developing autism. And very recent research shows that prematurity and taking Prozac-like meds, the SSRIs (See Glossary) during pregnancy increases the risk of ASD. In other words, environmental factors plus a genetic tendency combine to cause the under-connected brain of autism. But I want to emphasize that the environmental risks while real are quite low. In other words 97% of mothers who take a Prozac-like medication won’t have a child with autism.”

Mom: “Could I have avoided this by eating better?”

Dr. Rick: “No, it’s in the air as well as the food and water. There’s really no avoiding environmental toxins. We’re all contaminated.”

Factors That Increase the Risk of Autism
• Extreme prematurity
• Taking SSRI’s (Prozac-like) medications during pregnancy
• In utero (in the womb) exposure to toxins
• Being an older mother
• Being an older father
• Changes in father’s sperm cells
• Maternal obesity and diabetes
• In vitro fertilization
• Others

**Dad:** “That’s really sad.”

**Dr. Rick:** “What has also become clear is what does NOT cause autism. It is *not* caused by immunizations (See Resources & Websites: Autism & Immunizations: The Facts); and it is *not* caused by diet or allergies to wheat or milk.”

**Brain plasticity: There is real hope.** Despite the problem with genes, toxins, and environmental factors, children with ASD luckily have something called *neuronal plasticity*. Children’s brains are very changeable or ‘plastic’, growing at an astounding rate in the first seven years of life. Brain size doubles by age three and ninety percent of brain size is reached by age seven! In essence, ‘brain plasticity’ is the ability of the brain’s nerve cells to change and make many new connections, to be re-shaped from the outside in, through effort and experience. This is true of autism especially when compared to other developmental disabilities. This is what makes children with autism different and this is why children with autism need intensive intervention as early as possible.

**Dr. Rick:** “So, while Jacob’s autism is not your fault, there is still a lot we can do to help him. But before we get into intervention, let me talk about where Jacob is on the spectrum.”

**Autism Definition**

As I explain to the Grants, autism spectrum disorders (ASD) are defined by delays in language/communication, delays in social interaction, and having dominating interests and behaviors. Sensory and motor abnormalities are also common. This is the definition used by psychiatrists and psychologists and can be found in the Diagnostic and Statistical Manual 5th Edition, also known as the DSM 5 (See Resources & Websites: DSM 5).

Jacob’s parents were thrown off the diagnosis by paying attention to exceptional behaviors. Jacob’s dad said: “But Jacob makes eye contact and is very loving.” He didn’t see the big picture of delays in language, poor social interaction and dominating and repetitive interests.

**The Autism Spectrum Definition**

*DSM 5 – Diagnostic & Statistical Manual 5th Edition*

- Delays in language/communication
- Delays in social interaction
- Dominating, repetitive and stereotyped behaviors and interests
- Sensory and motor abnormalities (e.g., visual self-stimulation, hand flapping, toe walking, etc.)

Also confusing to parents is the broad range of severity of the autistic spectrum disorders. Children can have no words, very poor social interaction, and very dominating behaviors (e.g., lining up toys, opening and closing doors, etc.). These children would be on the ‘severe’ end of the spectrum.

Children can have almost normal language, some difficulties with interaction and dominating interests (e.g., cars, trains, superheroes). These children would be of middle or moderate severity on the autism spectrum.

Then, there are those who have fairly normal language but are still socially inept or very awkward and have dominating intellectual interests (e.g., dinosaurs, planets, Star Wars, etc.). These children would have a mild autism spectrum disorder and be described as having high functioning autism. In order to be on the spectrum, however, there must be significant social impairment. As children improve they may appear eccentric but quite functional socially (a common term still in use for these children is *Asperger Syndrome*) and about 10% of children with autism can actually outgrow their condition!

These variations can make it hard to diagnose a child’s condition. That’s why it’s very important to get good professional evaluations (See Resources & Websites: First Signs). Recent research concludes that children can be reliably diagnosed with an ASD as early as two years of age and possibly as early as 14 months.

In some states, the school system can make an ‘educational diagnosis’ but for an earlier diagnosis it’s best to go to professionals with experience like a developmental/behavioral pediatrician, neurologist, pediatric psychologist or child psychiatrist.

**Dr. Rick:** “I’m actually optimistic about Jacob. He has some words, he can be fairly easily engaged, and his self-isolating behaviors are not too severe. *So, he has a mild to moderate form of autistic disorder with a good prognosis.*”

**Dad:** “So you’re saying Jacob has autism, not high functioning autism.”

**Dr. Rick:** “Yes, for now, but with intensive intervention, children on the spectrum can really make amazing progress. I see it all the time and Jacob could be one of those children. I don’t have a crystal ball, but I’m very hopeful that he will make very good progress.

**Mom:** “I read recently that children can be cured of autism.”

**Dr. Rick:** “Well, I never say ‘cured’, but there was a study that found up to 10% of children improve in their symptoms to such an extent that they no longer meet the DSM 5 criteria. I have many cases where children just kept getting better to the point where they functioned typically in school and made real friends.”

**Dad:** “I didn’t know that was possible.”

**Mom:** “I’m afraid to ask, but could Jacob be in that 10%?”

**Dr. Rick:** “It’s possible, but we won’t know until we get started with intervention which I want to talk about next.”

**Dad** (looking sadly at his wife): “We’ll do whatever it takes.”

**Dr. Rick:** “I know you will. But let me turn this recording off and let’s talk a little about how you guys are doing.”
Summary

- The members of the Grant family—Jim, Julie, two and a half year old Jacob, and fifteen month old Charlie—are introduced.
- I review Jacob’s profile and diagnose him with mild to moderate autistic disorder (See Appendix A: Jacob’s Initial Evaluation).
- The causes of autism—genetics, toxin exposure in the womb, and other environmental factors—are discussed.
- I define ‘autistic spectrum disorder’ according to the official criteria and explain why it is increasing so much.

Resources & Websites (also See Scientific Notes & References for Visit 1 below)

Websites

- Autism Speaks 100 Day Kit: https://www.autismspeaks.org/family-services/tool-kits/100-day-kit
- University of Michigan Your Child website: http://www.med.umich.edu/yourchild/topics/autism.htm
- First Signs.org: http://www.firstsigns.org/
- DSM 5 Diagnosis of Autism: https://www.autismspeaks.org/what-autism/diagnosis/dsm-5-diagnostic-criteria
- Autism and Immunizations: http://www2.aap.org/advocacy/releases/autismfactsforparents.pdf

Books


Coming Up Next

- In Chapter 2, I talk to Jim and Julie about how they feel about Jacob’s diagnosis of ASD.
- In Chapter 3, I’ll talk about what I advise parents to do when they leave my office and begin intervention; that is, what I would do for my child if he or she had an autistic spectrum disorder.

Scientific Note for Visit 1

Autism genes code for proteins in the brain that typically help make strong nerve connections. In autism, these connections are weak. Brain areas affected include: the frontal lobe where decision
making happens; the *cingulate gyrus* where impulses are kept under control; the *hippocampus*, which makes it possible to remember new information and recent events; and the *basal ganglia* which helps to coordinate automatic movements. In the *amygdala*, which is the emotional center of the brain, there are too many neurons, but they are stunted and do not branch appropriately. This is why children with ASD have problems with understanding other people’s emotions. The *cerebellum*, which controls fine and gross motor coordination, has fewer neurons in autistic brains, which may explain the common signs of hand flapping, toe walking, bizarre movements, etc. Finally, the *corpus callosum*, a large white matter mass that coordinates activities between both sides of the brain, tends to be thinner in children with autism. This points to poor coordination between, as well as within, areas of the brain.

Interestingly, because of these brain abnormalities, the brain of the child with autism is actually *enlarged* early in life resulting in an *increase in their head circumference*, which has recently been accepted as a neurological sign of autism. In most children with autism the head circumference normalizes later in childhood.

When we look less at the anatomy and more at the physiology of autism, research is now showing abnormalities on functional MRI (fMRI) scans, which look at areas of oxygen consumption in the brain tissues. Here, the findings are consistent. People with autism have trouble—there is less metabolic activity in the area of the brain having to do with—understanding facial expressions and reading other people’s emotions. They tend to pay attention to unimportant social cues. They prefer looking at objects instead of at people’s eyes, for example. Children with autism are very visual, which is why they often stimulate themselves visually (e.g., lay their heads on the floor and push a train in front of their eyes) and think in pictures.

Dr. Nancy Minshew, a nationally regarded child neurologist, and her team, using neuropsychological evaluations, have consistently found that people with autism have difficulties on all sorts of complex tasks, not necessarily related just to language and social skills. They may have problems with handwriting or speed of doing a task. They tend to be ‘concrete’ thinkers and take things literally. So when you tell them to ‘hop to it’, they literally hop. Abnormalities in the frontal and temporal lobe lead to difficulty with what’s known as *theory of mind*, which is the inability to understand other people’s perspectives. In other words, they don’t have a *theory* that other people have a *mind* of their own.

**References for Visit 1**


Chapter 2  
Visit 1: Part 2  
After the Diagnosis: Grief, Guilt, Hope and Action

I turn off the recording of our session and give the Grants time to feel. Another wave of sadness wells up for Julie and she begins to tear up again. Jim scoots his chair close to hers and gently holds her hand. I offer another tissue and need one myself. We sit there together in a long, sad silence. I have done this too many times to count and it never gets easier.

Charlie, sensing the tension in the room, toddles over to his mom who lifts him into her lap, gives him a sippy cup, and he sips away contentedly. Jacob entertains himself with the toys and seems oblivious to all the feelings going on in the room.

Mom (recovering a little): “I’m sorry Dr. Solomon. I just feel so sad for Jacob. He doesn’t deserve this.”
Dr. Rick: “You have nothing to be sorry about, Julie. It’s so important to feel your feelings. And it doesn’t seem fair.”
Dad: “I have to admit I didn’t see it at first but Julie kept telling me: ‘Something is wrong, something is wrong.’”
Dr. Rick: “Even when parents suspect the diagnosis, it’s still so hard to hear. No parent wants to hear that anything could be wrong with their child, let alone a diagnosis of autism. That’s what denial is all about, protecting your heart.”
Dad: “I still don’t want to believe it.”
Dr. Rick: “That’s what grief is—the sadness you feel when you stop denying and start accepting that your child has a condition. In other words, in order to accept your child for who he or she is, you must grieve. And don’t get me wrong. I know you love your child, but love is different than accepting their condition. First, you must grieve for the loss of the child you expected and then fall in love with the child you have.”

The Grieving Process
These feelings of profound sadness are the immediate reaction to a grieving process that will go through many phases over time. Good grieving begins a healing process that leads to action and acceptance. Pathologic grieving, including not grieving—called denial—can lead to inaction with calamitous results for the child and family.

Denial. Forms of denial include angry or defensive thoughts like: ‘Solomon doesn’t know what he’s talking about.’ Shock: ‘I don’t believe it. It’s not really autism. We need to get a second opinion.’ Rationalization: ‘I didn’t talk until I was four and I turned out all right.’ Straight denial: ‘There’s nothing wrong. He’ll be fine; he’ll outgrow it.’

There are two big risks to denial. The first is that it divides spouses. One spouse knows something is wrong and the other denies that there is a problem. The one who ‘knows’ feels isolated, not ‘heard’. This causes a rift in the marriage and if it continues for a long time, the rift can lead to estrangement and ultimately even to separation and divorce. Of course there are other factors that lead to marital difficulties but this issue of denial is one of the important factors.
The second danger here, of course, is that denial leads to waiting, and waiting leads to a delay in intervention at a critical time in the child’s life. I warn parents that there is a worse feeling than grief and that is the guilt of looking back on what you should have done. I have some parents who waited years before they could accept the diagnosis of autism. By then, precious time had been lost for effective early intervention.

Depression. On the other hand, being overwhelmed by feelings of grief is not good either. The reason for denying feelings is that these feelings are so painful, and some psychological self-protection is necessary. If you feel too much, you can become overwhelmed with feelings, become seriously depressed, and not function to help your child.

I have some parents who just can’t let the grief out. They hide the diagnosis from the grandparents and close friends. They feel upset when their child shows ‘autistic’ behavior in public (e.g., hand flapping), so they avoid going out. They won’t talk about their feelings with their spouse and cry in isolation. They put on a stoic face and act as if everything is OK but, inside, they feel miserable. I advise parents who are overwhelmed with such grief, anger, and/or upset to get counseling and work through their feelings so they can get closer to acceptance.

Acceptance. The ultimate goal of grieving, according Elizabeth Kubler-Ross, the famous grief researcher, is ‘acceptance’. When parents begin to accept their child for exactly who he or she is, then paradoxically, this is the fastest and best way to help their child become what the parents want them to be—a functioning member of society. This cannot happen if there is too much denial or too much sadness.

My initial goal, then, is to help the family accept their child’s condition in order to engage the child in interactions that are fun. This will make the child truly happy. It is my opinion that happiness, while related to success, is more important than ‘success’, especially early on and especially for children with autism. Playing and having fun is more important than teaching and learning. Fun, play-based social interactions lead to emotional intelligence, EQ. And EQ is more predictive of societal success than IQ.

So my formula is this: acceptance leads to better interactions and more fun with people. Fun with people leads to happiness, functional skills, and emotional intelligence. Emotional intelligence leads to success.

Action. In my experience, usually one parent is more feeling oriented (often the mother but not necessarily) and one parent is more action oriented and wants to get going. One parent might feel too sad and not be ready to act, making the action oriented parent angry. It’s important to acknowledge all feelings that come up and hold/support/love the one who feels sadness. On the other hand, it is important to realize that an action orientation is very helpful for the family to cope with the grief process. It’s important not to be immobilized. Feel your sadness but act. Act but feel your sadness.

Finally, some parents are actually relieved to get the diagnosis. They knew something was wrong and they wanted it to be confirmed. By the time they see me, they’ve already done a lot of grieving and are past the deep initial sadness and just want to get going.
Guilt. Jim Grant was ready to get going, but Julie still had one more set of feelings to work through.

Dad: “So what do we do next?” (Getting emotional, his voice rising) “Dr. Solomon, is Jakey going to be one of those kids who grows off the spectrum? Will he go to regular kindergarten? Will he...”

Dr. Rick: “...get married, be happy? You’re such a dad!” (We all laugh which breaks the tension.) “I have high hopes for Jacob too, dad. He’s got a lot of good prognostic signs. Given my experience with so many kids like Jacob, I would be surprised if he didn’t do well. But it’s going to be a long road ahead.”

Mom: “I can’t even go there yet. I’m sorry Dr. Solomon, but I feel like maybe we should have brought Jacob in sooner. Are you sure we didn’t do anything to cause this? He got the symptoms after I got him his shots. Is that what caused his autism?”

Dr. Rick (lifting the recorder): “OK if I start taping again?” (They nod.) “I want you to hear this. Erma Bombeck, the comedian, once said: ‘Guilt is the gift that keeps on giving’ (We all laugh.), and I hear lots of guilt in your questions.”

Mom: “I had a feeling that something was wrong with Jacob’s development a lot earlier. I should have trusted myself.”

Dr. Rick: “As far as bringing Jacob in sooner, sure you could have, but you got him in before the age of three, which is good. We have a lot of time to work with him. Besides, you have to depend on your pediatric professionals to guide you and they weren’t worried until Jacob was over two so don’t blame yourself?”

Dad: “What about the shots?”

Dr. Rick: “The MMR immunization is given around 15 months and autism’s first symptoms usually begin between 15 to 18 months. It’s the difference between cause and coincidence. In this case it’s coincidence, not cause. There are now over 20 articles that clearly indicate that immunizations do NOT cause autism. And, there are no articles to the contrary.” (See Resources & Websites: Autism is Not Caused by Immunizations)

Mom: “And you’re sure it’s nothing I did during pregnancy?”

Dr. Rick (Half jokingly): “Look me in the eyes Julie.” (She looks.) “I’m sure.”

Dad: “And my folks were blaming daycare because every time they went to pick Jacob up, he was playing alone. My mom said the day care ‘neglected Jacob’ and that’s why he was behind.”

Mom: “That’s why I stopped working, to be home more with Jacob.”

Dr. Rick: “Being home for Jacob is a good thing, as you’ll see when we talk about intervention; but it wasn’t daycare that caused Jacob’s autism and it’s not related to parenting.” (I raise my voice and speak loudly into the tape recorder.) “Listen to me you guys. I hereby relieve you of all guilt!” (We all share a good laugh.)

Like the Grant family, most families worry that they caused the autism. Often, I have to repeatedly reassure the parents that autism is not their fault. Sure, there are risk factors (See Chapter 1: “Jacob has autism.”), but it’s worth mentioning again that autism spectrum disorders (ASD) are not caused by neglect or family conflicts, not caused by something moms ate or did during pregnancy (though certain medications that a pregnant woman takes can increase the risk of autism). All forms of autism are largely genetic conditions, out of parents’ control, that cause neurological changes in the brain.

Dad: “What am I going to tell my folks? They’re old school and say: ‘He’s just a boy and he’ll grow out of it.’”
Dr. Rick: I would tell them that you need them to ‘hear’ you. Use guilt! Tell them that if they don’t accept the diagnosis, you won’t be able to talk to them about your feelings. Tell them you love them and want to share your life with them.”

Mom (toward Jim with an accusatory tone in her voice): “They’re one of the main reasons we didn’t get in sooner.”

Dr. Rick: “Mom, let it go.”

Mom: “I’m sorry Dr. Solomon, but they are in denial. And they do a lot of babysitting for the boys.”

Dr. Rick: “How are your folks about this, mom?”

Mom: “My mom and dad are more on the same page, but they live farther away.”

Dr. Rick (winking conspiratorially): “Well, we’ll have to bring Grandma and Grandpa Grant along.”

(Into the recorder) “It’s very important that all close family members are on the same page about the diagnosis and the intervention plan.”

Julie smiled.

Extended Family. Early in the diagnostic process, it’s very important for both parents and extended family to understand what autism is and to accept that the child has this condition. Sometimes grandparents add to the denial and guilt because they too would be so sad and overwhelmed if they let the diagnosis in. But not to accept the diagnosis is to deny what parents know and feel, and this can really tear families apart. It is so important to support each other during this period of finding your way to acceptance.

Hope. Though grief must run its course, hope will shorten the distance it has to run. And for all my families, I can offer true hope. Children with autism can make remarkable improvements in their development. I have seen so many children get better from intensive intervention that I can be honestly optimistic. Even the most severely affected children make progress with appropriate intervention. Hope leads to action.

Dad: “So what do we do next?”

Dr. Rick: “Let’s talk about that…”

Summary
• I discuss with Jim and Julie Grant the basic reactions to the diagnosis of autism: sadness, grief, denial, guilt, and acceptance.
• I talk about ways to help all family members (including grandparents) accept the diagnosis.
• I define acceptance as: ‘We must mourn the loss of the child we wished for; and fall in love with the child we have.’
• Acceptance leads to better interactions and more fun with people. Fun with people leads to happiness and emotional intelligence. Emotional intelligence leads to success.

Resources & Websites

Websites
• Autism and Immunizations: http://www2.aap.org/advocacy/releases/autismfactsforparents.pdf
Book

Coming Up Next
- We’ll get the Grant family on the road to hope by talking about the definition of ‘intensive intervention’, which therapies NOT to do, and intervention programs that work
Chapter 3
Visit 1: Part 3
When You Walk Out My Door: First Steps

As the first visit with the Grants winds down, I want to make sure I lay out their intervention options before they go. This has all been a lot to take in, but I’ve recorded it on an audio file, I’ll dictate a report (See Appendix A: Jacob’s Initial Evaluation), and we will have a follow up meeting to go into more detail on all the different interventions Jacob will need in order to get going over the next few months.

Throughout the two-hour visit, Jacob barely interacted with his parents, but now his requests to leave the playroom (by pulling dad by the arm to get to the door which I’ve blocked with my chair!) are increasing. I try to distract him with a jack-in-the-box, but he will have none of it. Charlie is starting to get whiny. It’s getting close to lunchtime. I get them a couple of suckers and they’re happy (for the time being).

Dr. Rick: “OK. Let’s finish up here. We’ve got about 10 minutes and our little guys here are getting antsy. I want to outline what you’ll need to do when you walk out my door. I’ll keep the recording going so we document this. I’ll also send you a dictation of the visit. When I first started taking the history, you mentioned that Jacob is enrolled in the Early Intervention (birth to three) Program through the school district.”

Mom: “But he’s going to turn three in the fall.”

Dr. Rick: “So we should talk about preschool options too (See Chapter 5: Visit 2: Early Intervention and Special Education Preschool), but I really want to focus here on intensive intervention.”

Mom: “What about a gluten free/casein free diet? I was reading on the Internet that a lot of parents find that helpful.”

Dr. Rick: “I’ll tell you what. Let me be systematic about this and I’ll address diet and biomedical therapies in a minute.”

Mom: “One of my friends whose girl has autism was giving her B12 shots and…”

Dad: “. . . Honey, let Dr. Solomon finish.”

Mom: “OK. Sorry, but it’s on my mind.”

Dr. Rick: “That’s OK. I’ll get to B12 shots.”

Many parents go to the Internet to find out what to do, but instead find a bewildering barrage of websites that tout their particular approaches. It is one of my main responsibilities to sort through the mass of information out there and make sense of things for parents.

Dr. Rick: “What I want to do, mom, is give you my best advice based on the scientific literature, the recommendations of experts, and on my clinical experience. Then, we’ll talk about the so-called biomedical treatments.”

Mom: “Sounds good.”

**Intensive Intervention**

Dad: “I really want to know what you think we ought to do.”

Me: “In a word, dad, the answer is intensive intervention. If my own child was diagnosed with autism, this is where I would start.”
“In 2001, the smartest people in the country, under the auspices of the National Research Council (NRC), met to develop recommendations for young children with autism spectrum disorders (See Intensive Early Intervention below).

“You can read all 300 pages of the book Educating Children with Autism (See Resources & Websites), but I'll give you the executive summary in five key points: First, you want to start early (and getting in before Jacob was age three is early). Second, and here's the kicker, children with ASD need 15-25 hours per WEEK of intervention. Third, intervention must be engaging, and fourth, intervention usually has to start with one-on-one attention with an adult working individually with the child. Finally, the intervention must address all the needs of the child. In other words it has to be comprehensive and strategic.

**Intensive Early Intervention**

- National Research Council 2001 Recommendations
  - Early intervention: 1.5-3 years of age
  - 25 hours/week of direct intervention
  - That is engaging
  - Individualized (1:1 or 1:2)
  - Comprehensive
  - And has a strategic direction
  - Goal: Personal independence and social responsibility

“Comprehensive means that the intervention addresses the multiple areas of developmental delay in ASD (language delays, social delays, educational delays, sensory-motor issues, etc). Strategic means there should be clear goals with high expectations.”

**Dad:** “Fifteen to twenty five hours per week! That seems like a lot.”

**Dr. Rick:** “Well, it depends on how you do it. Even in homes where both parents are working or there's a single parent home, the adult is spending 45 waking hours per week with their child. In your case, with Julie staying at home, you have even more potential time for interaction.”

**Dad:** “I hadn't thought of it that way.”

**Dr. Rick:** “What I recommend is that parents make every interaction count. Now you still have to plan to get 1-3 hours of direct engaging interaction each day.”

**Dad:** “Why the range? 1 to 3 hours?”

**Dr. Rick:** “It depends on the severity of the child’s autism. The more severe the more the time is important. For Jacob I'm thinking two hours per day would be a good place to start. The most important thing I can tell you is not to let Jacob play by himself for long periods of time. Don't let him spend hours watching TV or playing with the same toys over and over again, even if he seems happy playing alone.”

**Mom:** “You're telling me not to leave Jacob alone, but I don’t even know how to engage him yet. What am I supposed to do with him for hours a day?”

**Dr. Rick:** “I know it sounds daunting, but let me lay out your options and I think you'll feel better when we're done. I'm going to make sure you are supported all the way.”

**Mom:** “That makes me feel better.”
**Intensive Intervention Options**

In many states in the U.S. (there are some exceptions), parents’ options for intervention are limited to:

1. Special education services
2. Speech and language therapy and
3. Occupational therapy

While these are all part of a comprehensive approach, they are not enough. They do NOT meet the National Research Council (NRC) recommendations that I described above for intensity. There are only two generally available intervention approaches for early intervention that meet the NRC criteria for intensity and are evidence based. There are other programs around the country, but they are not generally available in most states. And I’m talking about young children here, 18 months to 6 years old.

One set of approaches involves behavioral intervention—typically provided by trained professionals—which uses repetitive teaching of key skills. The other—typically implemented by parents—is the ‘play-based’ developmental approach that promotes engagement and social interactions. These are not mutually exclusive. In fact, they complement each other. There are other models that combine developmental, behavioral and educational approaches (See Resources & Websites: The Early Start Denver Model), but these tend to be very expensive and are not readily available in most communities at this time.

**Intensive Intervention Models for Autism**

- Applied Behavior Analysis/Early Intensive Behavior Intervention (most common, most available)
- Developmental, Individual Differences, Relationship-based (DIR/aka Floortime)
- PLAY Project (based on DIR theory)
- Early Start Denver Model
- Pivotal Response Therapy (PRT)
- RDI (Relationship Development Intervention)
- Son-Rise
- SCERTS
- Others (See Autism Speaks)

**The Dose Matters**

Dr. Rick: “Before I describe the two main (and most available) intervention types—behavioral and developmental—let me just say a little bit more about the ‘dose’, the time spent in intervention. If I have a strep throat and I take one penicillin pill, I won’t be cured. Even though I took the right medicine, I didn’t take the right dose. The dose matters! The evidence is clear. Someone—either the parents or therapists—needs to spend at least two hours per day in direct engaging intervention. This doesn’t have to be two hours straight but can be broken up into short 15-20 minute sessions.”

Mom: “It doesn’t have to be two hours straight, right?”

Dr. Rick: “Right. In fact, shorter sessions are great and you should use your intervention methods throughout the day when Jacob is waking up, getting dressed, eating, or when you are going out.”
These are all opportunities to connect. But I want you to play together too. Just play. Just do what Jacob wants to do.”

**Mom** (almost thinking out loud): “Playing. With Jacob. That’s a new idea. I mean Jim roughhouses but that’s not my cup of tea.”

**Dr. Rick:** “There are plenty of other ways to play, but you need to get rough and tough too.”

**Mom:** “I don’t think so. But I would love to play with Jacob more.”

**Dr. Rick:** “It’s definitely possible. And wouldn’t it be great to have some fun together?”

**Mom:** “I would love that.”

**Dad:** “Can we get back to the different treatments? Sounds like you’re saying we should do either a behavior type or a development type of treatment. Which one is the best for Jacob?”

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**Behavioral Interventions**

**Dr. Rick:** “Well, the best known and most studied of the behavioral programs is called ABA, which stands for *Applied Behavior Analysis* (See Resources & Websites: ABA), developed by Ivar Lovaas, PhD, in the 1970’s. So it’s been around for a long time. As the name suggests, behaviorists break down specific behavioral skills into small, discrete, easy steps (or ‘trials’) that are highly structured and designed to help children with ASD make gains in language, cognitive, and pre-school skills. This is called *Discrete Trial Training* or DTT. Children are repeatedly rewarded with food, small toys, or fun activities for achieving the skills. I directed a DTT Lovaas program when I worked at Allegheny General Hospital as an Associate Professor at the Medical College of Pennsylvania in Pittsburgh. I worked with Lovaas himself, so I know what ABA involves.”

*ABA* When applied to young children with autism, the approach is called EIBI (Early Intensive Behavioral Intervention) and there are a few versions. As mentioned above, the original version was developed back in the 1970’s by Ivar Lovaas, PhD, and was (and still is) called ‘Discrete Trial Training’ (DTT). In this model, children with autism were repeatedly taught skills, at a table in their seats, on average 40 hours per week! In DTT children are given tasks—“Touch nose, Johnny.” And when the child complies he gets a reward—“Good job. Here’s your reward” (often edibles like a piece of cookie). It’s based on Skinnerian operant conditioning.

Lovaas’ original research purportedly showed that half of the children of this very intensive intervention were able to attend regular school by age six without any help. Half! When the book *Let Me Hear Your Voice* by Catherine Maurice (See Resources & Websites) was written about her child who ‘recovered’ from his autism using DTT, parents all over the country flocked to this therapy.

This early research and the many subsequent studies have confirmed the benefit of EIBI. Recently, however, the research has been criticized. The number of the children in the original Lovaas study was small—20 in each group—and replication of the research in real world settings was less successful than in the original settings.

Newer versions of ABA/EIBI are less rigid, and more playful. Examples include Applied Verbal Behavior (AVB) and Pivotal Response Therapy (PRT). (See Resources & Websites). Developed by Vincent Carbone, Mark Sundberg, and James Partington, AVB uses the principles of ABA but it is more ‘developmental’, language focused, and playful. *Pivotal Response Therapy* (PRT), developed by Robert and Lynn Kern Koegel (a husband/wife team), is the most playful and child centered of the ABA therapies and bases its method on using the child’s interests as a reward.

As a general guide to intensive early interventions, it’s helpful to think in terms of those interventions that are more program centered and those that are more child centered. ABA, as a rule, is more program centered, next comes AVB. Closer to the child centered approach is PRT. But the most child centered are the developmental models.

(I like to joke that as the ABA methods evolve and become more sensitive and responsive to the child, they start to look a lot like developmental models!)
Me: “While ABA/EIBI has, by far, the most research evidence to support its practices (See Resources & Websites), if you are going to go the ABA route, make sure you have a very good and experienced program supervisor. The average cost of a well-run ABA/EIBI program runs from $30,000 to $50,000 per year!”

Dad: “Wow. That’s a lot.”

Dr. Rick: “If it works, though, it’s worth it.”

Insurance Coverage for ABA.

Mom: “I just saw on the news that the Lieutenant Governor of Michigan is pushing for a law that makes insurance companies pay for ABA services (See Resources & Websites: State of Michigan Autism Website). I was reading that we could get up to $50,000 a year for services through this law!”

Dad: “Do you think we should go for the benefit? We’ve got Blue Cross and I think they are one of the companies that would cover it.”

Dr. Rick: “I would definitely go for it. You can’t turn down 50K! I think you should keep all your options open. Just don’t get too excited yet. I’ve been to a number of states where these laws were passed and not nearly as many children ended up getting served as people thought.”

Dad: “How so?”

Dr. Rick: “Long waiting lists to get into limited services, very strict rules for getting an accurate diagnosis, and other bureaucratic barriers.”

Dad: “Do these laws cover the developmental approaches?”

Dr. Rick: “Not yet, just ABA, as well as speech and language and OT. I’m hoping that with our new evidence (See Appendix B: Evidence for the PLAY Project), the PLAY Project will be covered too.”

Dad: “If the law passes and we get the benefit can we do both, ABA and PLAY Project?”

Dr. Rick: “You can do both. Plus you’re going to get started with PLAY right away.”

Dad: “Do they work OK together?”

Dr. Rick: “Sure. They are very complementary (See Introduction to Section 2: PLAY Project and/or ABA?). Of course, I think the PLAY Project is the best at helping the child improve social interaction, but you can’t look a 50 thousand dollar gift horse in the mouth. That’s a huge benefit.”

Dad: “We could try out the ABA and see if we like it—if we can get it.”

Dr. Rick: “Exactly.”

Mom: “At least for now we’ve got speech and OT covered (See Chapters 6 and 7).”

Dr. Rick: “If you do decide to do ABA, I want you to understand not just the upside but the critique as well.”

Dad: “For that much money it better work.”

Critique of ABA.

Dr. Rick: “First of all, one size of intervention can’t possibly fit all children with autism. So it doesn’t matter how much you spend; ABA is not going to work for all children. It certainly didn’t work for many of the children we served in Pittsburgh. There are inherent weaknesses with ABA even when it does work.

“The main criticism of ABA/EIBI is that the children ‘don’t generalize’ what they learn. What they learn during training, they don’t carry into the real world. These children have been sometime been drilled for so long they can appear to be ‘robotic’ and ‘prompt dependent’. They are not motivated from within, but need to be prompted and rewarded by an adult to perform the skills. I saw this quite a bit in Pittsburgh when I ran my ABA program. The ABA programs know this and they are improving on their ability to help children generalize, but it is still a problem.”
“It’s my opinion that ABA is good for what it aims to achieve: teaching children academic and cognitive skills and specific language concepts. Though it can teach specific social skills, it is not nearly as good for teaching social interaction or perhaps, more importantly, promoting a love of interaction with others. The basic interactional process of ABA is: ‘Do this. Good job. Do that. Good job.’ While this basic two-step dance is effective for gaining specific skills, it is not the way people really interact.”

Mom: “One of our friends did ABA with her child and that’s what he was like. He did what she asked him to do, but he played alone when he had a chance.”

**Developmental Interventions**

Dr. Rick: “Even though I’ve supervised both behavioral and play-based intervention models, I much prefer the play-based interventions to start. Play is the way children, including those with autism, learn best—if you know how to have fun with them. While the behavior models have more scientific evidence behind them (for now), the developmental, play-based models (which are harder to measure) are gaining research support (See Resources & Websites: Developmental Models; and Appendix C: Evidence for Developmental, Relationship-based Models) and will soon, I predict, have the necessary evidence to become a standard intervention option for parents.”

*More on developmental approaches.* Just as there are several versions of ABA, there are several versions of developmental interventions including DIR/Floortime, Hanen, Responsive Teaching, ECO/Communicating Partners Model, SCERTS, and Son-Rise (See Resources & Websites). The developmental models all focus on helping caregivers and professionals engage the children in increasingly complex social interactions. These interventions are child centered. The PLAY Project, which is the model described in this book, is a classic example of a play-based developmental, parent-implemented approach.

**The PLAY Project**

Dr. Rick: “Our play-based, developmental model is called the PLAY Project. It’s in part based on the DIR theory of Stanley Greenspan, MD, and Serena Weider, PhD (See Resources & Websites: ICDL and Profectum). Let me tell you what ‘DIR’ stands for and then we can talk about the rest of your intervention options. Let me take each letter, one at a time:

- ‘D’ stands for Developmental. According to Greenspan’s theory, children develop through a series of six levels by the age of five years to become progressively more social and emotionally tuned in. There are more levels later but let’s keep our focus on Jacob and his age.
- ‘I’ stands for Individual differences. Each child is genetically and physiologically unique in how they perceive the world and process sensations. Children with autism, for instance, are often easily overwhelmed by too much noise so they may shut down and not respond to their names. They can be hypersensitive to certain foods or they might visually over-focus on toys like lining up toy trains. These differences are important when considering intervention . . .”

Mom: “You’re describing Jacob to a ‘T’.”

Dr. Rick: “That’s not one of the letters.”

Mom: “Very funny.”

Dr. Rick:

- “The ‘R’ in DIR stands for Relationship-based. The whole purpose of intervention is to help children with autism want to be social, in a warm, connected relationship with parents, siblings, peers and significant others.”
Mom: “That sounds appealing to me.”

Dr. Rick: “Well, autism is a complex condition and each family is complex and unique. Again, one size does not fit all when it comes to finding the right intervention. Though most experts recommend ABA, I think each family needs to see what the options are in their community and pick the interventions that make the most sense AND have the most evidence.”

Dad: “So how is DIR different from ABA?”

Dr. Rick: “Where ABA is an ‘outside in’ approach, using sophisticated drills to teach skills, the DIR (and every other developmental) model uses an ‘inside out’ approach where the adult follows the child’s lead. I tell parents this: When you do what the child loves (not what you think he should learn) the child will love being with you. You break into the child’s Comfort Zone and end their isolation.

“The goals of this approach are to help improve attention and engagement, foster the child’s initiation (i.e., avoid constant prompts), and promote long back and forth interactions. As the child progresses, the focus changes to problem solving, pretend play, and emotional thinking—the higher levels of Greenspan’s theoretical framework.”

Dad: “That sounds more like us, don’t you think hun?”

Mom: “I’m still worried that I won’t be able to engage Jacob?”

Dr. Rick: “Not to worry. In the PLAY Project Home Consultation Program, a home consultant comes to your home once a month for 2-3 hours usually. He or she is a master’s level trained child development specialist who will model for you and coach you on how to engage Jacob. He or she will also videotape your interactions and give you a written plan with activities and techniques to help your play.”

Mom: “Videotape me?”

Dr. Rick: “Don’t worry. You’ll get used to it! That’s one of the key features of our model. That way, you will really see how you are interacting. We point out what you are doing right. We use something called ‘The 7 Circles of PLAY’ (See Section 2: The PLAY Project Approach) that makes it very systematic and easy to know what to do next.”

The PLAY Project
Home Consultation Program
- Based on a structured “7 Circles of PLAY”
- 2-3 hour home visits one time per month
- From a master’s level child development expert
- Who models and coaches how to PLAY
- They videotape your interactions
- Gives verbal and written feedback on your PLAY methods
- Gives you social support and helps find resources

Dad: “So are you recommending that we start with the PLAY Project?”

Dr. Rick: “You should explore all of your options. It’s my initial job as your doctor to present all the best options and then you have to decide what feels right for you. I highly recommend that you check out the Autism Speaks website’s 100 Day Kit (See Resources & Websites) that also outlines your choices. In a way, I’m doing that for you, but you should still check the website out. In some states, services are not paid for or are hard to find.”

Mom: “What about the Michigan Insurance legislation?”
Dr. Rick: “I would definitely get in line to do that program, but I'd start the PLAY Project right away. If you do ABA without the insurance law, it will cost you $30-50 thousand per year.”
Dad: “Whoa!”
Dr. Rick: “And even in states where ABA laws have been passed, access to services can be backed up. The PLAY Project in particular was designed to be relatively inexpensive.”
Dad: “How much are we talking?”
Dr. Rick: “Depends on the state and what insurance will accept but in general it’s about 10 times less expensive than ABA.”
Dad: “How can that be?”
Dr. Rick: “Well, in ABA, a professional is doing the therapy. In PLAY you are doing the intervention. If we paid you for your time, the PLAY Project could come to $30,000 too. Honestly, even if money was not a consideration, if I had a child with autism like Jacob, I would get started with a play-based approach and then add an ABA program later when my child had more language. I would want an approach that helped me with my relationship first. The two approaches are complementary and can be done at the same time. Of course, I developed the PLAY Project so I’m biased. There are other developmental models that I like a lot like Hanen, Floortime, etc., but the PLAY Project has the best evidence and it’s available. This is an important first step. You should take some time to think about it.”
Dad: “What is the evidence for the PLAY Project?”
Dr. Rick: “I’m glad you asked. We just completed a large, very rigorous, scientific study (See Appendix B: Evidence for the PLAY Project) of the PLAY Project Home Consultation Program and I’m happy to say the evidence is strong. Not only does the PLAY Project teach parents how to play well with and engage their child, but it also helps the child get better from their autism.”
Dad: “Impressive. I like the sound of the PLAY Project. Can we get going right away?”
Dr. Rick: “Within the month.” (See Resources & Websites: PLAY Project Website, for programs state by state – look on the “For Parents” page).
Mom: “Would this be under your supervision?”
Dr. Rick: “Most PLAY Projects around the country don’t have me as their medical director, but I’ll be reviewing and guiding Jacob’s progress.”
Mom: “Do we keep our school programming?”
Dr. Rick: “Absolutely. PLAY works best when it’s combined with other services, including ABA. Remember, the National Research Council recommends that the intervention plan be comprehensive and strategic. School can add a lot to Jacob’s program.”
Mom: “Jacob is finishing his Birth to Three Early Intervention program, and we’ve got him enrolled in the special education preschool program for fall (See Chapter 5: Visit 2 Early Intervention and Special Education Preschool).”
Dr. Rick: “That’s perfect. Let me know if you need any help with that. I also recommend speech and language (See Chapter 6: Visit 3: Part 1 Climbing the Language Mountain), as well as occupational therapy (See Chapter 7: Visit 3: Part 2 OT & Sensory Integration), at least half an hour to one hour one time per week for Mr. Jacob.”

**Jacob’s Initial Intervention Plan**

- PLAY Project or ABA or both
- Special education preschool
- Speech and language therapy half an hour to one hour weekly
- Occupational therapy half an hour to one hour weekly
- Regular visits with Dr. Rick every three to four months
Dad: “I looked into it and my insurance will cover 30 visits per year each of speech and OT.”

Dr. Rick: “I have some specific recommendations for how to use those 30 visits and I have recommendations for who, in my opinion, are the best therapists in your area; but so much depends on who is covered by your health insurance. Our receptionist, Amy, will give you the list of therapists on the way out. Also, I have some handy dandy handouts on Early Intervention, Speech and Language, and OT intervention. And for you, mom, I have a special handout on the biomedical treatments, diets, and the relationship between immunizations and autism.”

Mom: “I really want to talk to you about this.”

Dr. Rick: “I’ll tell you what. Give me a call this week and we’ll talk. The most important thing is to get you on the path toward intensive intervention as soon as possible. The dose matters! You want to start engaging Jacob two hours per day, broken up into multiple 15-20 minute sessions. You have months to get yourselves organized. This isn’t a sprint, it’s more like a marathon, but you shouldn’t wait too long to get going.”

Mom (looking at her husband): “I think we should at least get started with the PLAY Project.”

Dad: “Let’s do what Dr. Solomon is suggesting and look at the different options and then decide.”

Dr. Rick: “I think that’s best. This is a big decision. You’ve got time. Your choices are fairly limited and clear. Let me know what you decide to do. And Julie, please give me a call about the biomedical treatments.”

Postscript
Julie Grant called that night and left a message on the office answering machine. First, they decided to do the PLAY Project and want a home consultant to come to their home as soon as possible and second, she wants to talk about biomedical treatments.

Summary
- The five key elements of a successful intervention approach are described. I emphasize the recommendations of the National Research Council guidelines.
- I point out the dangers of the Internet for trying to find out what the best interventions for ASD are.
- The most important intervention options are discussed including the behavioral types of ASD intervention and the developmental types of ASD intervention.
- I briefly describe the differences between the behavioral and developmental methods of intensive intervention, the two most commonly available intensive approaches.
- The PLAY Project Home Consultation Program is briefly described.
- This visit leads to developing a comprehensive and strategic plan for Jacob Grant.
- The parents still have to decide between ABA and the PLAY Project or some combination of both.

Resources & Websites

Websites
• **Autism Speaks** website: 100 Day Kit: [http://www.autismspeaks.org/family-services/tool-kits/100-day-kit](http://www.autismspeaks.org/family-services/tool-kits/100-day-kit)


• **Autism Speaks**: Insurance Laws - [http://www.autismspeaks.org/advocacy/states](http://www.autismspeaks.org/advocacy/states)


Developmental Models

• PLAY Project: [www.playproject.org](http://www.playproject.org)

• DIR/Floortime Resources:
  - ICDL: [http://www.icdl.com/](http://www.icdl.com/)
  - Profectum: [http://www.profectum.org/site/c.8gLlNK0MFLiYF/b.7883667/k.D912/Integrating_DIR174Floortime_ABA_and_other_approaches.htm](http://www.profectum.org/site/c.8gLlNK0MFLiYF/b.7883667/k.D912/Integrating_DIR174Floortime_ABA_and_other_approaches.htm)


• Hanen: [http://www.hanen.org/Home.aspx](http://www.hanen.org/Home.aspx)

• SCERTS: [http://www.scerts.com/](http://www.scerts.com/)

ABA Models


• To locate the ABA/EIBI program near you go to: [http://www.bacb.com/](http://www.bacb.com/)

Combined Models


Books


• *Far From the Tree*, Andrew Solomon, Simon and Schuster (2012)

Coming Up Next

• In Chapter 4, I give my assessment of the ‘biomedical’ approaches to autism

• In Chapter 5, we talk about language and Speech and Language Therapy

• In Chapter 6, we discuss Occupational Therapy and Regulatory Disorders
Chapter 4
Diet, Biomedical Treatments, Immunizations and Autism

I returned Julie Grant’s call the next day. She mentioned in her message that beside starting the PLAY Project and wanting to talk about the biomedical treatments, she had to ‘make a decision right away’.

**Biomedical Treatment**
I knew what it was about. The celebrity Jenny McCarthy, who publicly proclaimed that her son ‘recovered’ from his autism by consuming a gluten free/casein free diet\(^1\)\(^2\) and using a number of biomedical treatments, was speaking in the Detroit area as part of her national book tour. Everyone in the autism community was buzzing about her. A forceful, compelling, and charismatic speaker, McCarthy was also *against* immunizations, claiming they contributed to autism’s increase.

**Biomedical Treatments**
- Vitamin/mineral Supplements
- Gluten Free/Casein Free Diet
- B12 Shots
- Chelation Therapy
- Yeast Free Diet and Anti-fungal treatment
- Hyperbaric Oxygen
- Secretin
- DAN (Defeat Autism Now) Protocol

**Mom** (hopefully): “Should I go to see her?”

**Dr. Rick**: “Who am I to tell you what you should or shouldn’t do?”

**Mom**: “I don’t think we mentioned it, but we had an appointment to see a ‘DAN doctor’ to help with Jacob’s diet and supplements. Anyway, he thought I should go to see Jenny McCarthy, but I wanted your professional opinion.”

**Dr. Rick**: “I’ve been following the ‘DAN Protocol’ with great interest ever since it was developed several years ago now, and I must say, I’m very disappointed. The protocol was designed to do research and evaluate whether the various biomedical treatments work. To date, there has been no evidence that their protocol of vitamins, diet, enzymes, etc., works. It’s very discouraging.”

**Mom**: “But it seems to work for lots of kids. There are all kinds of reports on the Internet.”

**Dr. Rick**: “Well, I consider myself to be a very open minded doctor who is always looking for ways to help the children, but after following hundreds of children with autism whose parents have tried various diets and biomedical treatments, I can honestly say that the vast majority of my patients have had no benefit.”

**Mom**: “That’s disappointing.”

**Dr. Rick**: “I’m disappointed too. Wouldn’t it be great? Change the diet or give a supplement and your child gets better from his autism? I’m afraid it’s mostly wishful thinking. After all, autism is largely a genetic disorder. I remember back in the day when there was a megavitamin craze for treating kids with Down Syndrome. With rare exceptions, it makes no sense to treat a genetic condition with diet or vitamins. Don’t get me wrong, Julie, I truly wish for a ‘silver bullet’ too. I
wish, along with all of my parents, that I could give a B12 shot, do chelation therapy, use hyperbaric oxygen, or a gluten free/casein free (GF/CF) diet and help my patients with their autism. What you're seeing on the Internet is called 'the placebo effect'. This is a scientifically proven phenomenon where a fake treatment can sometimes improve a patient's condition simply because the person believes it will be helpful. The more a person believes they are going to benefit from a treatment, the more likely it is that they will experience a benefit. It's a form of wishful thinking.

“But the only thing I've seen work consistently are the intensive developmental and/or behavioral interventions which we talked about during the last visit.”

Mom (not convinced): “Isn’t there any benefit? I mean why should so many parents report that their kid got better with a GF/CF diet? I found lots of evidence on the Internet that it helps.”

**Autism and the Internet**

It's true that when you type ‘Treatment of Autism’ into your Internet browser, hundreds of thousands of links are listed. On the first webpage most of the links—even the Autism Speaks link!—mention dietary approaches to autism. Other sites recommend vitamins, B12 shots, supplements, anti-yeast treatments, hyperbaric oxygen... The alternative treatment list goes on and on. Another group of websites describes the dangers of immunizations as the cause of autism.

*How are parents supposed to sort through all this information to arrive at the truth of what works and what doesn’t?*

**Dr. Rick:** “Watch out for so called ‘evidence’ and don’t believe everything you read on the Internet. The worst form of science is a case study: ‘I tried it and it worked!’ I would challenge you to give me one, just one, scientific article with a good study design, which shows that diet helps autism. In fact, there are none.”

**Mom:** “None?”

**Dr. Rick:** “None. In fact, there are studies that show diet doesn’t help[1][2]. But to be completely fair, I’ve seen some benefit to overall health from changing the child’s diet.”

**Mom** (hopeful again): “You have?”

**Dr. Rick:** “Children with autism tend to have very unhealthy diets anyway and they are often very sensitive to their internal states. When they don’t feel well, they don’t function as well.

“I have seen children who are truly allergic to wheat (gluten) or milk (casein) get better in their attention and engagement when the offending allergens are taken out of their diets, just as a typical child would if they had those allergies – these are not specific to children with ASD. I have seen children’s sleep improve with dietary changes. I have even seen a decrease in ‘stimming’ (self-stimulation) behaviors (i.e., hand flapping, toe walking, humming, etc.) when their tummies don’t hurt. But I have never seen a child ‘recover’ from autism with alternative therapies alone.”

**Mom:** “Jacob’s been on the diet for a couple of months now.”

**Dr. Rick:** “I remember you telling me that you were considering it.”

**Mom:** “I haven’t seen any dramatic changes. And, it’s really been a pain. That’s all he likes is gluten. Pretzels, cereal, crackers.”

**Dr. Rick:** “It is a hassle. Did I miss something during our evaluation? Does Jacob have allergic symptoms?”

**Mom:** “Not really. He’s been healthy as a horse, but our DAN doctor thought that he might have hidden allergies.”
Dr. Rick: “If you’re worried about allergies, I recommend going to a bona fide, board certified, pediatric allergist.”

Mom: “But how will we know if any of this stuff works?”

Dr. Rick: “That’s another problem. After you invest time and money in treatments, you tend to see differences even if they’re not there. First, there’s the ‘placebo effect’, believing is seeing. Then, there’s something called the ‘Hawthorne Effect’—just by being vigilant and looking for any change at all, you attribute the change to the treatment you’re giving at the time.”

Mom: “That’s so true! We are hawking Jacob. Every little thing that happens we think maybe it’s because of the diet.”

Dr. Rick: “You might have to do an elimination trial—get rid of gluten and casein for a month or two and then re-introduce it. And see what happens.”

Mom: “Sounds complicated.”

Dr. Rick: “Unless the improvement is dramatic, it’s not worth it.”

Mom: “But I was so excited that I could help Jacob by changing his diet. It was something I could really do.”

The Harm of Biomedical Treatment

Dr. Rick: “If it sounds too good to be true, it usually is. People are always looking for a simple solution to a complex problem. I just don’t want you to act on false hope, Julie, and go off in the wrong direction.”

Mom: “But what’s the harm in doing biomedical treatments?”

Dr. Rick: “Well, you can spend a lot of money.”

Mom: “That’s true. These vitamins and supplements are adding up. The doctor is sending me for lab studies, and that’s costing a bundle.”

Dr. Rick: “Yep. It’s big business. Many of these people are well intentioned, but there are also unethical people out there who prey on desperate families. Another harm is that you can waste a lot of time, which can distract you from doing what we know works. And perhaps the most serious harm is that it drives families crazy.”

Mom: “What do you mean?”

Dr. Rick: “Aren’t you worried that you’re missing something?”

Mom: “Absolutely, and it’s driving me crazy.”

One Cost of Biomedical Treatment: Anxiety. We both laughed, but it’s not funny. A deep sadness for me is seeing the consuming anxiety that false hope engenders. Families are running from this therapy to that therapy and constantly looking over their shoulders wondering ‘What else do I need to do to ensure the best for my child’. This anxiety will never go away completely because families should keep their eyes open for anything that will help their children, but I have seen too often what this anxiety of ‘wishing for the cure’ does to a family. It costs them money; it robs them of time; but, perhaps most importantly, it saps their energy.

Dr. Rick: “You worry constantly that there is something more to do.”

Mom: “But we don’t want to leave any stone unturned if it will help our Jacob.”

Dr. Rick: “Exactly. If you believe that any one of these treatments might even have a remote chance of working, then you’ll feel guilty if you haven’t tried all of them.”

Mom: “Exactly how Jim and I feel.”

Dr. Rick: “I have several families whose lives have become consumed by trying every biomedical treatment.”
Mom: “Everybody is saying ‘You have to try this, you have to try that’. I read about this, I read about that. It’s driving me. . .it makes me feel like I’m not doing enough.”

Dr. Rick: “I really understand. Believe me, I would tell you if I saw an alternative intervention that was helpful. I’m not a science snob who needs final proof before I recommend a treatment. There are several interventions that have little to no evidence that I refer to all the time.”

Mom: “Like what?”

Dr. Rick: “Speech and language or occupational therapy. They don’t have much scientific evidence behind them, but I think they’re very helpful and they make sense. I trust my clinical judgment. I just haven’t seen the benefits of the biomedical treatments.”

Mom: “I’m disappointed, but I feel better about what I’m doing. I think we’ll still keep experimenting, but you really helped take some of the pressure off.”

Dr. Rick: “It’s good to try things or you’ll have doubts. Just don’t expect miracles.”

Mom: “What about B12 shots?”

Dr. Rick: “I’m comfortable with whatever your DAN doctor suggests. Just don’t spend too much money. . .”

Mom: “…or too much time. I get it.”

Dr. Rick: “Stay focused on what we know works—intensive intervention. And watch out for the predators and the true believers. It’s a dangerous world out there on the Internet.”

The Danger of True Believers

Mom: “You’re not saying that Jenny McCarthy is preying on families?”

Dr. Rick: “Not at all. She is a true believer, but for that reason she may be even more dangerous than a predator. The predators knowingly go after your money. True believers go after your heart’s deepest desire: to help your child get better dramatically and quickly. Predators and true believers have one thing in common—they both rely on your desperation to help your child. The problem with true believers is that, if they are wrong (and they often are), they can rally whole communities to do the wrong thing. They can unintentionally do harm to lots of families and children.”

Mom: “You think she’s wrong about diet and shots?”

Why Parents Believe In Biomedical Treatments

- We all wish our children would ‘recover’ from ASD
- True believers and predators rely on this wish to promote/sell simple solutions to a complex problem
- Testimonials are a poor form of evidence
- It’s natural to confuse ‘coincidence’ with ‘cause’
- Wishing leads to positive expectations: The Placebo Effect
- Watching intently for change leads to seeing change: The Hawthorne Effect
- Science shows no benefit from a GF/CF diet, etc.
- Science proves that immunizations do not cause autism

Dr. Rick: “I can tell you from following many, many families that diets did not work for them; going to a DAN doctor and doing all the biomedical approaches did not work. But you won’t read about them. I could fill an auditorium with families who received no benefit from diet and alternative treatments, but you won’t read their testimonials online. We need more science, not more testimonials.”

Mom: “So you think Jenny McCarthy is doing harm to families and children?”
Dr. Rick: “If a family does a gluten free/casein free diet instead of intensive intervention because of someone like a Jenny McCarthy, then she has hurt that family’s chances of doing the best thing for their child. If people, for fear of their child getting autism, don’t get immunizations, and their child gets whooping cough or measles and, God forbid, dies from complications, then the greatest harm has been done. A lot of families worry that immunizations cause autism and the rate of childhood illnesses is going up. It’s a real concern in the pediatric community.”

**Immunizations and Autism**

Mom: “So, I take it that you don’t believe that immunizations or the mercury in the shots cause autism.”

Dr. Rick: “It’s not a matter of belief. The scientific evidence is overwhelming that immunizations with or without mercury don’t cause autism (See Resources & Websites: Immunizations Do NOT Cause ASD). What’s more interesting to me is why people believe that the two are connected.”

Mom: “There’s dozens of stories on the Internet about kids who got autism right after they got their shots. How could parents be so wrong?”

Dr. Rick: “I’ll tell you how. When two events coincide, it is human nature to link them together. Immunizations are given at 15 months, 18 months, and two years. Guess when the onset of autism is?”

Mom: “Same time.”

Dr. Rick: “Right. Autism’s onset is typically between 15 months and two years. A family brings their child in for a shot and within the month, the child loses language milestones. Such ‘regressive’ autism occurs in up to 30% of children with autism. The parents connect the shot with their child’s autism and blame the shot. But there is no link between autism and immunizations. There are dozens of studies that show no relationship between autism and immunizations and no studies that link the two (See Resources & Websites: Immunizations do NOT cause ASD).

“Besides, pediatricians don’t want to hurt children. When the rotavirus vaccine was shown to cause problems, they took it off the market right away. When the DPT caused neurological damage, they created the vaccine insurance bill. And who do you think found that there was too much mercury in vaccinations? A pediatrician! Why would they keep giving immunizations if they caused autism?”

Mom: “What about Andrew Wakefield, who had that big article on the measles shot causing autism?”

Dr. Rick: “Haven’t you read? His study was just debunked (See Resources & Websites: Andrew Wakefield). It turns out that he was a fraud! He fudged his data to make it come out the way he wanted! The most esteemed British scientific journal, the _Lancet_, for the first time in their long history, retracted his article with profuse apologies to the public. Wakefield lost his medical license.”

Mom: “I did not know that.”

Dr. Rick: “And when Jenny McCarthy, who had been using Wakefield’s study to support her view, was told about his fraudulent research she continued to maintain that immunizations caused autism because ‘it happened to my son’. This is the fate of true believers. They don’t want to be confused by the facts.”

**Cause or Coincidence: The Danger of Anecdotal Evidence**

Mom: “OK. I’m thinking I might not go to see her after all, but I have one last question.”

Dr. Rick: “Shoot.”

Mom: “Don’t you believe that Jenny McCarthy’s son got better and is no longer autistic?”

Dr. Rick: “I don’t doubt that her son got better. I just think she’s wrong about why he got better. Besides the money she spent on diet and alternative therapies, she also spent tens of thousands of
dollars a month on intensive therapies including ABA, multiple speech and language therapy and occupational therapy sessions. Plus, she had Jim Carey, the comedian, to play with her son.”

Mom: “Very funny. I hear what you’re saying, but I don’t know Dr. Rick. I still can’t quite believe that so many parents could be wrong.”

A Case of ‘Cure’.

Dr. Rick: “OK Julie, let me explain how this works. First of all, did you know that 10-20% of children with autism get better with no intervention?”

Mom: “Really?”

Dr. Rick: “Really. I have many children who just simply improve over time. Let me give you just one case study from my practice so you can see the problem with the ‘I tried it and my child got better’ approach to scientific evidence.”

The Boy Who Got Better. So I told her about my patient, 3-year-old Johnny Smith (not his real name). It was not long after Jenny McCarthy was on the Oprah show (talk about coincidence!) that Johnny and his parents came into my office after six months of doing intensive play-based intervention (i.e., PLAY Project). He was coming back to see me for a follow up visit.

From the time it took him to walk from the waiting room to the playroom, I knew something dramatic had happened. He actually greeted me! He looked me in the eye and said, ‘Hi Dr. Rick.’ A three-word, very social sentence! Before, at age 2 ½, he had been withdrawn in an autistic shell and had only a few single words.

As I took the history of gains over the last six months, I was stunned. Johnny had gone from not talking to non-stop talking; from not being social to not leaving his parents alone and wanting to play all the time; and from having lots of repetitive and rigid interests to having much more flexibility in his interests. My heart was so happy for this family.

I said: Johnny's developmental gains have been tremendous! What in the world did you do?”

His mom said 'We just did what you told us to. We turned off the TV; we've been engaging him for hours a day playing; we started speech and language and occupational therapy every week; and he's in preschool—the works.'

She denied giving any special diets, vitamins, or alternative treatments of any kind.

'I would love to take credit for Johnny’s amazing progress,' I remember saying. But he just got better. I have several children who spontaneously make a giant leap forward like this. And if it's going to happen it usually happens between 2 and 3 years of age. I congratulated her on Johnny's progress. I was so pleased. Of course I had to add an editorial comment. ‘It’s a good thing you didn't start a gluten free/casein free diet or B12 shots or you would have been running down the street shouting ‘Hallelujah! I put my Johnny on a special diet and it cured him of his autism!'

Dr. Rick: “They would have had the perfect testimonial.”

Mom: “I see what you’re saying. If they had changed the diet, they would have truly believed that the diet made the difference!”

Dr. Rick: “Right. And they would have put it out there on the Internet, and then others would have believed it and on and on. The real reason Johnny got better was that he improved on his own (with some help from intensive intervention).”
Mom: “So really this DAN stuff doesn’t work?”

Dr. Rick: “It might help the child feel better.”

Mom: “This is very discouraging.”

Dr. Rick: “As long as there are desperate, vulnerable people (which all parents with children with autism are), there will be those who take advantage. I’m just giving you advice based on my experience and scientific studies.”

Mom (discouraged): “I don’t think I’m going to go to Jenny McCarthy’s talk.”

Dr. Rick: “I didn’t mean to rain on your parade.”

Mom: “That’s OK. I actually feel relieved. I’m tired enough doing what I have to do for Jacob and Charlie. I was getting exhausted with the gluten free diet and honestly haven’t noticed any real improvements. We might give the B12 shots a go though.”

Dr. Rick: “Hey, if it doesn’t cost too much money or take up too much time, you can experiment with various alternative treatments, but just don’t get stuck in the wishful thinking rut. It’ll drive you nuts. And never let the alternative treatments overwhelm your efforts at the intensive interventions. The key is time of engagement. Jacob has tremendous potential. We’re going to get this boy going!”

Summary

- Julie Grant was planning on attending a talk by a national celebrity who believes autism is caused by immunizations and can be treated effectively with supplements and a gluten free/casein free (GF/CF) diet
- I share my observation that, over my 25-year career, I have never seen a child with ASD improve dramatically from diet, vitamins, supplements, or alternative treatments alone
- Julie wants to know why there is so much ‘evidence’ on the Internet supporting a GF/CF diet if it doesn’t really work
- We discuss why parents believe in the ‘silver bullet’ approaches to ASD
- We discuss the difference between ‘anecdotal evidence’ and real science
- There is a lot of scientific evidence that immunizations do not cause ASD
- There is no scientific evidence that diet effectively treats ASD

Resources & Websites

- Immunizations Do NOT Cause ASD: http://www.cdc.gov/vaccinesafety/concerns/autism.html

Coming Up Next

- Jacob is finishing up his Birth to Three, Early Intervention (EI) program. Jim and Julie Grant are concerned about the transition to the special education preschool program.
- I talk to them about the importance of understanding the education laws, how to navigate the education system, and how to help Jacob to get the most appropriate services in the school.

References


Chapter 5
Visit 2
Early Intervention and Special Education Preschool

It was a beautiful, warm, and sunny day in July in Michigan, three months after our first visit, when Jim and Julie Grant returned (without the boys) to talk about Jacob's school placement. Now that he was turning three, Jacob's Early Intervention (EI) program was ending, and Special Education Preschool would begin in the fall. Of all the things I do in guiding parents, matching the child to the best educational setting is one of the most common—and most difficult—tasks.

Dr. Rick (checking my notes from the last visit): “So how did Jacob do in his EI program?
Mom: “The home visitor was nice and Jake and I enjoyed some play groups.
Dad: “I’m still kind of miffed with the school system because they didn’t diagnose Jake with autism and tell us what to do.”
Mom: “In the big meeting we had with the school in May they said Jakey had an ‘Early Childhood Developmental Delay’. I made a point of remembering that.”
Dr. Rick: “That ECDD label is the most common educational diagnosis but, now that he’s going to special ed preschool, I agree with Jim. They should re-evaluate Jacob for an autism spectrum disorder. That’s my fault, we should have talked about that.”
Mom: “I should have called you. It crossed my mind.”
Dr. Rick: “How did that IEP meeting go?”
Dad: “Our what?”
Dr. Rick: “IEP stands for Individualized Education Plan, Jim. It’s part of the IDEA laws—the Individuals with Disabilities Education Act (See Resources & Websites)—that defines Jacob’s special ed services when he turns three. That May meeting was your IEP meeting.”
Mom: “Don’t you remember, Jim, we had to sign all those forms at the school again? That’s why I thought to meet with you before that meeting, Dr. Rick, because I had a bad feeling after that meeting.”
Dr. Rick: “Parents should always trust their gut feelings. Tell me, what happened?”
Mom: “For this fall, they said Jacob (turning to her husband) should go to a . . .”
Dad: “. . . ‘Cognitive Impairment’ class. I think they called it a ‘CI Classroom’. Julie was worried about it so she went to see the classroom.”
Julie: “It’s a lower class. The kids were pretty severe.”
Dr. Rick: “So you signed the IEP that would put Jacob in the CI classroom?”
Mom: “I guess we did.”
Dad (reading my face): “Should we not have done that?”
Dr. Rick: “If you signed the IEP, that means you agreed to Jacob’s placement in a classroom for cognitively impaired children. I’m not sure that’s best for Jacob. He’s not cognitively impaired. He has autism.”
Mom: “I just got a twinge in my stomach. Did we commit Jacob to that CI room?”
Dr. Rick: “Yes, but you can always change your IEP at any time. You would have to make an immediate request in writing. It’s summer so it’s going to be harder to make things happen.”
Mom: “Oh no!”
Dr. Rick: “Don’t worry; we’ll deal with it. Even if he starts in the CI classroom in the fall, we can get him switched to another classroom. It might be the best classroom for him after all. Usually the
schools make good recommendations. Let’s just go about this systematically and figure out what’s best for Jacob.”

**Overview of Special Education Services in the U.S. (Children Birth to 5)**

So begins our discussion of school placement for Jacob Grant who is transitioning from Early Intervention (Birth to Three services) to Special Education Preschool (three to five year old services).

But before we get to the Grants’ question about the best school placement for Jacob, let me overview special education services in general and the process of getting children enrolled. Below is a list of the typical services offered by special education in the U.S.

**Note:** Special education services are largely the same across the country because they are based on the federal IDEA law (though there may be some variations state to state). For detailed information in your area contact your local school district. (If you know all about this, you can skip to the section called “Early Diagnosis & Better Services”).

**Special Education Services**

- **Child Find**
  - Screens children birth to three for developmental delays
  - Children under than three are referred to Early Intervention
  - For Child Find developmental screening contact your local school district

- **Early Intervention:** For children under than 2 years-11months old
  - Full multi-disciplinary team evaluation (MDE) is done
  - Must meet state criteria for ‘developmental delay’
  - Often limited diagnostic services for autism (i.e., may not make an ASD diagnosis)
  - Administered by state’s Department of Health or Department of Education
  - Services limited to weekly home visits and/or play groups
  - Limited S&L and OT services
  - Families receive an intervention/service plan called an IFSP, Individualized Family Service Plan
  - Falls under Part C of the IDEA law (See next section)

- **Special Education Preschool:** For children between 3 and 5-years-11 months
  - Full multi-disciplinary team evaluation (MDE) is done
  - Must meet state criteria for ‘developmental delay’
  - Better diagnostic evaluation for ASD
  - Administered by the state’s Department of Education
  - Preschool provided for 4-5 days per week, 2-3 hours per day (half days)
  - More extensive S&L and OT services
Classrooms may have typical peers integrated into the preschool
Families receive an education plan called an IEP, Individualized Education Plan
Falls under Part B of the IDEA law (See next section)

*Jacob's Special Education Services.* Here’s how Jacob ended up in special education preschool. Jacob’s pediatrician (after first telling them to ‘wait and see’ when Jacob was 18 months!) confirmed the parents’ concerns at his 24-month well child visit. She referred the Grants to *Child Find* who screened Jacob and referred him to Early Intervention.

The *Early Intervention (EI)* program completed a multi-disciplinary team evaluation (The team included an educator, speech and language pathologist, and occupational therapist.) Jacob’s developmental delay qualified him for services (though they did not make a diagnosis of autism at that time.). The Grant family signed an IFSP (Individualized Family Service Plan) that fully describes the services to be provided under the law. Jacob was enrolled in Early Intervention. (Each state has different names for EI. In Michigan it’s *Early On*; in Ohio, *Help Me Grow*; and in Indiana *First Steps*). He could attend a weekly play group (with a parent in attendance) and an Early Intervention teacher came to their home once a week for an hour to help Jim and Julie promote Jacob’s development. Early Intervention did not recommend intensive intervention.

Now that Jacob was turning three he would be transitioning to *Special Education Preschool* services. The school did not re-evaluate Jacob for autism and recommended placement in a ‘Cognitively Impaired’ classroom. Michigan still uses an ‘impairment system’ of educational labels (which is a throwback to the early days of disability). Other states use more positive labels.

*The IDEA Laws: 5 Secrets of Good Advocacy*

**Dr. Rick:** “Before we figure out if the CI classroom is best for Jacob let me ask, has anyone from the school talked to you talk about your rights under the IDEA law?”

**Dad:** “Not really. At least I don’t remember. Do you, Julie?”

**Mom:** “I think they might have said something, or given us some papers, but everything was happening so fast when we were at the school.”

**Dr. Rick:** “Let me share with you my Five Secrets of Good Advocacy.”

**Dad:** “I think we need this.”

1st Secret: Believe that You Have Power in the School System.

Dr. Rick: *Number one: The single most important thing I can tell you is that parents have a lot of power in the special education system. In many ways, you are the boss of your child’s education plan.*

**Dad:** “We didn’t feel like we were the boss, did we hun?”

**Mom:** “I was a bit overwhelmed.”

Dr. Rick: “The IDEA laws were originally created with a lot of parent input and really put the parents in the power seat IF parents know the law but schools rarely, in my experience, inform parents about their rights under the law in a way that parents can really understand.”

2nd Secret: Know the Key Elements of the Law.

Dr. Rick: “The vast majority of the time, the schools have your child’s best interests in mind, but if you have important disagreements with what the school wants to do, you have to be your child’s
best advocate. So number two: You have to know a few key elements of the law and a few key terms. Here’s a quick summary. (I hand them a copy.)”

**IDEA Laws**

- Birth to three Services are described under Part C of the IDEA law
- Special Education Preschool Services are described under Part B of the law
- Free and Appropriate Education (FAPE) means special education services are free and must be educationally appropriate for your child
- Least Restrictive Environment (LRE) is your right to have your child with typical children in regular classes (if available)
- Individualized Family Service Plan (IFSP) (B-3) or Individualized Education Plan (IEP) (3-5 years old) is the requirement to provide families with their child's complete educational plan in writing
- Parents have the right to an advocate and legal recourse if you don’t agree with the IFSP or IEP
- There are many other elements to the law (See Resources & Websites)

Dr. Rick: “Both the Birth to Three and Special Education Preschool services are provided publicly, i.e., they are free, paid for by state and federal taxes as mandated by the federal IDEA laws and they should be appropriate for the child’s education. Birth to three services fall under Part C of the IDEA laws. For children three to five years of age, the law is described in Part B.

Dad: “Part B, Part C?”

Dr. Rick: “It’s just the actual name of the section of the law. I wouldn’t mention it but the IDEA law is a document with a lot of sections and you need to know what sections are important for you. For younger children ages birth to three, section B or Part B of the law covers what you get. For older children ages three to five, section C or Part C covers what you get.”

Dad: “That’s helpful.”

Dr. Rick: “Another important aspect of the law that gives you a lot of power is the fact that your child has the right to be in the least restrictive environment which means Jacob can be placed in a regular class with his same age typical classmates. A CI class is the most restrictive.”

Mom: “You mean we can decide about Jacob’s program? The school recommended the CI placement for Jacob and I just assumed they knew what was best.”

Dr. Rick: “Usually the school has the best interests of the child but you should still know what your options are. I think you should always ask about all school placement options within your school district for your child.”

Dad: “You can do that?”

3rd Secret: You can get an advocate from the school district.

Dr. Rick: “Absolutely. And did you know that you have the right to an advocate, someone from the school district who is independent, knows the special education IDEA laws, and can guide you in your relationship with the school including sitting with you at an IEP meeting.”

Mom: “That would have been great. Why didn’t we get an advocate?”
Dr. Rick: “You have to ask.”
Mom: “No one told me to ask.”
Dr. Rick: “That’s why I’m sharing the 5 Secrets of good advocacy.”
Dad: “So let me ask you this, Dr. Rick. If we have control over Jacob’s plan, why can’t we ask the school to give us more intensive intervention?”
Dr. Rick: “That’s a really good question and the answer is that the IDEA laws do not provide for it; and the special education systems are not designed to offer intensive services for children on the autism spectrum. What is happening in the country now is that insurance companies are beginning to pay for intensive intervention, not the schools.”

Note: As of this writing, only a handful of state Early Intervention (Birth to Three) programs (e.g., California’s Regional Center system) provide intensive intervention for children with ASD (e.g., 15-25 hours per week of 1:1 or 1:2 teacher to student ratios) consistent with the National Academy of Sciences recommendations before the age of three (See Chapter 3: When You Walk Out My Door: First Steps).

Early Diagnosis & Better Services
Dad: “I can understand not getting intensive intervention from the schools but why didn’t they diagnose Jacob with autism and why didn’t they at least tell us about how important intensive intervention is?”
Dr. Rick: “There are a few states that do make the diagnosis of autism early and provide intensive intervention right away, but as of 2016, the large majority of Early Intervention systems, like Michigan, don’t.”
Dad: “Our luck.”
Dr. Rick: “In fact, a lot of EI (Birth to Three) programs can’t make an early diagnosis.”
Dad: “What do you mean ‘can’t.’”
Dr. Rick: “They don’t have official permission from the state. In many states, the official diagnosis especially before age three has to come from a doctor or psychologist or a university autism center and there can be long waiting lists to see the diagnosticians.”
Mom: “That sounds terrible. I thought you were supposed to make the diagnosis as soon as possible.”
Dr. Rick: “It can be made as early as 14 months and should be made by 18-24 months most of the time.”
Dad: “You mean even if they think your child’s got autism, they can’t say anything?”
Dr. Rick: “Well, they don’t want to be wrong and until recently, it wasn’t easy to make a diagnosis. But there are newer diagnostic tools that the Early Intervention professionals are using in some states now (See Resources & Websites: First Signs), and things are changing, which is a great thing because we have to get these little ones into intensive intervention as soon as possible.”

Moving to Another State? Not One of my 5 Secrets!
Dad (half joking): “Maybe we should move to a state that has better services.”
Me: “This is not one of my secrets! Though, I have had families move to states like California or New York or Wisconsin where services are better!”
Mom: “We’re not moving. All of our family is here.”
Dad: “It just aggravates me that states are not consistently doing what’s right.”
Dr. Rick: “They’re trying to do what’s right. It just takes time for the systems to improve. And watch out what you wish for. I had one family who moved to get better services, but when they got settled, the services weren’t as available as they thought. So I always advise my families that before
they do anything drastic, they have to make sure they find out exactly what’s available now in a given state, in a given county, in a given school district, in a given school!"

**Mom**: “Well, we’re not going anywhere. But I’m really worried that, for the fall, the school’s placement for Jacob is not the right one.”

4th Secret: Put Every Important Communication with the School in Writing.

**Dr. Rick**: “Now we’re getting to the 4th Secret of Good Advocacy: Put every important communication with the school in writing. If you want to change Jacob’s school placement for the coming year you are going to have to change his IEP.”

**Mom**: “Isn’t it too late? We already have an IEP.”

**Dr. Rick**: “It’s never too late. I would just put a request in writing for a new IEP. ‘Dear Special Ed Director, With this letter I hereby request an IEP review for my son Jacob Grant.’ You can add what you want in writing. Ask them to evaluate Jacob for autism, attach my initial evaluation, and they will have to do it. Tell them in the letter that you want to reconsider Jacob’s placement. Putting things in writing triggers the law and the school has, I believe, 30 business days to respond to your request for a new IEP meeting.”

**Dad**: “Amazing. A short letter like that and we can get a new IEP, maybe a new class placement, and an evaluation for autism?”

**Dr. Rick**: “Secret number one: You have power. In fact I recommend putting all important requests and communications both to and from the school in writing! Keep a journal of communications. Keep all official communications in an organized folder. Hold on to emails. Write letters that express your concerns, don’t just tell someone. Once it’s in writing, it’s legal and must be addressed by law.”

**Mom**: “If we can fix it that easily I don’t feel as guilty.”

**Dr. Rick**: “You could get push back from the school. They may say that they would like to wait and see how Jacob does, but stick to your guns. The law is on your side.”

5th Secret: Know Your Legal Recourse if There is a Dispute.

**Dr. Rick**: “And this leads to the last secret: Know your legal rights if there is a dispute. If you find yourself strongly disagreeing with the school district, there are a series of actions you can take that will compel the school to legally address your concerns. You have the right to have a mediator listen to your concerns and ultimately, you have the right to sue the school district. I rarely recommend these, but I have many parents who threatened mediation and/or lawsuits but never had to go through with their threats. The school will usually relent. It’s a very expensive process for the school to go to mediation.”

**Dad**: “I feel so much more powerful!” (We share a round of high fives.)

**Dr. Rick**: “Now let’s settle which placement is best for Mr. Jacob.”

**Inclusion & the Least Restrictive Environment**

I explained that the classroom Jacob is scheduled for—where all the children with disabilities are taught in a separate class—is called the most restrictive educational setting because it has no typical children in it.

In several states the classrooms for children with disabilities include typical children. These are called inclusive or integrated classrooms where the children with disabilities can imitate or model after their typical peers. This would also be called a less restrictive classroom because it includes all types of children in it. These inclusion models are harder to implement and more costly than having separate classrooms for children with disabilities but the trend in the U.S. is toward more inclusion.
The *least restrictive* environment would be a regular preschool classroom but this would not necessarily be good for Jacob because there is not enough support for him.

*Thou Shalt Not Be the Highest Functioning Child in Thy Classroom.*

**Dr. Rick:** “So we want Jacob in the *least restrictive* school setting that’s going to be best for him. Julie, I have a question for you. You went to the CI class. Did you think the children there seemed lower functioning than Jacob?”

**Mom:** “That was my impression, yes.”

**Dr. Rick:** “If that’s true then that would break my cardinal rule for classroom placement: *Thou shalt not be the highest functioning child in thy classroom.*”

**Mom:** “The more we talk, the more the cognitive classroom sounds like a bad idea.”

**Dr. Rick:** “I agree with you Julie. After watching your last videos from the PLAY Project, I can see that Jacob’s making progress quickly. We want to keep that going. We want him to model upward.”

**Dad:** “You mean by imitating kids who are higher developmentally than he is?”

**Dr. Rick:** “At least at his level or higher. So let’s figure this thing out.”

**Classroom Options**

**Dr. Rick:** “While it may seem like there are a lot of options, there’s basically five and I’ll order them from least to most restrictive.

**Classroom Options: Preschool**

1. Typical, private preschool or Head Start preschool
2. ‘Inclusion’ preschool with typical children plus children with disabilities
3. Special Education Preschool (SEP) for children with mild developmental delays
4. SEP for children with moderate to severe developmental/cognitive delays
5. SEP for children with Autism Spectrum Disorders

- **Least Restrictive**: When children with disabilities are included in preschool classrooms with typical peers that’s considered the least restrictive. In some states, this option is readily available. In Michigan, a few districts offer these ‘inclusion or integrated classrooms’. Parents can take the child out of special education services altogether of course and place their child in a regular/private preschool setting. But for most children with disabilities this is not a good option because there is not enough support in the private classroom setting.

- **Less restrictive**: Next are the self-contained (i.e., no typical children) classrooms with children all of whom have Milder Developmental Delays (i.e., they have developmental delays according to the state’s definition). The teacher to child ratio by law must be at least one teacher to twelve children plus aide support. Many of these children have language delays or mild cognitive impairments.

- **Most restrictive**: The most restrictive classrooms are those A.) With children where all the children have Moderate to Severe Cognitive Delays (the one Julie observed) and B.) The classrooms where all the children have Autism Spectrum Disorders. In these self-contained classrooms the laws require a ratio of one teacher to six children plus aide support.
Dr. Rick: “Let’s talk our way through the various placement options for Jacob by going through the benefits and risks of each type of classroom option.”
Dad: “We should have done this before we signed our IEP.”
Mom: “Well, I didn’t know.”
Dr. Rick: “It’s hard to know what to do the first time around. I’ve done this dozens, if not hundreds of times and it’s still hard. Each child is different, and each school district is different. But let’s take it from least to most restrictive and start with typical preschool, which is the least restrictive.”

Is Typical/Regular Preschool Right for Jacob?
Dr. Rick: “Legally speaking, you always have the option of putting your child in a typical preschool with typically developing children which you would pay for in the private sector.”
Mom: “You mean we could put Jacob in Charlie’s preschool? I think he’d be lost in regular preschool.”
Dr. Rick: “The benefits of typical preschool would be that:

• Jacob would still have an IEP through the school district. So services like speech/language and occupational therapy can be delivered in the regular preschool setting.
• He would have typical children to model after for behavior and social skills.
• Academic demands would be age appropriate.

“But the risks of typical preschool would be that:

• Jacob would get no special help in the classroom (unless you arrange to pay for an aide yourself). There are no special ed teachers, no aides and fewer teacher helpers.
• You may get less day-to-day feedback because of class size and demands on the teacher.
• The faster pace and typical demands would be overwhelming for Jacob, leading to stress and behavior problems.

“I’m afraid Jacob would go off on his own and not get the kind of stimulation he would need to learn.”

Dad: “So that’s out. What’s our next option?”
Dr. Rick: “Special education preschool for children with mild developmental delays. It’s more restrictive than regular preschool but . . .”
Dad: “. . .less restrictive than the cognitive impairment classroom, right?”
Dr. Rick: “Exactly right dad.”

Special Education Preschool for Children with Mild Developmental Delays
For Jacob, the benefits of this type of preschool are:

• Class size is smaller than typical preschool. By law the teacher to student ratio must be at least one teacher to twelve students plus aide support.
• The teachers have been trained to work with children with special needs.
• The preschools are knowledgeable about special education and autism.
• The speech/language pathologists (SLP) and occupational therapists (OT) are typically on site. While you usually get about half an hour per week of S&L and/or OT, if your child needs more (and you are willing to fight for it—in writing!), you can get more one to one therapy written into your IEP.
• The other children in the class may have mild cognitive impairments or mild to moderate language delays. So children with mild autism can fit into these classes quite well. In other words Jacob would NOT be the highest functioning child in his classroom.”

Mom: “This sounds like the placement we should have put Jacob in in the first place.”
Dad: “Why did the school recommend the CI class at all?”
Dr. Rick: “Probably because they mistook Jacob’s autism for a cognitive delay. But with Jacob responding so well to intervention at home, the CI class turns out not to be the best for him. And Julie, don’t be so hard on yourself. The school thought it was best. It was really smart of you to go see the class. That really helped us to make a better choice.” (Julie smiles.)

What about an Autism and/or Cognitively Impaired Classroom?
Mom: “But what if the school was right? Now I’m having doubts.”
Dr. Rick: “Well, the most restrictive environment can actually be the best for a particular child. Sometimes, the best teacher and team are in the most restrictive, self-contained classroom.
• Class sizes are, by law, smaller than the developmental delay classes with a required ratio of one teacher to six students (1:6) plus aide support
• If there are two aides supporting the teacher, these classes can get down to a 1:2 ratio which would meet intensive intervention standards
• Most of the time, these teachers have been trained to work specifically with children with autism and/or cognitive impairments
• And Speech/Language (S&L) and OT therapists are typically on site so you can usually get more S&L and/or OT therapy written into your IEP.”

Mom: “So, maybe I made the right decision after all. I’m so confused.”
Dr. Rick: “I’m just discussing all your options but for Jacob I think he needs to be in the Mild Developmental Delay classroom. I repeat my cardinal rule:
• Thou shalt not be the highest functioning child in thy classroom. I think Jacob would be the highest functioning child in a self-contained CI classroom or ASD classroom.
• The problem with these classes is that they may underestimate Jacob’s abilities and not challenge him to reach his potential. This has been shown by research to be the main problem with these types of self-contained classrooms.
• Finally, children in these classes can have behaviors that you don’t want Jacob imitating. You do not want your child consistently modeling downward, i.e., imitating strange behaviors, screaming, spinning, etc. You want Jacob modeling upward.”

Dad: “So that settles it. We’ll send the letter. We’ve got to get him diagnosed with an ASD label from the school district and then re-do his IEP to get him into the ECDD classroom.”
Mom: “They’re going to be upset.”
Dr. Rick: “They’ll just know that they’re dealing with parents who are savvy about their rights.”
Mom: “After hearing all the options, I think the milder developmental classroom is best for Jacob.”
Dad (to me): “All this information on our rights under the law is amazing.”
Dr. Rick: “I think we’re doing the right thing for Jacob, and that’s what matters. Now we’ve got to talk about his other therapies like speech and language and occupational therapy.”

Postscript
Julie Grant called the office to say that she wrote a letter to the school requesting a new IEP and an evaluation for autism. Even though it’s summer, the laws require a response from the school district within 30 business days. Good going Julie!

Summary

- The Grants have to make an important decision about Jacob’s educational placement for the coming school year
- A review of Jacob’s current individualized family service plan (IFSP) reveals concerns about diagnosis and labeling
- I describe how children are enrolled in the Early Intervention system
- The Grants learn about the Individuals with Disabilities Education Act (IDEA) laws
- There are two systems of services in the U.S. for young children with disabilities
  1) Birth to three year old Early Intervention (Part C) services and
  2) Three to five year old Special Education Preschool (Part B) services
- I review the key provisions of the IDEA laws relevant for parents of young children with disabilities
- I describe my five secrets of good advocacy
- The Grants and I review school placement options for Jacob
- I help the parents arrive at an individualized education plan (IEP) for Jacob that is different from the one he currently has. We have to get the plan changed.

Resources & Websites

Websites

- IDEA Laws: http://idea.ed.gov/
- Screening and diagnosis of ASD: http://www.firstsigns.org/

Books


Coming Up Next

- What the Grants should consider before they start Speech and Language and Occupational therapy for Jacob
Chapter 6
Visit 3: Part 1
Climbing the Language Mountain

The Biggest Wish
All parents have one big wish for their child with autism: ‘We want our child to talk.’ In this visit, I talk to Jim and Julie Grant about how to help Jacob climb the ‘Language Mountain’ so he will have the best chance of developing functional language—language that truly communicates with others.

After deciding on an intensive intervention approach (the Grants chose to do the PLAY Project) and special education services finding a good speech and language pathologist (SLP) and occupational therapist (OT) for Jacob are the next steps in putting together a comprehensive intervention plan (we’ll discuss OT at the next visit).

While special education school programs almost always provide some speech and language (S&L) and OT therapies for children with ASD, the amount of time per week is typically small (as little as half an hour per month and as much as half an hour per week). Parents can always advocate for more hours of therapeutic services as part of their educational plan (IFSP or IEP—See Chapter 5), but most of my parents, if they can afford it and/or have insurance coverage, add some private S&L therapy and OT to their child’s program.

Dr. Rick: “So who’s watching the boys?”
Mom: “Grandma. My mom.”
Dr. Rick: “It’s great that you have that kind of support.”
Dad: “I even like them.”
Dr. Rick: “That’s a plus. The question is do they like you?”
Mom: “Ha! They adore Jim. My dad and Jim go fishing together.”
Dad: “I help them around the house. They’re getting up there in age.”
Mom: “But they can still keep up with the boys. It gives me a much needed break.”
Dr. Rick: “So how are you doing? Did you hear back from the school system about that IEP meeting?”
Mom (proudly): “In fact we did. The new IEP meeting is scheduled!”
Dr. Rick: “Way to go! And did you ask for an advocate?”
Dad: “We did. In writing. And we already heard back from her. We’re putting together a plan for the meeting along with some IEP goals.”
Dr. Rick: “You guys have done great.”
Mom: “Today, we wanted to talk about speech and OT goals for Jacob so we could put them into our IEP.”

Insurance Issues.
Dr. Rick: “You are getting so savvy! I agree, Jacob needs both speech and language and occupational therapies but before we get into the details, let me ask you if your insurance covers speech and language and OT services, because that’s the first step in this process.”
Dad: “I checked with my health insurance and they said they’d pay for 60 sessions a year—30 for speech and 30 for OT.”
Dr. Rick: “Good work, Jim. That’s not bad. I have a lot of families who get less than that especially if the diagnosis is ‘autism’. Did they say they’d give you coverage for autism?”
Dad: “Not exactly. I said Jacob wasn’t talking.”
Dr. Rick: “You have to watch out. In a lot of plans you can’t use the ‘A’ word or you won’t be covered. ‘Autism’ is not a diagnostic code.”
Dad: “They don’t cover autism?! That’s crazy, isn’t it?”
Dr. Rick: “The insurance companies argue that health coverage is supposed to be for acute medical conditions not developmental problems like autism. Even ‘language delay’ is not sufficient. You have to use terms like ‘apraxia’ for speech or ‘hypotonia’ for OT.”
Dad: “It really burns me that you have to play that game…”
Dr. Rick: “Usually they’ll give you your standard therapy benefit without too much hassle.”
Mom: “What if they don’t?”
Dr. Rick: “Call them and find out exactly what the benefit is and which codes are paid for. Get a letter from your doctor. I do letters all the time. Usually the SLPs and OT are good at knowing the codes.

“If you still don’t get the benefit, then I recommend going up the bureaucracy’s chain of command as far as you can go until you find the person who can make the decision.”

Dad: “Who’s that?”
Dr. Rick: “Usually the insurance company medical director or a special insurance board. Be persistent. They don’t want you to be unhappy. If you’ve got a real need, they’ll usually try to help you.”
Dad: “Sometimes I think they’re just protecting their bottom line.”
Dr. Rick: “The insurance landscape is changing and autism is being seen as a ‘medical condition’; so in the future it might get covered but for now we have to play a game.”

Traditional Speech and Language Therapies Are Not Intensive
Dr. Rick: “And I don’t mean to rain on your parade, but even if you do get an hour or two per week, you’re still not getting much intensity.”
Mom: “So one hour a week won’t make any difference?”
Dr. Rick: “The real problem with these traditional services is that they are based on an old medical model: ‘Bring your child to our outpatient clinic, and we’ll fix him.’ That might work with stuttering or eating problems, but it’s not going to work with autism. It’s disappointing to say, but there’s little evidence that traditional language services help children with autism get better.”
Dad: “No evidence?”
Dr. Rick: “Not for traditional S&L therapy. There is some evidence for a program called Hanen (See Resources & Websites). Hanen SLPs train parents to interact in a playful way through a twelve-week course. Then, parents apply the method at home.”
Mom: “Jacob got Hanen through his early intervention program.”
Dr. Rick: “I love their book ‘More Than Words’.”
Mom: “After the sessions, though, there wasn’t any follow up.”
Dr. Rick: “That’s true, but you can learn a lot from those sessions.”
Dad: “In the PLAY Project, the therapists come every month, right?”
Dr. Rick: “Right. We give support for one to two years typically.”
Dad: “So should we even do the therapy?”
Dr. Rick: “Absolutely. You must. Good SLPs can be very helpful. They know their business and they can guide Jacob up the Language Mountain. All I’m saying is that one hour of therapy isn’t going to be that helpful. So, what I recommend is this:

- **Stretch** the S&L sessions out to every other week or even once a month. This will make your insurance benefit last longer.
- **Observe** the sessions and learn the methods the therapists are using. You should always be invited in.
- **Videotape** selected sessions for ten minutes and get at the heart of what the SLP is doing.
- Then, **implement** the methods at home and use them throughout the day.

Dad: “That makes total sense. With our insurance benefit of 30 sessions per year, if we do speech therapy once a week we’ll be done with it in half a year. Then we’ll have to pay out of pocket and it’s not cheap. We’re talking $80 for a half hour! But if we do what you’re saying, we can stretch out the benefit for a least a year.”

Dr. Rick: “Dad, your math is exactly right.”

Mom: “So in the meantime, we go in to the sessions, videotape some of them, and then use the methods all day long.”

Dr. Rick: “Bingo.”

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**The Wish for Talk.**

Dad: “To be honest, Dr. Solomon, I’m a little frustrated with this whole discussion.”

Dr. Rick: “How so?”

Dad: “It sounds like it’s going to take a lot of time and therapy to get Jakey to talk.”

Mom: “We had high hopes for the speech and language therapy.”

Dad: “Because for us, Dr. Solomon, Jacob’s talking is our top priority.”

Dr. Rick: “But he’s already starting to communicate. He takes your hands to get what he wants. He’s starting to understand some routines, right?”

Dad: “But that’s not talking. He doesn’t even say ‘Hi’ when he meets someone.”

Dr. Rick: “But he’s got some words that he uses sometimes.”

Dad: “I know, I know, but I want him to talk—like Charlie does.”

Dr. Rick: “Charlie’s almost 18 months?”

Mom: “And he’s starting to put some words together.”

Dad: “You can actually carry on a little conversation with Charlie. I just wish Jacob could do that.”

Dr. Rick: “I’m confident that he will, but he’s got to climb what I call the Language Mountain.”

Mom: “The ‘Language Mountain’?”

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**Climbing the Language Mountain**

All parents have the fundamental wish that their child will **talk** and be able to carry on a conversation. Of course, I share this wish too, but I know that in order to get to the mountaintop of conversation, children (and their parents) must start at the bottom of the mountain and take their first steps upward.

These first steps begin with the simple ability to **share attention**, then stay **engaged** long enough to interact in a **two-way back and forth** fashion until the child can communicate mostly through **gestures**. This can take a year or even more, depending on how fast your child can climb, so to speak.
The real key in the beginning is to have fun during social interactions by following what the child likes and wants (usually rough-housing) in a way that will make your child want to interact with you.

Paradoxically, this non-verbal play is the fastest way to help your child gain language that leads to social communication!

Then, once your child is communicating back gesturally (i.e., showing you he wants more by holding up his hands and/or nodding his head and/or smiling), he will start to understand routines. This ability to understand is called receptive language. He will be able to truly make sense of the world. When you say, “Time to eat” he’ll take his seat in the kitchen or dining room. After several more months, he will be able to understand the spontaneous one step commands like “Go get that ball. Bring the ball to daddy.”

Children Will Talk When They Can.

- Communicate gesturally
- Follow routines
- Solve simple problems (e.g., get you to get food)
- Play very simple pretend (phone to ear, feeding baby)
- Have longer back and forth interactions
- Follow one-step spontaneous (not routine) commands to ‘go get’ an object and ‘give it’ to someone

When all these preliminary milestones at the bottom of the Language Mountain are in place, then single words will multiply. This is called expressive language. After several more months to a year, two word sentences will emerge. Finally, longer sentences will lead to the ability to carry on longer and longer conversations. Conversation is the last milestone and, depending on the child, this could take a couple of years.

I explain all this to the Grants, but my intuition tells me that they are not really hearing me. They want Jacob to talk no matter what.

Speech vs. Language.

Dad: “Isn’t there any way we can speed up the process?”
Dr. Rick: “Putting in more time—intensity—will speed up the process but if you go beyond the 2-3 hours per day, Jacob will burn out, you’ll burn out, and everybody in the family will suffer.”
Dad: “Oh, we’re going to put in the time, but I’m talking about speeding up speech somehow.”
Dr. Rick: “Actually, you can speed up speech.”
Dad (excited and interested): “How?”
Dr. Rick: “By repetitive drilling and focusing on speech itself. But you have be careful not to speed up speech at the cost of language.”
Mom: “I thought they were the same.”
Dr. Rick: “There’s a big difference between speech and language. Do you know about kids with Asperger Syndrome?”
Dad: “They are smart but odd, like Temple Grandin. I saw her on YouTube.”
Dr. Rick: “But she’s an adult. When children with Asperger Syndrome are young, they have good speech, but they have problems with engagement and the back and forth of real communication.”
They can’t carry on a conversation. SLPs call this having problems with ‘pragmatics’—problems with socially effective communication. They are good at speech but bad at language.”

Dad: “I get it. Speech is what comes out of your mouth…”

Dr. Rick: “…Language is the ability to communicate.”

Mom: “So you can speak but not really communicate.”

Dr. Rick: “Exactly. I have a lot of parents who drilled their children to speak before they were truly ready. The children developed words, but they weren’t connected to people in a natural way. Many of these children sounded robotic, had poor gestural communication (with flat voices or odd sounding talk), or just used words to get what they wanted, but they didn’t enjoy interacting and conversing with people.”

Mom: “We don’t want that.”

Dr. Rick: “It’s tempting to just go for speech. It takes a lot longer and a lot of patience and time to build the capacity for real communication.”

_A House of Bricks._

Dr. Rick: “Instead of climbing a Language Mountain, think of building a house. First comes the foundation—attention, engagement, a few back and forth circles of interaction. Then come the walls—lots of circles (the ping pong back and forth) of communication, gestures, and problem solving. Then comes the roof—words, sentences, conversations. There’s no way around these functional developmental levels when you’re trying to build a solid structure.”

Dad: “Like the house of bricks in the Three Little Pigs. I’ve been reading the story to the boys.”

Mom: “They’ve been huffing and puffing all around the house.”

Dad: “So we can speed up the process of talking…”

Dr. Rick: “…and build a house of straw. Or we can focus on ‘language’ and communication more than speech.”

Dad: “…and build a house of bricks.”

Dr. Rick: “Right on dad! It takes longer this way, but it’s better. It’s hard convincing parents to start basic, but that’s truly the way to go in my opinion.”

_When Will He Talk? There’s no way around the Language Mountain!_

Dad: “OK, I’m convinced we shouldn’t force speech. But if we do it your way, how long before we get to the top of the Language Mountain?”

I was right. The Grants didn’t really hear me earlier, but I think they are ready now.

Dr. Rick: “I don’t have a crystal ball, but let me walk you through a rough time line on how long it will take for Jacob to climb up the Language Mountain.

“First and most importantly, you have to have fun together. That will lead to shared attention and engagement, then longer and longer back and forth interactions. We’re going to focus on these right away in the PLAY Project. Then, assuming all goes well, he’ll march up the mountain with gestures and improving receptive language (understanding) and by then, he’ll have a lot of single words. All this will take nine months to a year. I’m being optimistic here based on Jacob’s profile.

“Then, he’ll start talking in two word phrases after that, hopefully in another nine to twelve months or so. In general, having a mild autistic disorder like Jacob’s costs a child at least two years of his or her developmental life.”
Dad: “So, if Jacob is three . . .”
Mom (with a disappointed voice): “. . .then he’s at a one year old level?”
Dr. Rick: “He has some emerging single words like a one year old and he’s communicating mostly in gestures.”
Dad: “That’s pretty discouraging.”
Dr. Rick: “But with intensive intervention, assuming all goes well, we should be able to keep him moving up at a nice pace.”
Dad: “. . .You mean like when he’s six, he’d be like a four year old?”
Dr. Rick: “Some children catch up with their same age peers but most children with autism will stay behind a year or two in my experience.”
Dad (looking at his wife): “One year behind would be OK. But two years behind sounds bad to me.”
Dr. Rick: “One year behind by age six would be wonderful. And it is possible. I’m being optimistic here.”
Dad: “Then by the time he’s 40, he’ll be like a 38 or 39 year old!” (Dad and I laugh, but mom is looking sad).
Mom: “So Charlie’s ahead of Jakey?”
Dr. Rick: “I’m afraid so.”
Mom: “That really makes me sad.”
Dr. Rick: “I know. I know. It’s sad when the younger child’s development is better than the older child’s. I know this is a very hard discussion, but please don’t be discouraged.”
Mom: “I’m trying not to, but every day it’s something else. Now, it’s going to be years before Jacob talks.”
Dr. Rick: “Look at me. I really believe that Jacob is going to do well. I wouldn’t say this if I didn’t believe it. I’m actually encouraged. Jacob is already communicating.”
Mom: “But he only has a few single words, and he doesn’t use them very much at all.”
Dad: “Julie, that’s what Dr. Solomon has been trying to say. Words come later.”
Dr. Rick: “Right, Jim. The words will come.”

I look at them, and they both look so forlorn.

Dr. Rick: “OK. Now, you’re making me sad.”
Mom: “So you’re saying it’ll take about two years, and he’ll be talking.”
Dr. Rick: “Not just talking, but really communicating. And it’s going to be fun along the way. Please, you guys, you have to have some faith in the process.”
Dad (raising and lowering his hands above his head): “I believe. I believe.”
Mom (elbowing him - still a little irked): “Don’t be sacrilegious.”
Dr. Rick: “I like his sense of humor.”
Mom: “That makes two of you.”
Dr. Rick: “I’m so sorry this discussion has upset you.”
Mom: “It’s just another disappointment.”
Dad: “We were really hoping he’d talk sooner.”
Dr. Rick: “He will. I know he will. Let’s just take it a step at a time, OK?”
Mom: “I’ll be fine.”
Dad: “What’s next?”

Gestures
Dr. Rick: “Let’s talk about what you can do right now to promote language, and then, we’ll talk about finding a good language therapist. OK if I record this discussion?”

They’re sad, but they’re with me. I get out my recorder and begin.

Dr. Rick: “The next step in language for Jacob involves gestures. Let me repeat myself with gestural emphasis.” I stand, raise my hands above my head and shake them as I bob my head with forceful enunciation and take a step closer to Mr. and Mrs. Grant, “I cannot emphasize enough the importance of gestural communication to your child’s language development.”

Dad: “You’re scaring me.”
Dr. Rick: “Up to 80% of our adult communication is in the form of gestures. I distinguish three types of gestures: big, little, and micro gestures.”

Types of Gestures

Big
• Taking hand
• Turning head
• Body orientation

Little
• Pointing
• Head nodding or shaking

Micro
• Eye contact
• Vocal inflexion

Mom: “Jacob is gesturing a lot.”
Dr. Rick: “A lot. So let’s make sure we pay attention to the intentions behind his gestures and treat gestures as if they matter because they do!”

Don’t Ignore the Meaning of Gestures. In my workshops I give this example of ignoring gestures: There’s a little boy, we’ll call Johnny, who wants some juice from the fridge. He’s gesturing. He’s reaching, pointing, making faces that clearly indicate with gestural language that he wants juice.

His mom says: ‘Johnny, what do you want?’
Johnny’s arm is out pointing; he’s grunting, he’s reaching.

Mom: ‘What do you want?’
Johnny: Grunting, getting frustrated, still not saying what mom wants him to say. Finally, Johnny gives up crying and starts to wander off.
Johnny: comes back in anticipation.
Mom: ‘Say ‘juice’. ‘I want juice, please’.

Eventually after many trials, Johnny may learn to say ‘juice’, but this is a mistake of parents who think that speech is the goal. No! Language is the goal. And early language is about gestures, not words. Johnny was clearly communicating what he wanted through gestures. By ignoring his gestures, Johnny’s mother is ignoring his most important communication system. As a result, Johnny’s gestural language may be impoverished.”
Dr. Rick: “How would you like it, mom, if you went up to Jim and (gesturally) pursed your lips as you leaned forward to give him a kiss and he says, pulling back: “What do you want, Julie? Say ‘kiss,’ say ‘kiss.’” It would be insulting and infantilizing, right? It’s no less frustrating for children.”

Mom: “I never thought of it that way.”

Dad: “I’d never do that. She’s the one who makes me work for a kiss.”

Mom (in mock warning): “Jimmy, if you want a kiss, you better watch what you say.”

Dad: “Yes, dear.”

Dr. Rick: “Smart man. By not paying attention to gestural intention, we trade the child’s true communication system (i.e., gestural language) for speech. A bad trade. If you ignore gestures, your child will learn that his gestures and intentions don’t matter. As I said before, you must have faith that speech will come naturally as language develops. As I say to parents ‘You can’t push the speech river.’ Trying to hurry speech can ruin language.”

Dad: “Right. We want language, not just speech. Got it.”

True Speech Delay.

Dr. Rick: “There is one exception to the rule that speech will follow language development. Sometimes this is called apraxia or dyspraxia. I call it an expressive language delay, which occurs when receptive language is much better than expressive language.

“When your child can follow one to two step commands (e.g., ‘Go get that cup and give it to daddy’) and is still not talking in one word phrases, then he/she has an expressive language delay.

“Solutions range from traditional speech therapy, to computerized communication devices, to alternative speech interventions. This is where your SLP comes in. They are truly experts on speech delays.”

Promoting Language: Techniques

Mom: “Do you think Jakey has dys...”

Dr. Rick: “Dyspraxia? No, I don’t think so. Time will tell, but he’s got a few words, and he pronounces them fairly well. We’ve just got to start where he’s at and build.”

Dad: “Where do we go from here?”

Dr. Rick: “There are a number of wonderful methods and techniques for building language. The most important is to have fun together. But there are techniques. I’ll just mention a few here to get you going; but that’s the real reason you need a good SLP—to guide you up the Language Mountain.”

Language Techniques

• Honor gestures as communication
• Speak for the child. Use statements not questions.
• Onomatopoeia—word sounds like what it means
• ‘Asked and answered’
• Salient Language
• Speak to the child in normal tones and rhythms. No baby talk!
• The 20 top words that matter

Dr. Rick: “When your child gestures, try one of my favorite techniques: Speak for your child’s gestures in the form of a statement that he might say. In my experience, parents ask way too many
questions and then wonder why their children’s voices go up at the end of the sentence: ‘Want juice?’, ‘Go outside?’, ‘Eat cookie?’ Make statements. Keep it simple. When he reaches for the juice you can say, ‘Oh, you want juice,’ as you hand him the juice; or simply ‘Juice, here’s your juice.’”

Dr. Rick: “Don’t feel too guilty. Most parents do that. Just be aware of how you’re talking and try to make more statements. Another technique I like a lot is called onomatopoeia.”

Mom: “I remember that from high school English.”

Dr. Rick: “The word sounds like what it means. Like ‘buzz’ sounds like a bee buzzing. Or making your voice go up when you say ‘U-u-u-u-p’ and down when you say ‘D-o-w-n-n-n.’ Use guttural sounds ‘uh oh’, ‘zooooom’, ‘grrrr’, ‘vrooooom’. It makes sense to the children. They love it especially when you rough house and make sounds at the same time.

“A cool technique I learned from one of my SLP friends is called asked and answered. So in the case of getting juice, you would ask: “Jacob, you want juice?” Then you answer: “OK. Here’s some juice.” That way he hears the word ‘juice’ twice.

“Remember to use simple, salient language. Both of the techniques above use salient language. Salient means ‘stands out’. Label objects (like ball, car, bubbles) and actions (like jump, on/off, open/close). Name people (mommy, daddy, Charlie).

“Jacob will first talk using single words and the words he’ll say will be the most important words to him, not to you. So the next technique is to decide what words are the most important. I call this the Top 20 words.”

Dad: “You mean like ‘out’. He loves to go out.”

Dr. Rick: “Exactly. Words like ‘three’ for 1-2-3. Or ‘go’ as in ‘ready-set-go’. These are the pay-off words. Here’s a set of a child’s first words with their functions (I hand him the list.)”

Child’s First Words

- Rejection: No
- Nonexistence/Disappearance: All gone, away
- Cessation or prohibition of action: No, stop
- Recurrence: More, again
- Action on objects: Get, do, make, throw, eat, find, draw, fix, wash, kiss, bump, push, squeeze
- Locative action: Put, take, up, down, out, fit, sit, fall, go, dump, turn
- Attribution: Big, hot, dirty, pretty
- Possession: Mine
- Commenting: Look
- Social Interaction: Hi, bye-bye, night-night

Dad: “Very helpful.”

Mom: “So in the beginning when we’re speaking for Jacob, we should use one word or two word phrases that Jacob might say if he could talk.”

Dr. Rick: “Bingo. On the other hand, when you are speaking to Jacob, talk in sentences with normal tones and rhythms.”
Dad: “Aren’t you contradicting yourself?”
Dr. Rick: “It may sound contradictory, but it makes sense. You talk to Charlie in full sentences don’t you?”
Dad: “We do.”

Dr. Rick: “Why? Because you want him to hear what appropriate language sounds like. So don’t baby talk!”
Mom: “I think I baby talk to Jacob all the time.”

Dr. Rick: “I’m glad you can see that. Now, you don’t want to talk in language that is too complicated. Keep it simple but use full sentences, a normal tone, and rhythm. You’re allowed to sing!”
Mom: “I love to sing.”

Later Language Milestones
Dr. Rick: “So let’s finish up this discussion on how language progresses up the Language Mountain because we still have to talk about finding a good SLP for you.

“After talking in one to two word sentences, Jacob hopefully will be able to:

- Imitate any word you ask him to say
- He will be able to answer ‘What’ (“What is this?” “A dog”)
- ‘Who’, and
- ‘Where’ questions (“Where is daddy?” Child points at daddy.)
- He will answer ‘yes and no’ appropriately

Later Language Milestones
- Imitate most words you say
- One word sentences (Labeling objects)
- Two word sentences (‘Mommy, out’)
- Simple conversations
- ‘What, Where, Who questions
- Verbs and actions
- No AND Yes
- Open ended ‘what’ (‘What are you doing?’)
- Simple Pronouns (me, mine)

Eventually, Jacob will be able to answer open ended ‘what’ questions like, “What are you doing?” or “What do you want to do?” This is when he will be talking.”

Dad: “I can’t wait.”
Dr. Rick: “I hope you can see how the Language Mountain works.”
Mom: “We start with interaction, then gestures, then words.”

Dr. Rick: “By George, she’s got it. Eventually, he will ask and answer ‘Why’ and ‘How’ questions and will be able to recall the past, e.g., “What did you have for breakfast?” or “What did you do at school today?” Pronouns come in later too. Over this time, the number of words, the length of sentences, and the sophistication of grammar will increase.”

Choosing an SLP
Dad: “This has been very helpful, and I think we're feeling better, but we've got to make a decision.”
Mom: “Where do we go for a good language therapist?”
Dr. Rick: “I’d start with the SLPs that are covered through your insurance. That way there's no out of pocket expenses.”
Dad: “But we want a good SLP.”
Dr. Rick: “Most of the hospitals and university clinics are very good. I'll give you some names of private rehab centers. They take insurance too. I've also got a list of private therapists who don't take insurance.”
Dad: “Why not?”
Dr. Rick: “They don't have to.”
Dad: “I get it. They're really good.”
Mom: “I think we'll look for the ones who take insurance first. But how do we know they're good?”
Dr. Rick: “Here’s my criteria:
• First of all, they should be fully credentialed and licensed so you know they're well trained. All SLPs at hospitals and universities are licensed.
• It would be very helpful if they were recommended from someone you trust.
• Next, they need to make a connection with Jacob.
• They should know how to help Jacob climb up the Language Mountain.
• And lastly, they won’t be afraid to let you in to observe and videotape. They should be willing to teach you how to help Jacob at home by giving you some homework.”
Dad: “That brings us full circle.”
Dr. Rick: “One more thing. In my experience, S&L therapists come in two types—those who are more speech and language centered and those who are more child centered; the first type tends to focus on language goals and the second type tends to focus on the child's play interests. Speech and language centered therapists will use drills and activities more often than not. Child centered therapists will use play to motivate the child to pay attention and engage through fun back and forth interactions. Many talented therapists can use both approaches effectively.
“My bias is this: Jacob is still at the early intervention stage at the beginning levels of the Language Mountain. He needs a more child centered SLP. When he's developed better receptive language and is beginning to understand simple ‘wh’ questions (about age two equivalent), then I'd recommend a more speech and language centered therapist. It would be best if you found someone who can do both.”
Mom: “Thank you so much Dr. Solomon.”
Dr. Rick: “Are you feeling better about the ‘talking’ issue?”
Mom: “It's best to know the truth. I'll get over it. I'll feel a lot better when we get going.”
Dad: “We’re going to help Jacob climb that Language Mountain from the bottom up.”
Dr. Rick: “I really think that’s the best. I’m very hopeful about Jacob's language. The other thing we have to talk about is occupational therapy because we don’t want Jacob’s sensory issues interfering with his progress. Plus, occupational therapy is fun, and that’s the first order of business.”

Summary
• Jim and Julie Grant's main wish is for Jacob to talk in sentences and be able to carry on a conversation.
• They want to get speech and language therapy so Jacob will ‘talk’.
• We discuss insurance coverage and how to make the most of speech and language therapy.
• I introduce the Grants to the Language Mountain and distinguish between ‘speech’ and ‘language’.
• It’s hard for Jim and Julie to hear how long it takes for a child with autism to march up the Language Mountain and gain conversational skills.
• Language begins with functional development at the bottom of the Mountain, namely, paying attention, staying engaged, and initiating two-way interactions.
• In order to improve functional development, parents need to have fun and enjoyable interactions that honor the child’s ideas and intentions.
• I think I convinced the Grants that if they try to force speech, and skip gestural and receptive language to achieve ‘talking’, the cost will be a loss of complex language.

Resources & Websites
• Hanen: http://www.hanen.org/Home.aspx
• Fern Sussman, More Than Words and Talkability, as well as other Hanen resources: http://www.hanen.org/Guidebooks--DVDs/Parents.aspx

Coming Up Next
• What is Jacob’s ‘sensory profile’?
• How can we help Jacob regulate himself?
• What are ‘Sensory Integration/Occupational Therapists’ and how can they help?
Chapter 7
Visit 3: Part 2
OT & Sensory Integration

Why Occupational Therapy for ASD?
Mom: “I think we have a much better understanding of speech and language therapy, but I don’t get why Jacob would need an occupational therapist. Don’t they help kids who have physical problems?”
Dr. Rick: “That’s what traditional OTs do.”
Dad: “But Jacob doesn’t have any physical problems. I think he’s pretty coordinated. He can use a fork. He climbs like a monkey. Strong as an ox.”
Mom: “You think he’s coordinated? I thought he was kind of clumsy, the way he just bulls his way everywhere, stepping on things. It’s like he’s totally not aware of his surroundings.”
Dad (conceding): “That’s true.”
Dr. Rick: “Even though OTs, along with PTs (physical therapists), work on rehabilitation after injuries and skills of daily living like eating and dressing, they also help children with sensory-motor problems.”

Sensory-Motor Domains
Dad: “What exactly do you mean by sensory-motor?”
Dr. Rick: “Sensory means input from your senses, and motor means the input from your muscles and joints. Most children with autism, because of their under-connected brains (See Chapter 1), are often stuck in their bodies. Their sensory-motor systems stay immature, and they can have real trouble with controlling what I call their ‘sensory-motor domains’. It’s as if their body controls them.”
Mom: “Is that why Jacob is so hard to reach when he’s absorbed in his toys?”
Dr. Rick: “That’s a good example of what I’m talking about. He can’t regulate or control himself to connect with you when he’s so visually absorbed.

“But his sensory-motor system is telling you something important about him. Every child has a unique sensory-motor profile based on a list of sensory-motor domains (see below):

<Insert 1.1 JPEG OT v2 here>

“When you ‘listen’ to what this sensory-motor system is ‘saying’, then you can connect better with your child. Just as there is a language system for words and gestures, there is also a ‘language of the body.’ A good OT understands that language and can pull the child out of their sensory self-isolation. An OT might say they are ‘helping the child integrate their sensory-motor system’, also known as ‘sensory integration’. I refer to them as SI/OTs, sensory integration/occupational therapists. SI/OTs use the child’s sensory-motor system to connect with the child socially.”

Dad (confused): “So sensory integration OTs helps with regulation?”
Dr. Rick: “I’ll talk more about self-regulation later but think of ‘regulation’ as self-control. It’s as if Jacob’s senses take over and control him. Think of ‘integration’ as not being stuck in sensations. So ‘sensory integration’ means that the child is able to control their sensations and be connected with the world."
Mom: “Otherwise it’s all too overwhelming.”
Dr. Rick: “Exactly. And it’s not just kids with autism. There is growing evidence (See Resources & Websites) that all of us have sensory integration issues.”

Dad: “Really noisy restaurants annoy me.”
Mom: “Is that why Jacob hates going to the mall?”
Dr. Rick: “See, now you’re thinking like an SI/OT.”

* Scientific Note: There is growing evidence from Lucy Miller, PhD (See Resources & Websites), that many of us (not just children with ASD) have problems with sensory issues. She has shown, through repeated physiologic measures, that some of us are oversensitive to sensation while others of us are under-sensitive to sensations. She also noted a group of people who are ‘sensory seekers’ and crave sensation.

**Jacob’s Sensory-Motor Profile**

Mom: “Jacob’s definitely ‘stuck in his senses’. I can call him, and it’s like he’s deaf sometimes. Is that what you mean?”
Dr. Rick: “Right. That would be called an ‘auditory processing problem’. He’s not processing or making sense of sound. Did you see the way he visually studied his lined-up cars when he was here the last time? So, Jacob has the type of issues that an SI/OT addresses.”
Dad (laughs): “He’ll even put the cars on the table at eye level so he can study them better. He’s visual all right.”
Dr. Rick: “So if an OT helps us to understand Jacob’s sensory-motor profile, then we can ‘speak the language of his body’ and engage him.”
Dad: “But when he’s watching his ‘Baby Einstein’ videos, I can’t really engage him very much.”
Dr. Rick: “That’s what the sensory system can do too; the love of certain sensations can put the child in a jail of isolation. But other senses can get them out of jail, so to speak, so the children can be with us. It’s been my consistent experience that the visual system tends to be more isolating, and the touch systems like wrestling and chase and squeezing tend to help the child be more social.”
Dad: “He loves it when we wrestle. Comes back over and over for more ‘crashes’. That’s what we call it.”
Dr. Rick: “See that? The visual system isolates him and the touch system connects him. Any other sensory or motor issues?”
Mom: “His hearing is amazing. Remember Jim when he heard that airplane before any of us? But he also hates loud noisy places.”
Dad: “It’s not only the mall. We can’t go to the grocery store or restaurant without him wanting to leave.”
Mom: “And he puts things in his mouth and loves to chew. We have to watch him like a hawk.”
Dr. Rick: “Welcome to the world of occupational therapy! Jane Ayers (See Resources & Websites), one of the foundational thinkers in OT, asserted that these sensory-motor issues are neurologic in nature. She claims that through OT, the child’s brain can be changed so the children are less dominated, absorbed, and controlled by their senses, i.e., they become ‘more integrated’.” I look through Jacob’s chart. “What about Jacob’s motor, I mean, muscle system? My notes show that Jacob walked early.”
Mom: “And he’s been on the go ever since.”
Dr. Rick: “His ‘motor’ runs fast, so to speak.”
Mom: “Very fast.”
Dr. Rick: “And he struck me as pretty reactive. He gets upset easily.”
Dad: “I’d agree with that. He wants what he wants when he wants it, and when he doesn’t get it, watch out. Is that part of his sensory-motor system too?”
Dr. Rick: “Impulsivity—how fast and how strong a person reacts to events—is part of the brain system. This has to do with emotional regulation.”

Dad: “And you can deal with that through OT?”

Dr. Rick: “Many OTs think you can help emotional regulation using body-based methods. While certain sensory modalities, like rocking and swinging, can be very calming, I think it takes more than OT methods alone to help with things like, say, tantrums.”

Mom: “I’m glad you brought that up. Jacob’s been having tantrums when he can’t get what he wants or when he gets frustrated. Not big ones but lots of little ones.”

Dad: “All day long. He gets over them pretty quick though.”

Dr. Rick (making notes): “So he has some ‘trouble controlling himself’, ‘trouble regulating his emotions’. Some kids are over-reactive (to emotions, to noise, to smells). Bad experiences will make them anxious, irritable, even aggressive. And some kids are under-reactive; nothing seems to bother them. You can take their toy and they won’t care. They are shut down.”

Mom: “I think Jacob has a little bit of both tendencies. Charlie used to be able to take Jacob’s toy but not anymore.”

Dad: “He can get really upset sometimes, and other times, he just ignores you, wanders off.”

Dr. Rick: “So let me see if I can summarize Jacob’s profile. Jacob’s a very visual guy who can get absorbed in visual self-stimulation. I’ve seen him put his head on the floor and run trains in front of his eyes for example. He’s got sensitive hearing and problems with sudden, loud noises or noisy environments. When it comes to motor planning, he’s a bull in a china shop, but I remember you telling me that he also gets pleasure from jumping, climbing, and spinning. He likes to chew on things, and he’s impulsive, gets upset quickly, and throws tantrums—he’s got a short fuse.”

**Jacob’s Sensory-Motor Profile**

- Visually absorbed. Loves to look at lines. Hard to engage when he’s ‘stimming’.
- Hypersensitive hearing. Loud noises bother him. Ignores voices a lot.
- Trouble with motor planning. ‘Bull in china stop’. Physically strong.
- Loves to climb, jump, and spin. Fast ‘engine’.
- Loves deep pressure (rough housing).
- Mouths everything. Picky with textures.
- Emotionally reactive but can tune out.

Dad: “That’s him in a nutshell.”

Mom: “It’s amazing to see how Jacob’s…”

Dr. Rick: “…sensory-motor profile…”

Mom: “…sensory motor profile affects him so much.”

Dr. Rick: “SI/OTs help find the right balance for the child’s system, so the over-reactive kids calm down and under-reactive kids get more engaged.”

Dad: “You keep saying SI/OT but I keep thinking of OTs as therapists who help adults after having a stroke.”

Mom: “So now we have to add OT. It’s all so overwhelming. There are so many things to think about.”

Dr. Rick: “It is a lot to think about. But our intervention has to address all of Jacob’s issues. We have to take a comprehensive approach. But don’t you worry too much, mom; we’ll figure this out together.”
**Traditional OT and SI/OT Methods**

**Dr. Rick:** “I'll tell you what. Let me cover what I see as the difference between traditional OTs and Sensory Integration OTs (SI/OT) and then we can make a plan for Jacob:

“Traditional OTs will typically focus on:

- Fine motor (small muscle) coordination (like handwriting)
- Gross motor (large muscle) coordination, balance and motor planning (like clumsiness or sequencing a series of actions)
- Muscle tone, posture, range of motion, and strength (low tone, stiffness, problems crossing the midline); and
- Skills of daily living (eating, dressing, toileting, brushing teeth, etc.)

“Traditional OTs, for example, work with children who have had limb or head injuries in car accidents, or gotten bad burns that limit range of motion of their arms and/or legs, or those children who have very poor coordination because of cerebral palsy, brain injury, etc. These OT and PT (physical therapy) services are often provided in children’s hospitals or rehabilitation clinics. The use of swings, inclines, other movement equipment, fine motor games, etc., helps children achieve improved bodily skills. Such services are often paid for by insurance and have a long history of effectiveness.

“For children with autism, however, these traditional OT approaches are going to be limited to helping with fine motor issues like handwriting problems, or oral motor/feeding issues. They also work on low tone, posture, balance, and motor planning/coordination problems, all of which children with ASD have.”

**Mom:** “Jacob definitely has food texture issues.”

**Dad:** “He’s getting more particular the older he gets.”

**Dr. Rick:** “That’s exactly the type of thing a traditional OT could be helpful with and something we should talk about in one of our next visits (See Section 3: Daily Hassles). But let me talk about SI/OTs by giving you a clear definition of sensory integration.”

**Sensory Integration OT (SI/OT)**

**Dr. Rick:** “The OT who focuses on sensory integration helps you, as the parents, to ‘speak the language of your child’s body’ so you understand that, on the one hand, Jacob hungers for some sensations, and on the other hand, he has difficulties with and wants to avoid other sensations. He needs help to process all this sensory-motor input so he can better connect to the world and especially to people. What you are doing fundamentally is helping Jacob make ‘sense’ of the world. You are helping him integrate his senses into a ‘gestalt’ or whole picture.

“Children with autism experience the world as fragments of separated sensations—like puzzle pieces that don’t fit together. A face is not ‘a face’. It is just a collection of physical parts that never come together – the parts are not recognizable as a whole. Trains are not thought of as ‘trains’. It is color, spinning wheels, and a series of rectangular shapes that form a line.

“When the world is experienced this way, it is easy for the child to get stuck, isolated, and absorbed in one sense or another. For example, the child with autism will watch a wheel spinning over and
over and over. So, sensory integration is the process of helping the child put the pieces together to form a whole puzzle.

“So besides the traditional OT modalities, sensory integration OTs (SI/OTs), also offer an array of other treatment modalities based on the child’s sensory profile, including:

- Sensory diet and replacement therapy
- Desensitization
- Sensory-motor processing, and
- Sensory Integration all of which add up to better
- Self-regulation and shared attention with people

After I list all the SI/OT modalities, Mrs. Grant’s eyes widen, and her forehead rises. She looks anxious. I pause and look at her expectantly.

Mom: “This just seems like so much to do. I hope I can handle it.”

Dr. Rick: “It seems like a lot, but it actually makes your life easier, not harder, when you understand Jacob’s sensory and motor needs. Hang in there with me, and let me go over these elements of sensory integration.”

Dad (supportively): “Let’s just take it a step at a time, honey. We’re going to be fine.”

Mom: “Okay. I just get anxious with all the expectations.”

Dr. Rick: “There is so much to learn in the beginning, and it is a lot of responsibility. But by understanding Jacob’s sensory needs, he’ll get better, and in the long run, you’ll be happier.”

Mom (not completely convinced): “I hope.”

Dr. Rick: “Let’s start with the idea of ‘sensory diet’.”

Sensory Diet.

Many children with autism ‘hunger’ for certain sensations. If their hunger is not met, they walk around feeling ‘hungry’, so to speak, and cranky, like we would if we hadn’t eaten. When we ‘feed’ them sensory or motor input (based on their unique profile), we are giving them a sensory diet. By feeding them a good sensory diet, children with ASD grow calmer, more attentive, more regulated, and happier. Such a diet might include three or more sessions a day of providing deep pressure (wrestling, squeezing arms and legs, squishing them on the bed, etc.) or opportunities to climb, spin, swing or jump.

Dad: “Jacob would like that ‘diet’.”

Mom: “I don’t think we do enough for him that way. He craves physical pressure.”

Dr. Rick: “A good OT would help to define a sensory diet.”

OT Note: The Wilbarger Protocol. One particular type of sensory diet, called the Wilbarger Protocol, involves extensive brushing (with a surgical scrub brush) and joint compression (literally pushing on arms and legs to move the joint space) protocols several times per day. Parents report this to be a hard regimen to do consistently at home, but I have heard a few positive testimonials. It may be worth doing if your child has extreme aversions to touch or very poor coordination.

“Another aspect of sensory diet is replacement therapy, where an unacceptable sensory need/behavior is replaced by a more acceptable behavior. An example is when the child chews on and ruins toys or clothes. The inappropriate chewing is replaced with chewing gum or a rubber chewy necklace or small rubber hammer provided by the SI/OT. Smelling people’s hair is replaced by giving a lock of hair to
smell. I had one little boy who only wanted to touch his mother’s breasts. We had to find a soft, round, seed-filled pillow that he could squeeze when he wanted to touch her.”

Mom: “Thank goodness we don’t have that problem. But Jacob does like to...um...”
Dr. Rick: “Touch himself?”
Dad: “He actually humps on the floor.”
Dr. Rick: “Masturbation at this age is very common and will probably go away over time. But if it doesn’t, let me know and we’ll deal with it behaviorally. I wouldn’t use an SI/OT approach for that (we all laugh).”

**Desensitization.**

Dr. Rick: “Many children with autism are sensory defensive, i.e., they feel bombarded by the world around them and try to defend themselves by avoiding too much input. This often involves becoming quite rigid which drives parents nuts!”
Mom: “Jacob wants to wear the same clothes over and over, and he has to have the tags removed.”
Mom: “He hates it when Charlie cries even when he makes Charlie cry!”
Dad: “And his eating is driving me nuts. He won’t eat what we eat and he’s eating fewer and fewer foods. That would never have happened in my home. You ate what was put on the table.”
Mom: “And it’s the strangest thing, but talk about rigid, Jacob only wants to go one route to the grocery story and one route back home.”
Dad: “And if we don’t go that one route, he throws a fit.”
Dr. Rick: “An OT probably wouldn’t help with that. They focus more on taste, sound, touch, coordination, etc. Not so much on strictly behavioral issues related to rigidities.”
Mom: “So what should we do about that? It’s getting bad.”
Dr. Rick: “I can help you with that (See Section 3: Daily Hassles). But I just want you to see that an SI/OT can help you design desensitization protocols where you could expose Jacob slowly and progressively to some of his sensory aversions and to help him lower his defenses and become more flexible.

“For instance, an OT might recommend that you put just a spot of food on a separate plate so Jacob gets used to seeing new food. If he tried the new food, he could get a little prize (See Resources & Websites: Just Take a Bite). Behavioral psychologists and developmental and behavioral pediatricians can also be helpful especially when the issues fall outside the domain of an occupational therapist like the masturbation issue or the tantrums.”

**Sensory Processing.**

Dr. Rick: “Once the child is able to have his or her sensory needs met through a good sensory diet and becomes less defensive and overwhelmed by the outside world through desensitization, then the SI/OT evaluates how well the child can process information coming in to the brain, i.e., how the child makes sense of their sensations.

“Think of the brain as having three fundamental processes: Input from the senses (step 1) get processed by the brain (step 2), which leads to an output/intention to do something (step 3). This input-process-output arc is very important to understand. Let me ask you. If you call Jacob’s name, does he respond right away?”

Dad: “About fifty-fifty.”
Dr. Rick: “So you move closer and call him again.”
Dad: “Then, he'll usually look unless he's lining up or watching a DVD.”
Dr. Rick: “So if you have his attention, then input gets better. And if you repeat yourself, then he processes what you mean better. And then he looks, which is the output—looking at you.”
Dad (laughing): “I thought he was just ignoring me.”
Dr. Rick: “He's not really ignoring you. He has a problem with his input-process-output system.”
Mom: “It sounds like what you’re saying is that we have to get his attention, repeat things so he really understands, and give him time to respond.”
Dr. Rick: “Exactly. Watching and especially waiting are really important.”
Dad: “What about when we're having a lot fun roughhousing, and Jacob, all of a sudden, just walks away. Then, all of a sudden, he comes back and wants to play again.”
Dr. Rick: “That's different. I think that's more about processing a strong emotion. No problem with input, except maybe it's too much input. He's probably feeling overwhelmed by having too much fun! And he has to process the excitement to calm down a little. Then, he wants more. No problem with output.”
Dad: “That's so interesting. That's just the way he behaves.”
Mom: “So, let me see if I've got this right. ‘Sensory integration’ means understanding how Jacob looks at the world through his senses so we can help him feel better, calmer.”
Dad: “...and function better.”
Dr. Rick: “Exactly. It's a fundamental tenet that when a child like Jacob is calm, regulated, and attentive, he'll be easier to engage and this will help him improve.”
Dad: “Can you give us an example for Jacob?”

Making SI Work for Jacob

Dr. Rick: “Okay. Let's start with the visual system. As I said before, the visual system is self-absorbing (like a man watching football on Sunday afternoons!), and you've said that it's often hard to engage Jacob when he's visually stimming.”
Mom: “Very hard, and it seems to happen more with me.”
Dr. Rick: “Funny you should mention that. I've found that moms tend to teach and use visual aids like books, Play-Doh, and puzzles, which can cause the child to become visually absorbed, while dads tend to roughhouse and wrestle, chase and capture, fly and spin, and horsey back ride, which tend to be much more engaging.”
Mom: “When I think about it, it's true. I do a lot of teaching.”
Dr. Rick: “Nothing wrong with that, but just broaden the senses that you use in your interaction. Get rough! Get tough! And you will see a marked improvement in Jacob's engagement and eye contact and desire to play with you.”
Mom: “I was one of three so I had to be tough and I was.”
Dad: “She still is.”
Dr. Rick: “Great. So make sure you use all of Jacob's senses to engage him. There are effective ways to join the visual stimming to get interaction, but the touch sense (deep pressure, tickling, squeezing, etc.) on the other hand, is a much more social sense and easier to join.”

Non-visual Systems.

In fact, SI/OTs generally use the non-visual systems—swinging, climbing, deep pressure, etc.—to help the child integrate their sensations through repetition, fun, and relationship. By working primarily with the child's tactile (light touch and deep pressure), proprioceptive (the feeling of muscles and joints—running and jumping), vestibular (turning in space—spinning), and motor systems (planning sequences of actions—sports) in a way the child enjoys, the child learns that the word 'swing' means fun, that the OT is a person who brings enjoyment. Parents can bring the fun
OT exercises home and help their child make more sense of sensation. Remember: when you do what the child loves, the child will love being with you.

Through SI/OT methods, the child integrates pure sensation into larger concepts of the world—the puzzle forms a picture. This can be a slow process that starts with better attention and self-regulation, then better interactions, which leads to better language and making real sense of the world.

Self-Regulation: The Sensory Modulation Continuum

Dad: “So the whole point is to bring Jacob more and more into our world.”

Dr. Rick: “The ultimate outcome of:

• Meeting Jacob’s sensory needs, through a good sensory diet,
• Helping him to be less hypersensitive to the environment,
• Facilitating his sensory-motor processing, and
• Helping him to integrate sensations in a way that helps him make sense of the world is that Jacob will be calmer and more regulated so he can share attention and stay engaged with YOU! If Jacob is ‘out of sync’ with his ‘motor’ running too fast or too slow (See Resources & Websites), then he will have trouble connecting to the world and to you.”

Mom: “And that’s Jacob. He’s in his own world, doing his own thing most of the time.”

Dad: “Or he gets wild and has tantrums.”

Dr. Rick: “OK. This is the last thing I want to talk with you about: self-regulation and the ‘sensory modulation continuum’.”

Dad: “The what?”

Dr. Rick: “I’ll explain. When it comes to self-regulation, children with ASD come in two basic types:

• The over-reactive types who have trouble with self-regulation. I call them the ‘wild and crazy guys’. This type is hypersensitive to the environment, often hyperactive, and over-responsive. They get out of control quickly.
• The under-reactive types who have trouble connecting. I call them the ‘lump-on-the-log guys’. This type is the under-responsive, hard to get connected, in their own world, leave me alone, type of child.

“Mom, you mentioned that Jacob has both tendencies and that’s true of him. Here’s the Sensory Modulation Continuum chart (I hand them copies) that describes these two types of children:

<1.3 JPEG OT here>

“(I hold my arms wide open) This is how big the continuum is from tuned out (‘Failure to Orient’) to the world to wild (‘Over Orientation’). For a child like Jacob, our job (I move my hands closer together) is to help him move to the middle of this continuum—not too wild, not tuned out—so he ‘Attends’. See that—‘Attend’—in the middle?”

Dad: “But it says here ‘Shutdown’ on both ends. I understand that an under-reactive kid would be shut down, but I don’t get it for an over-reactive kid.”

Dr. Rick: “When the world is overwhelming—like when you go to a big family party, and it’s noisy and chaotic—the over-reactive guys will shut down too.”

Mom: “Jim, don’t you remember? That just happened when we went to the family picnic.”
Dad: “Oh yeah, Jake ran away and hid behind a tree and wouldn’t come out from behind the tree.”
Dr. Rick: “So he was shutting down.”
Dad: “But then when I pulled him out, he screamed like I killed him. In front of everyone!”
Mom: “He’s like that in the store too. People look at me like I’m the worst parent.”
Dad: “Is it possible to be both types?”
Dr. Rick: “Definitely. Jacob has what I call ‘regulatory issues’, meaning he swings back and forth like a pendulum. One moment he’s tuned out, the next moment he’s upset. But let’s be systematic here.”

The Under-reactive Jacob.
Dr. Rick: “Let me start with Jacob’s under-reactive tendency—when he’s in his own world. This is on the chart under ‘Failure to Orient’ on the left. It says he has a ‘high physiologic threshold’, which means it takes a lot to get his attention. These kids are ‘sensory seekers’.”
Mom: “That doesn’t make sense. Why would he seek sensations if he’s in his own world?”
Dad: “He’ll sit there lining up trains for hours. That doesn’t seem like ‘seeking’ to me.”
Dr. Rick: “Children who are under-reactive are dull to sensation. They only feel the world when they get a lot of sensation. So, if you want to get Jacob out of his own world, you need to rev him up. Dad, this is where ‘proprioceptive’ play and ‘vestibular’ play—like wrestling and roughhousing—come in. Because he doesn’t register input from the world very well sometimes—see where it says ‘poor registration’—he needs strong sensations.”
Dad: “Now that you put it that way, Jacob is a seeker. He flops himself into furniture. He loves roughhousing.”
Dr. Rick: “So he’s telling you, ‘Give me pressure!’ So you need to squeeze his arms and feet and squish him.”
Mom: “He loves his feet played with. He loves that ‘Motor Boat Motor Boat’ song.”

Motor boat motor boat go so slow
Motor boat motor boat go so fast
Motor boat motor boat turn on the gas!!

Dr. Rick: “That’s one of my favorite songs. Kids usually love it when you move their feet like pistons and pick up the pace with each line.”
Mom: “And he climbs up to high places and jumps! Scares me half to death.”
Dad: “He absolutely loves it when I put him on my shoulders and I flip him over.”
Mom: “That scares me to death too. I hated it when brother and sister fought.”
Dr. Rick: “That’s vestibular play. So he loves strong sensations. He’s a sensory seeker. Get it?”
Dad: “Got it!”
Dr. Rick: “Good. But tell me if I’m wrong, when not much is happening, that’s when he shuts down, goes behind his autistic veil, and ‘stims’ (self stimulates) on his trains.”
Mom: “Or he just wanders around like a little lost soul.”
Dad: “Or he’ll lie on the ground and line up trains in front of his eyes for a long time.”
Dr. Rick: “This under-reactive side of Jacob makes it hard to keep him engaged. He quickly, as it says here, ‘habituates as if to say, ‘Yeah, yeah, been there, done that, not interested’.’”
Mom: “That’s hard for me to see. It makes me sad to see him stuck.”
Dad: “It annoys me. I pull him off the floor when he does that stuff.”
Dr. Rick: “It’s one of the hardest things for parents—to see their child looking autistic. I know it would bother me too, but have faith. These ‘stimming’ behaviors will go away, but it takes time. We
have to ‘up regulate’ Jacob when he’s under-reactive, in his own world, and his ‘engine is running slow’.”

SI/OT’s recommend things like:

- Roughhousing, wrestling, chase and capture games
- Tickling (but be careful, sometimes tickling hurts, but the child still laughs)
- Squeezing arms and legs rhythmically while counting or singing
- Squishing his or her body under pillows
- Swinging him or her in a blanket
- Avoiding very absorbing toys and activities (TV, video, etc.)
- Joining the child’s interests

Dr. Rick: “Hopefully, by the time we’re done, Jacob will make enough progress that he’ll stop want-\text{n}g to do that stuff. With OT, Speech and Language, the PLAY Project, and special education, we’re going to do our best to get Jacob un-stuck.”

Dad: “But he’s not always stuck. Like at the picnic, he’s more like the wild and crazy guy you talked about.”

Dr. Rick: “That’s what makes Mr. Jacob so interesting. He’s not just under-reactive; he’s also over-reactive. So let me finish up by talking about the over-reactive Jacob.”

	extit{The Over-reactive Jacob.}

Dr. Rick: “If you look at the chart again (See above) where it says ‘Over Orientation’. At times, Jacob can be an over-reactive child, tantrumming over little frustrations when things don’t go his way or if the environment is overwhelming with noise and chaos like at the picnic or grocery store. He has a ‘low threshold’, meaning it doesn’t take much to set him off.”

Dad: “You can say that again.”

Dr. Rick: “Then boom, he goes into ‘fight or flight’ mode. He gets anxious or controlling or frustrated, and boom, he’s screaming, throwing, hitting.”

Dad: “And biting.”

Dr. Rick: “He’s biting?”

Dad: “Bit Charlie over nothing yesterday.”

Mom: “It wasn’t exactly ‘nothing’. Charlie wandered into a line of Jacob’s trains and Jacob just went wild.”

Dr. Rick: “So what did you do?”

Mom: “We didn’t really know what to do.”

Dr. Rick: “For the over-reactive child, the SI/OTs would recommend increasing the structure to make the environment more predictable or more soothing and relaxing in order slow down Jacob’s ‘fast running engine’ by:

- Reducing the stimulation, the noise, the chaos of the environment
- Making things predictable and orderly
- Giving soothing input like deep pressure or swinging
- Slowing down the pace of interaction
- Lowering your excitement level
- Following Jacob’s intention very closely to see what he really wants

Dad: “When he bit Charlie, I felt like giving him a good spanking, not ‘giving soothing input’.”
Mom: “But Jim, Jacob wouldn’t understand anything we said. In fact, when we did yell at him, he just got angry all over again and went after Charlie again.”

Dad: “So I grabbed him, held him tight, and stopped him. Then, he tried to bite me!”

Dr. Rick: “You did the right thing to stop him. By holding him tight, you probably helped him calm down (though you didn’t know it!) by giving him deep pressure. This is the type of thing an SI/OT would recommend. But it sounds like you got angry about it.”

Dad: “Well, yeah.”

Dr. Rick: “But why? It wasn’t Jacob’s fault.”

Dad: “He should know better than to bite his own brother.”

Dr. Rick: “Should he? Does he understand about sharing?”

Dad: “Well, no.”

Dr. Rick: “No. He was just thinking ‘Oh no! My line of trains! My line of trains is wrecked!’ And then he attacked. He over-reacted and got dysregulated.”

Mom: “But poor Charlie. He still has a mark on his arm. I really felt guilty for letting that happen.”

Dr. Rick: “You didn’t know Jacob was going to react so much. Really, this is not about you, or about parenting, or about Jacob’s character. He’s not doing this on purpose (yet!). This was about Jacob’s over-reactive brain.”

Dad: “She feels responsible for everything.”

Mom: “I can’t help it. I’m the mom.”

Dr. Rick: (I look Jim and Julie in the eyes): “But you understand what I’m saying here, right? It’s really not your fault, and it’s not Jacob’s fault.”

Mom: “Thank you, Dr. Solomon. We needed to hear that.”

Dad: “So what should we do; keep Charlie away from his own brother?”

Dr. Rick: “I wouldn’t let Charlie intrude on Jacob’s space when Jacob is doing his own thing (see Section 3: Daily Hassles). That’s what the OT would recommend—prevention. Structure the environment to make it safe, predictable, and orderly. Later, we’ll work on helping Jacob understand the idea of sharing, but he’s not capable of that yet.”

Mom: “See, Jim, I told you. Jim always says, ‘He should know better’. But Jacob doesn’t know any better.”

Dr. Rick: “But, dad, we are going to get to the point where Jacob will know better. Then, he’ll misbehave on purpose!”

Dad: “Oh great.”

**SI/OT, Emotions, and PLAY**

Mom: “So will doing OT at least help with some of these…”

Dr. Rick: “…regulatory problems? Well, yes and no. You’re not going to solve all these regulatory or self control problems just by doing occupational therapy. Some OTs would like to believe that by swinging the child in a hammock, or giving a warm bath, or by providing deep pressure, you can improve the child’s emotional self-regulation. And these things do help.”

“It’s not an OT’s job to talk to you about your feelings. It’s not an OT’s job to work with Jacob’s emotional life. Look at all the feelings you have. Dad gets angry. Mom, you get sad and guilty. Jacob gets furious about his brother stepping on his toys. Charlie is clueless about why Jacob bit him. You feel terrible when Jacob throws a fit in the store (See Section 3: Daily Hassles).”
Mom: “It’s a mess.”
Dr. Rick: “A big emotional mess. And the OTs aren’t going to deal with the emotional and behavioral side of things.
Dad: “This is what you do, right?”
Dr. Rick: “I help parents to understand the emotional aspects of this work. While the first step might be occupational therapy to understand Jacob’s sensory/motor profile, the next step is playing and interacting in a way that helps Jacob make sense of the world so he’s not so controlled by his senses. We have to get his functional development to improve to the point where the higher brain structures can control or ‘regulate’ the lower brain structures.”
Mom: “So understanding Jakey’s OT profile is just the first step.”
Dr. Rick: “Right. We have to meet him where he’s at, and right now, he’s mostly focused on sensory and motor activities and interests, and that’s what SI/OTs are good at. We want to help him move up from there and ultimately get him to the point where he can understand what he’s doing to Charlie. How to share. How to problem solve.”
Mom: “Poor Charlie didn’t know what hit him.”
Dr. Rick: “I know. It’s hard to watch. But I hope you see that Jacob swings like a pendulum from being under to over reactive as part of his regulatory system. See here on the shaded part of the chart where it says the over oriented child goes into ‘flight-fight’ mode?”
Dad: “It was more ‘fight’ than ‘flight’.”
Mom: “But then he ran away and hid behind a tree at the picnic.”
Dr. Rick: “That’s flight.”
Mom: “It’s amazing how well this describes him.”
Dr. Rick: “What’s so interesting to me is that it’s so neurologic.”
Dad: “It’s the way his brain works.”
Dr. Rick: “And not just Jacob’s brain. This is a problem for lots of kids on the spectrum. So fundamentally what we have to do is change his brain.”
Dad: “How long is that going to take?”
Dr. Rick: “For Jacob? Months at least. For some children it takes years. The SI/OT methods are a good start, but we are going to have to work intensively with Jacob’s functional development and his feeling life, not just his body.”

*How the PLAY Project Fits with OT.*
Dad: “And that’s what the PLAY Project does?”
Dr. Rick: “Right. And we’re going to be dealing with Jacob’s behavior a lot before long (See Section 3: Daily Hassles) because the better his development, the worse his behavior is likely to be.”
Mom: “You mean like Charlie? Charlie’s already testing me.”
Dr. Rick: “Yep.”
Dad: “Oh great.”
Dr. Rick: “So, just to summarize: Our primary goal in understanding Jacob’s self-regulation is to balance his sensory-motor system by up-regulating his under-reactive tendencies and down-regulating his over-reactive tendencies so that he can be calm (i.e., regulated) and able to attend to people. This is the first step to helping Jacob’s development.

“This correlates with Greenspan’s first Functional Developmental Level (FDL I) ‘Shared Attention and Self-regulation’. You can’t engage with people if you can’t stay calm and regulated enough to pay attention. Do you see how this leads into the PLAY Project?”
Dad: “The first level is . . .”
Dr. Rick: “Shared Attention and Self-regulation. Then comes FDL II ‘Engagement’. When he’s in his own world, we have to join him to get him into a shared world, and when he’s overwhelmed with too much stimulation or emotion, we can simplify the environment to make him feel less anxious.”

Dad: “Ah, the light just went on. It’s like we’re balancing his brain. When he’s too far down, we bring him up. When he’s too far up, we bring him down.”

Dr. Rick: “Beautifully said, dad.”

Functional Developmental Levels
- FDL I: Self-regulation and Shared Attention
- FDL II: Engagement
- FDL III: Two-way Communication
- FDL IV: Complex two-way Communication
- FDL V: Shared Meanings & Symbolic Play
- FDL VI: Emotional Thinking

Mom: “That way he won’t be so out of control.”

Dad: “Like we could take him to the store early in the morning when there aren’t so many people.”

Dr. Rick: “You can bring his trains so he can focus on something that calms him, that would ‘down-regulate’ him.”

Dad: “This is so interesting. It opens a whole new way of thinking about things.”

Dr. Rick: “This SI/OT perspective is pretty cool isn’t it?”

Mom: “Thanks so much for helping us make sense of our Jacob.”

Dr. Rick: “Thank the OTs. I’ve got a good OT for you who knows sensory integration as well as PLAY Project methods. OT works best as part of a complete program. And remember, use OT in your daily life. If you want The Dose and a relationship around OT activities, then you must bring the methods home! Go in to the therapy sessions, video tape the session, ask the OT to teach you what they are doing and then adapt what your OT does in the clinic to the home environment. You don’t have to turn your home into a gymnasium but a few selected items: big therapy ball, small trampoline, crawling tunnels, and a blanket for swinging should do it.”

Dad: “So we’ve got the PLAY Project, speech and language therapy, occupational therapy, and special ed preschool. Are we missing anything?”

Dr. Rick: “That should do it. Just remember to have fun together. I’ll see you again soon to talk about starting the PLAY Project, and I’ll be watching your videos from the home visits. I’m expecting great things from this boy. Call me if you have any questions.”

Summary
- I explain to Jim and Julie Grant why Jacob needs occupational therapy (OT).
- Sensory-motor systems are discussed with a focus on the difference between traditional OT and Sensory Integration OT (SI/OT).
- SI/OT methods are listed and ‘sensory integration’ therapy defined. The different modalities of SI are described.
- We establish Jacob’s sensory profile.
- By being stuck and focused on sensation, Jacob cannot make sense of the world. We have to help him ‘integrate’ his senses to form a more complete view of the world.
• Jacob also has regulatory issues, which are part of his profile. He is both under-reactive and over-reactive to his environment. We discuss how an SI/OT approach will help Jacob be more available for interaction.
• Good SI/OT leads to better interaction and engagement which, in turn, leads to better development and better relationships with people.

Resources & Websites

Websites
• Sensory Therapies and Research Center. Lucy Miller, PhD - The STAR Center: http://spdstar.org/
• Founder of SI/OT Jane Ayres, PhD, OTR: http://spduniversity.org/jean-ayres-biography/

Books
• The Out of Sync Child, Carol Kranowitz, (revised 2006): http://out-of-sync-child.com/
• How Does Your Engine Run?, Mary Sue Williams & Sherry Shellenberger, (1996)
• Just Take a Bite, Lori Ernsperger & Tania Stegen-Hanson, (2004)

Coming Up Next
• The Grant family begins the PLAY Project!
Section 2
The PLAY Project Approach
Climbing Up Jacob’s (Developmental) Ladder
Section 2: Introduction
PLAY Project and/or ABA?

PLAY and ABA
In Chapter 3 I discussed with Jim and Julie Grant the importance of implementing an evidence-based, intensive intervention program as soon as possible for Jacob. They decided on the PLAY Project, but I encouraged them to check out ABA intervention options as well.

In this introduction to Section 2, I want review briefly my involvement with both ABA and PLAY (for more details see the Prologue) and then compare the two main intensive programs available in most states: Behavioral vs. Developmental intervention, also known as:

• ABA (Applied Behavior Analysis)/EIBI (Early Intensive Behavioral Intervention). ABA (See Glossary) is the general behavioral approach to changing behavior where EIBI is the specific behavioral approach to helping children with ASD. I will use the terms ABA/EIBI.

• PLAY (Play and Language for Autistic Youngsters) Project. PLAY is based on the theory of the DIR (Developmental Individual-differences, Relationship-based) model that, as you will see, has a developmental framework instead of a behavioral framework like ABA.

Here is a handy dandy chart that summarizes our earlier discussion. The Grants, for reasons related largely to personal style and the fact that they were wait-listed for ABA, chose to start with the PLAY Project.

< Insert 1.4 JPEG PLAYABA here>

My History with ABA and the PLAY Project
As I mentioned in the prologue, I was recruited to be the head of Developmental and Behavioral Pediatrics at the University of Michigan in 2000. I had come from Pittsburgh where I had been the medical director of both an ABA/EIBI program and the PLAY Project (PLAY) program. When I arrived in Michigan, I had a decision to make: should I develop an ABA/EIBI program, a PLAY Project program, or both?

Before I answer that question (though you no doubt know the answer), let me quickly review a little of my professional history again. For 10 years between 1989 and 1998, I was the medical director of autism services at Allegheny General Hospital in Pittsburgh. I supervised a strict ABA/EIBI program! Yes, I, Dr. PLAY, was in fact a colleague of Ivar Lovaas, PhD (the inventor of ABA/EIBI for the treatment of autism) and participated in his research. I saw, up close, how ABA works. As a physician in Pennsylvania, with the stroke of my pen, I could order ABA therapy for 40 hours per week, one on one, by a trained therapist, in the home, free to children with ASD!

I know this may sound unbelievable to those of you who get little to no intensive services in your state, but that’s the way it was. And for 10 years, I developed autism intervention services in western Pennsylvania that served hundreds and hundreds of children.

Behavioral Intervention in Pittsburgh.
In the beginning, we provided only ABA/EIBI intervention to families. But after a couple of years, I introduced Stanley Greenspan’s DIR play-based, developmental intervention—and called it the ‘PLAY Project’ (PLAY)—so that parents had a choice: ABA, PLAY, or a combination.

I liked the way the behavioral ABA/EIBI approach systematically taught educational skills through training the child in a highly structured and prescribed manner using a step-by-step approach. The approach is intensive, directed, and precise. When the child succeeds, he/she is reinforced using food or other rewards. Many children (once they got used to sitting at a table) enjoyed (or at least tolerated) the repetitive nature of the drills. ABA methods are clear and the skills gained are easy to measure. Because of this, there is much better evidence for ABA/EIBI than any other type of intervention.

Concerns about ABA
I had some important concerns with ABA/EIBI. It was not a complete approach. It consisted then (as now) of very prescribed interactions that were strictly structured. In traditional ABA/EIBI the main method is called Discrete Trial Therapy (DTT) (See Glossary). In DTT the child sits at a table and performs ‘trials’ (drill-based teaching episodes) under the supervision of a behavioral therapist: ‘Do this’ (child does it). ‘Good job! Here’s a reward’ (e.g., cracker, hot dog, tickle, etc.). ‘Do this. Good job.’ ‘Do this. Good job.’ In classic ABA/EIBI the child may get up from the table only after they have complied with the DTT tasks. Think about it. How would you like it if someone prompted you in almost all of your interactions to do what they wanted you to do and then gave you a piece a candy or other tangible reward as your main form of interaction?

This Skinnerian operant conditioning approach (See Glossary) is good for teaching pre-academic skills and improving performance on IQ tests. But this is fundamentally not the way humans interact, and it is a very poor way to teach the child how to be social. I was more interested in helping the children get connected socially to become more emotionally intelligent (i.e., have a higher ‘emotional quotient’ (EQ)). I wanted a model that would help the child become warmly related, and ABA/EIBI using discrete trials was not that. Plus, 30-40 hours per week of sitting at a table and being drilled was too hard for many of the young children (ages 3-6 years old), and they ‘burned out’.

Also, in discrete trial ABA/EIBI, the adult decided what the child needed to learn. Far too often, the children didn’t even understand what they were doing. They were trained to pick the right color or put the same pictures together. But when they left the table, they couldn’t do it. They couldn’t apply what they learned during drills to other settings, i.e., they had poor ‘generalization’ (See Glossary).

While children who did ABA/EIBI tended to speak sooner than those who did PLAY, they didn’t use language functionally. I found their words to be ‘scripted’, memorized, and thus, somewhat robotic sounding (e.g., they would use the same phrase: ‘I want ____ please’ for everything they wanted).

As a result of all these issues, even after years of discrete trial ABA/EIBI, many of the children were not well connected to people. When left to choose, many of the ABA/EIBI trained children still broke off in their interactions and preferred to play alone in simple, repetitive, and unimaginative ways. They didn’t have functional communication.

Now, the ABA experts will argue that the newer, more sophisticated versions of EIBI—especially VB and PRT (See Glossary)—are addressing all these issues. The newer versions are more naturalistic.
and often use the *internal* motivations of the child (instead of external reinforcements like cookies or prizes) as reinforcement. I like to (half-) joke that as ABA/EIBI becomes more sophisticated, it starts to look a lot more like PLAY! There is also much less research on these newer forms of ABA—so in fact, they are not as evidence based as DTT. And all of them still employ *demand-response-reward* as their central operant conditioning method (See Glossary).

**The Central Issue of Autonomy**

So, behavioral programs work from the *outside in*. The child follows the adult, who determines what the child will learn. PLAY approaches work from the *inside out*. The adult begins by following the child's lead. The behavioral model knows what the child must learn and teaches it to the child. The child only has the right to *refuse*. The PLAY model *follows the child's intention* and *woos* the child upward through playful interactions. In this model, the child has the right, by word, gesture, or action to *disagree*.

I wanted to work in a model that respected the child's autonomy as one of its highest values. And this, fundamentally, is why I chose to do the play-based developmental approach in Pittsburgh, which I called the PLAY (Play and Language for Autistic Youngsters) Project².

Not only did the PLAY Project honor the child's autonomy, it was fun! In PLAY, interaction is guided by the child's 'lead', ideas, and intentions, which according to Greenspan, will lead upward to more and more complex development³. When parents did what the child loved, the child loved being with their parents. They *wanted* to play with people rather than be by themselves. This is a huge achievement for a child with autism.

**Natural and Organic**

Play-based approaches are more ‘organic’—like growing flowers. You do not pull up the emerging green shoot to make it grow; you nurture the soil, and the plant grows naturally. This ‘naturalistic’ approach, once learned, can be done all day long in every interaction. This makes generalization (the ability to apply what you learn) to other settings easier. Teaching this type of play to parents is much less expensive than teaching ABA/EIBI with its dependency on therapists and all the drills and programs.

One of the big problems with the play-based, developmental approach, however, is that it requires parents to be playful, and not all parents have the ability or inclination. By ‘following the child's lead’, there can be down time where nothing seems to be happening. And some children don't have much of a lead to follow. For some children, PLAY can be a more difficult path than ABA to follow.

Also, compared to ABA/EIBI, PLAY may take longer to see progress in the realm of academics. Parents have to have faith that this slower, more organic approach will work. But this article of faith worries parents: *If I primarily work on playful interactions without directive 'trials', will my child eventually talk and be ready for school and academics?*

After following hundreds of children for years, I can assure parents that, for the large majority of children with ASD, the PLAY Project *will* lead to the development of language and academic skills especially when combined with language therapy and pre-school.

**Evidence for Play**
The other worry parents have is ‘where’s the proof?’ As of yet, there is much less scientific evidence for play-based approaches (See Appendix B for recent important evidence on the PLAY Project) in large part because it is much harder to measure interaction—like measuring the flight of a butterfly—than the distinct ABA trials. Nonetheless, research on developmental relationship-based interventions (See Appendix C: DRI References) is growing even as I write this.

**Intensive Intervention Works!**

After my 10 years in Pennsylvania, I learned this: whether the children had ABA or PLAY, the intensive intervention worked!

By Pennsylvania State law, I had to see the children every three months to re-prescribe their services. Probably 60-70% of the children markedly improved their development. They went from not talking to talking, from not being social to being more social, from having lots of repetitive behaviors to having many fewer. I was amazed at their progress. Not all did great. There were slow movers, medium movers and fast movers. But almost all of them were movers—making gains. What I had learned in medical school—that children with autism did not get better—was wrong.

However, I noticed important differences between the children who did ABA/EIBI versus those who did PLAY. The children who had 30-40 hours per week of ABA/EIBI clearly learned more pre-academic and academic skills. They even learned certain language skills early. This led to improved cognitive intelligence or IQ scores. But they weren’t as connected or oriented to people and remained behind the ‘autistic veil’. Or, they were stiff socially and tended to be ‘prompt dependent’ which means they depended on adults to structure interactions and tell them what to do. They weren’t as flexible psychologically and tended to be poorer problem solvers, when compared to children who received the play-based intervention. And they were not as imaginative in their play with adults or peers. In other words, they had a lower emotional intelligence (EQ) than children who received PLAY.

The children who received PLAY interventions were more natural in their interactions with people. They had the ability to carry on simple and complex non-verbal social gestures (eye contact, body orientation, smiles). While it took somewhat longer, these children developed the ability to carry on long, back and forth verbal interactions. They connected language to their feeling life, they had better imaginations and, without prompting, would do pretend play. In technical terms, they had developed the ability to carry on ‘contingent, reciprocal social interactions’. Contingent means I do something because you do something. Reciprocal means a back and forth interaction.

Finally, and importantly, the PLAY Project approach considered the family central to helping the child. PLAY Consultants worked with the family as well as the child and helped the family work through issues of grief, guilt, and self-blame.

In short, the children receiving PLAY were simply better at interaction, were more social, and many were eventually more able to interact with their peers. The play-based developmental intervention was more sophisticated and deeper psychologically. These children developed both emotional intelligence (EQ) and cognitive intelligence (IQ). There was no question in my mind which intervention was best for the whole child.
To be fair, I found that some parents did better with ABA/EIBI because it was more in their natures to teach rather than play. Parents needed to trust their intuition and have choices. One size of intervention does not fit all children with autism.

Perhaps, the best program would combine ABA/EIBI with PLAY. When children who started with PLAY and later added ABA/EIBI as they prepared for school, they received the best of both worlds and often ended up in general education settings, sometimes with support and sometimes without. Usually, both types of interventions took between two and four years to help the child achieve their full potential.

These were my conclusions after doing this work for 10 years in Pittsburgh (and in the 15 years since then!). For helping to create a system of intensive intervention services in the state, my team was awarded the prestigious ARC of Pennsylvania ‘Professionals of the Year Award’ in 1998.

**Back to Michigan: ABA versus PLAY?**

Soon after that, however, my wife wanted to go back home to Michigan and I became the head of Developmental and Behavioral Pediatrics at the University of Michigan. Once there, I discovered to my utter dismay that Michigan, like the large majority of states in the U.S., did not pay for intensive intervention at all! (This has changed recently). I was very upset for my families. I knew they needed intensive intervention. I knew it worked. I was desperate to help them.

I had a decision to make. Which type of intervention should I bring to Michigan: ABA/EIBI or PLAY? I was at a crossroads. I knew that ABA/EIBI had the best evidence and I was at an academic institution where science and research had the highest value. But, in my heart of hearts, I knew that if I had a young child with autism, I would start with PLAY as my first intervention. I believed then, and I believe now, that emotional intelligence (EQ) is most important when it comes to being happy and successful in this society. Besides, PLAY would be less expensive and easier for parents to implement.

As I’m sure you have guessed by now, I brought the PLAY Project (www.playproject.org) to the University of Michigan and to the state of Michigan. The cost at the time? $2,500 per child per year (as opposed to ABA/EIBI which cost $30-50,000 per child per year!) Now, we have trained hundreds of home consultants and thousands of parents nationally, and the PLAY Project is available in dozens of states. In 2014, we published strong scientific research through a federal National Institute of Mental Health research grant (See Appendix B) that showed that parents can learn the methods and that children with ASD markedly improve in their social interactions and functional development. My dream of bringing a cost effective, intensive, play-based intervention for young children with ASD to communities in the U.S. is coming true!

**Coming Up Next**

- How the Grants learn the PLAY Project methods and how Jacob makes progress as he climbs up his developmental ladder

**References**


Chapter 8  
Visit 4  
Starting the PLAY Project Autism Intervention

Sadness, Support, and Action
As you may recall (See Chapter 9, Visit 2), during the Grant’s second visit with me, we realized that Jacob was in the wrong school placement for the fall. By our third visit they had put a request in writing for a new IEP but I hadn’t heard back. So I started by asking how that meeting went.

Dad: “It took some doing but we met just last week. We made our case and the school agreed to get Jakey out of the Cognitively Impaired class and move him to the Developmental Delay Classroom!”

Dr. Rick (making notes in Jacob’s chart): “Congratulations! Way to go you guys. I knew you could do it!”

Mom: “I went to see that developmental classroom too and I felt much better after my visit. The teacher was great and the kids were not as delayed. Jakey’s going to start there in a couple of weeks.”

Dad: “And we’re doing speech and language therapy and occupational therapy one time per week each for an hour.”

Dr. Rick: “And you’re just about to start the PLAY Project. It sounds like you’ve developed a wonderful program for Jacob. But it’s such hard work getting started! How are you two holding up?”

Mom: “It’s been quite an ordeal getting all the therapies that Jacob needs. I’m stressed to the max, but Jim has been a big help, and we’re getting there.”

Dad: “I catch her crying a lot, and that upsets me.”

Mom: “Jim says I have to stay focused but I can’t. I’m still so upset about everything.”

Dr. Rick: “And then you feel guilty on top of being sad?”

Mom: “ kinda, yes.”

Dad: “I don’t mean to make you feel guilty, hun.”

Mom: “Now I feel bad because I make him feel guilty because he makes me feel guilty! (She laughs). I just want to do what’s best for everyone.”

Dr. Rick: “I follow hundreds of families and let me tell you, you’re doing great. Really, you are both on the same page. You love each other and give each other support. You can be sad and keep going too. Both. I think it’s going to be much better when Jacob starts making progress.”

So begins a follow up visit with the Grants as they begin to provide intensive early intervention for 3-year-old Jacob, whom I recently diagnosed with an autism spectrum disorder with mild to moderate severity. (See Chapter 1 & Appendix A).

At today’s visit I will give the family an introduction to some of the most important methods of the PLAY Project:

- Following the child’s lead
- Circles of communication
- Techniques for engaging the hard to engage child, and
- The first three Functional Developmental Levels (FDLs)
After this office visit, the PLAY Project Home Consultant will go to the family's home on a monthly basis and guide them in their interactions with Jacob (See Chapter 9: The 7 Circles of the PLAY Project). I will see them back every 3-4 months to monitor Jacob’s progress.

Right now, though, Jacob is not even turning to his name consistently, and there are no words. While I hear their wish and share that wish, I know from long experience that Jacob will have to climb that language mountain (See Chapter 6: Climbing the Language Mountain) before he will start to talk consistently. I am consciously saving this discussion for later in the visit.

Dr. Rick: “So where is Charlie today?”
Mom: “With my folks.”
Dad: “We just wanted to focus on Jacob.”

I watch Jacob closely as he settles in to the office visit. He’s visually ‘stimming’ again, head on the floor, lining up Thomas the Tank Engine trains in a perfect long row in front of his eyes and really enjoying the way they look. He sits up and flaps with excitement at the visual scene.

Dr. Rick: “Does he still do that a lot at home?”
Mom (with dismay): “A lot.”
Dr. Rick: “Does he let you in to this type of play?”
Mom: “Not really. If I get close, he moves away.”
Dr. Rick: “Well, today we’re going to connect with Jacob in a way that honors his interests but at the same time engages him in a fun way.”

The parents have a doubtful look in their eyes.

Dr. Rick: “Mind if I record our conversations?”
Dad: “Not at all.”

**PLAY Methods: Being With, Doing Nothing, Waiting**

Dr. Rick: “At first, the most important thing you can do for Jacob is to wait and do nothing. Just be with him. This is an important PLAY Project method.”

The parents look at me blankly. I continue . . .

Dr. Rick: “There are several good reasons for simply ‘being with’ Jacob. But the most important reason is that it allows you to see clearly what Jacob wants. By being quiet within yourself, completely attentive, and really observant, you can see where his attention is and what his intention is. I call this ‘putting on your Zen head’, where you have no ideas of your own. You just follow the child. OK. Let’s just observe and be with Jacob. Tell me what he is doing now.”

Mom: “He’s playing with trains.”
Dr. Rick: “That’s a good start, but he’s not really ‘playing with trains’, is he? Where is his attention?”
Dad: “He seems to be looking at the wheels.”
Dr. Rick: “Right! Now, what is his intention?”
Mom: “He’s putting the trains in a row.”
Dr. Rick: “Right! That’s really accurate observing. So his intention is visual. What he’s really doing is lining up, putting things in order. So I’m going to follow his lead, another critical method, and let’s see what happens.”
**Following the Child’s Lead**

I get down on the floor facing Jacob.

**Dr. Rick** (talking to Jim and Julie. Jacob does not acknowledge me): “I’m waiting. I’m watching him like a hawk, second to second, to see what he is doing, what he’s intending, wanting.”

Jacob has picked out all the Thomas the Tank Engine trains—Thomas, Percy, Henry and Gordon—and is enjoying putting the trains in order. I start pointing and naming the trains in a rhythmic, orderly way, following his idea.

**Dr. Rick:** “Thomas, Percy, Henry, Gordon!”

I sound a little like Dr. Seuss. Jacob looks right at me and smiles as if to say, ‘Cool. Do that again.’ I do it again, and he laughs. We play that ‘name game’ several times, and he really enjoys it.

The parents are impressed (and I am relieved!) that my little intervention worked to get some shared attention and engagement and some laughing. I turn back to the parents.

**Dr. Rick:** “He’s got a great laugh.”
**Dad:** “That was cool.”
**Mom:** “He liked playing with you.”
**Dr. Rick:** “How could you tell?”
**Mom:** “He looked at you, and he wanted you to name the trains again and again.”
**Dr. Rick:** “But let’s be very accurate here. I wasn’t ‘naming the trains’ exactly. For Jacob, my words are not really words. I could have said, ‘Hubba, hubba, bubba, hubba!’ And he would have liked it just as much. They’re sounds that match his lining up. My sounds were lined up just like the trains.”
**Dad:** “That’s so interesting. This stuff is complicated!”

**Recognizing and Following Jacob’s Ideas, Interests, and Activities**

**Dr. Rick:** “It’s just a new way of looking at things. You’ll get it. But in some ways, it is complicated mostly because Jacob can change in a second, and we have to follow that idea and then the next. And a lot of his ideas are going to be sensory and physical.”
**Dad:** “Sensory and physical?”
**Dr. Rick:** “What’s fun for Jacob is going to be sensory—looking, running, seeking deep pressure. . .”
**Mom:** “He loves deep pressure. He holds his arm out to me so I can squeeze it, the harder the better. I think he knows the word ‘squeeze’.”
**Dr. Rick:** “That’s a good example of being sensory and physical.”

In fact, children change what they love as they make progress. There is a hierarchy of activities that starts with sensory-motor sensations, moves up to cause and effect play and then on the higher levels of play interests.

**Hierarchy of Activities**

- Sensory-motor sensations
- Cause and effect
- Sequences
Dad: “So you’re saying that Jacob is at the lower level of activities.”

Dr. Rick: “For now. That’s one way we’ll know he’s making progress. His interests will evolve. He will want to do higher level activities. But for now, if he loves deep pressure, we’ll give him deep pressure.”

As if on cue, Jacob stops lining up the trains, gets up, and flops on the chair in my playroom, apparently seeking pressure. So I get up quickly and push down on his back to give him a squeezing/pressure experience. He loves it and looks back at me as if to say ‘That feels good.’ I push him again and say “Squeeze”.

**Going for ‘Circles of Communication’**

Then, I explain that whenever the child purposely reacts to you, that’s like gold.

Dr. Rick: “In the PLAY Project, especially in the beginning, we are going to be very focused on getting Jacob engaged and we’ll know he is engaged because we will get ‘circles of communication.’”

Dad: “‘Circles of communication?’ (See Glossary)

Dr. Rick: “I can’t over emphasize how important it is for you to understand this concept of ‘circles of communication’. Let me take the ‘circle’ process step-by-step. First, I ‘opened’ —started or initiated—a circle by listing (i.e., making the sound of) train names and he ‘closed’ the circle—or responded—by looking at me and smiling. That completed the circle. Every true circle of communication must have an opening and a closing and it must be *social*, directed to people.”

Mom: “He definitely smiled at you. He liked what you did. That was really great to see.”

Dad: “So a gesture can ‘open a circle’?”

Dr. Rick: “Definitely. If he can’t talk yet, then gestures are going to be the main way he communicates in the beginning. If he’s initiating an interaction by inviting us with a smile, then that’s definitely ‘opening’ a circle.

Dad: “Let me see if I get this. So when Jacob went over to the chair and flopped down you went over and gave him a squeeze. So you ‘opened’ another circle.”

Mom: “But then Jacob looked at you like he wanted you to do it again. Was he opening a circle or just responding to you?”

Dr. Rick: “I *opened the circle when I squeezed him* but then he definitely invited me to do it again, so he opened a circle too. The opening and closing of circles can be subtle sometimes. That’s what makes this work so hard in the beginning. You have to ‘read’ the child’s subtle cues moment to moment. That’s another reason for waiting and watching. You have to be really ‘sensitive’ to his cues.”

“OK. That was a start. Now, I’d like both of you to put on your ‘Zen Heads’—no ideas of your own. Follow Jacob, and let’s take turns.”

The parents share a worried smile.

**The Anxiety of Interaction**
I know about that worried smile. This is a moment of anxiety for them. I’m putting them on the spot even though I don’t mean to. Some parents worry that they will not perform well in front of me, the ‘autism expert’. This is a second reason for ‘doing nothing’—there really should be no pressure to perform. All they have to do is observe. But in the beginning, most parents can’t relax. They want to ‘do it right’ and ‘get in the hours’.

I had one mom who told me that after she ‘got in her 30 hours per week’, she could relax and enjoy her child! My experienced parents tell me, though, that after the initial worry about being a good enough player and after the initial pressure to ‘get in the hours’, they settle in. They relax and enjoy their child most of the time. The PLAY Project is a lot more play than project.

Another common initial reaction is that parents don’t want their child lining up and ‘stimming’. They don’t want to encourage ‘autistic behavior’. They want their child to look ‘normal’. Jacob went back to lining up trains.

Dr. Rick: “What was that smile about? Please, I really want to know what’s going on for you.”
Mom: “I hate to say it, but I don’t like it when Jacob does that. I don’t want to encourage that.”
Dad: “It makes him look. . . .”
Dr. Rick: “. . .autistic? You mean ‘stimming’ and lining up?”

They nod.

Dr. Rick: “It has to be one of the hardest things—to see your child looking ‘autistic’.

I pause for what seems like a long time and look right at mom. She starts to cry. Dad gives her a tissue and tears up himself. I start to tear up too and all of us feel sad together. There is another long silence, but now, it feels intimate and comfortable. I thank them for being honest. I acknowledge the sadness that autism brings. I reassure them that we are going to work our butts off together to help Jacob get engaged and not ‘look autistic’.

Dr. Rick: “But if we want him to get better, we have to start exactly where he’s at and then take him where he needs to go. We have to hook him and reel him in, have fun, and make him laugh. I tell parents all the time: ‘When you accept your child for exactly who he is, that’s the fastest way to help him become the child you want him to be’.”

But this sadness of getting down on the floor and looking into the face of autism is the first barrier that parents must deal with on their way to playing with their child. It has to be one of the hardest things we ask of parents who are beginning the PLAY Project.

Dr. Rick: “Mom, are you OK? (She nods) Please, why don’t you go ahead then and play. But, here’s the catch—you can’t do exactly what I did.”

Jacob’s mom gives me that thanks-for-nothing look and gets down on the floor near Jacob who continues to look at the lined up trains. At first, she seems at a loss. Then, she takes one of the trains and goes “Choo choo! Choo choo!” running the train over Jacob’s back. He stiffens and ignores her. Then she looks at me. “I think I just got rejected.”
And this, parents tell me, is the next big worry. They are scared to death that they will not be able to connect with their own child (especially when I’m watching!). One of my hardest tasks is to help parents have faith that they will connect, but when they don’t, I have to be honest with them.

Dr. Rick: “OK. So that didn’t work. No problem. It’s a start. You are very brave. Don’t get down on yourself. You’re going to get this before you leave. I promise. As you just saw, sometimes it’s hard to follow the child’s lead. And what you did was completely natural. When parents don’t know what to do they come up with their own idea. In this case you came up with the idea of a pretend train that rides on Jacob’s back. The problem is: Jacob was putting things in order. He’s thinking ‘Look how these objects line up.’ He wasn’t thinking ‘This is a train’, was he?”

Mom (a bit dejected): “No. But I didn’t know what else to do.”

Dr. Rick: “In order to know what to do, ask yourself this question: Am I following Jacob’s intentions or am I leading with my own ideas? Don’t get me wrong; I am not saying ‘Don’t use your own ideas’. We’ll get to that. But first, I want to make sure you know what Jacob is experiencing. Engagement will follow. Trust me.”

The key to getting mom and Jacob engaged was to have mom play at the right level, which means that we cannot play too high or too low. If we play too low, Jacob will stay stuck in his Comfort Zone. If we play too high, he’ll ignore us because we are playing over his head.

Dr. Rick: “So, mom, do you think your play was too high, too low, or just right for Jacob?”

Mom: “Too high?”

Dr. Rick: “Yep. ‘Choo choo’ was your idea to use the train as a pretend toy. Does Jacob see the train as a pretend train? Probably not. So, let’s follow his lead and stick with his idea.”

Mom: “I’m really lost here.”

Dr. Rick: “I know. His ideas are not easy to see, but he has them. We just have to see them. And I thank you so much for being open and honest and taking a risk here. You’re going to get this, both of you. Let’s put our heads together and talk about how we can consistently engage this handsome young man. Then, we’ll try again.”

Mom, less flustered now, gets up off the floor and sits next to dad again, while Jacob continues to play by himself.

Engaging the Hard to Engage Child

I explain to Jacob’s parents that when a child gets stuck and tunes us out, I refer to him as being in his Neurologic Comfort Zone (See Glossary), or Comfort Zone for short. I call it ‘neurologic’ because he can’t help himself completely. His brain, his neurology, is taking him over, and he seeks repetition, security, and comfort. Comfort Zone activities are defined as: What the child will do when you let him do whatever he wants to do. Lining up objects is definitely a Comfort Zone activity.

Comfort Zone Activities

- Wandering, jumping, mouthing
- Watching fans, lines, wheels
- Lining up objects (especially trains, cars)
- Opening/closing doors
- Flipping pages of books
- Watching the same TV show or DVD over and over
Fixating on the same topic (trains, dinosaurs, weather, planets, etc.)

The question then becomes: *What can we do to get into Jacob’s Comfort Zone, woo him upward, get him engaged, and have fun?*

*The Rabbit Hole Techniques.* I give a handout with a list of the **Rabbit Hole Techniques** (See below) to Jim and Julie Grant.

**Dr. Rick:** “These techniques are very effective in engaging the (initially) hard-to-engage child. When the child with autism goes into his own world, into his Comfort Zone, I compare it to a scared little rabbit that disappears into his rabbit hole. The **Rabbit Hole Techniques** woo the child out of his isolation in ways that are gentle and—with some exceptions—follow the child’s lead.”

**The Six Rabbit Hole Techniques**

- Being With
- Narrate with feeling the child’s behavior and/or intention
- Help him do it better
- Parallel play what he is doing
- Theme and Variation
- Change the sensory mode

**Dr. Rick:** “We’ve already used the first technique—**being with.** Just entering his space changes his whole world. You don’t have to do anything. Mom, let’s start with you again.”

By this time Jacob has moved on to playing with my bead maze that has colorful beads on wires that go up and down and around. He’s moving the beads from one side of the maze, along the wires, to the other side of the maze and making sure they are stacked first on one side and then on the other. He has not looked at us at all. He’s in his Comfort Zone.

**Being With.**

**Dr. Rick:** “We’ll coach. Dad, your observations are welcome. OK, mom, **be with** Jacob. Get at face level in front of him and simply observe. Where is his **attention** and what is his **intention?**

**Mom** (moving into place near Jacob who, this time, gives her a quick glance!): “Did you see that?”

**Dr. Rick:** “Mom, Jacob just opened a nice little **circle of communication** with you!”

**Mom:** “His **attention** is on the beads and his **intention** is to move them from one side to the other.”

**Narrate.**

**Dr. Rick:** “Great, exactly right. Strong work mom (she smiles). Now, use the second Rabbit Hole Technique and **narrate.** Be a mirror and reflect back to him **in words** what he is doing. Really see his idea. And don’t ask questions. Make statements.”

**Mom:** “There goes a blue bead.” It falls into place. “Boink! There goes a yellow bead. Boink!” Jacob looks at her with a beautiful smile.

**Dad:** “Honey, you’ve got him!”

**Dr. Rick:** “Yay! I like the way you ‘boinked!’ Now, keep your eye on the prize. When he changes, you have to change. It’s like staying on a bucking bronco.”
Mom (timing her words as the beads fall): “Blue…yellow…green…red…orange! They’re all in a row, Jacob.” Jacob looks at her as if to say ‘Yep, all in a row’. “That was so great!”

She has tears (of joy, this time) in her eyes.

_Helping Him Do It Better._

Dr. Rick: “OK, dad, you’re up. Please switch around, and let’s do the third Rabbit Hole Technique and _‘help him do it better’_. Whatever he’s doing, help him achieve it. What is he doing now? Wait. Watch him. Zen head. Read his intention…”

Dad: “He’s pushing the beads from one side to the other.”

Dr. Rick: “Exactly right. Now that you know, you can help him a little. Tell him (don’t ask) what you’re doing in a fun, rhythmic way.”

As Jacob pushes a set of red beads across the maze, dad gently puts his big hand over Jacob’s little hand and pushes them along the wire while saying, “There they go. There they go.”

Dad: “He’s pushing the beads from one side to the other.”

Dr. Rick: “Exactly right. Now that you know, you can help him a little. Tell him (don’t ask) what you’re doing in a fun, rhythmic way.”

Dr. Rick: “Perfect. Keep doing that.”

Jacob: Doesn’t look or laugh but starts moving the next set of beads and dad gently helps.

Dad: “There they go. There they go.”

And together, they push the beads up the wire and down the wire to the other side.

_Changing Pace and Waiting._

Dr. Rick: “Now wait, dad. Slow down! Wait.”

Then, Jacob starts to push another set of beads across, and as he starts, he gives dad a look as if to say, ‘Well, are you going to help me or not?’ Dad is thrilled and gives him help.

Dr. Rick: “OK. Two big things just happened. First, dad waited and _slowed down his pace of interaction_. What did that do?”

Mom: “It gave Jacob a chance to…”

Dad: “…open a circle.”

Dr. Rick: “By George, I think you’ve got it! We’ll talk a lot more about the PLAY Project methods like ‘waiting’ but let’s stick with what’s happening. How many circles did you open and close? Let’s actually count them.”

Mom: “Let’s see, daddy put his hand on Jacob’s hand.”

Dr. Rick: “That’s right. That’s daddy _opening a circle_. And when Jacob _let_ daddy push the beads that was _closing the circle_. Right? He actually let daddy do that. He could have pulled his hand away (which would be opening a circle too—that would be called a ‘negative cue’), but he didn’t. So that’s one complete circle, right?”

Dad: “Then, Jacob looked at me.”

Mom (excited to get the idea): “_That’s_ opening a circle. And then, when _you_ did what _he_ wanted, that _closed a circle_.”

Dad: “Then, he _let me_ help him again. Right? So what was that, an open or closed circle?”

Dr. Rick: “Since he was responding, not initiating, that’s _closing a second circle_. Because you _slowed your pace_ and gave _wait time_ for Jacob to initiate, we got two full circles of communication. If you look at our adult communication, you’ll notice that we are opening and closing circles gesturally and verbally all the time. This is ultimately what we want for Jacob.”
Mom: “We’ve got a long way to go.”
Dr. Rick: “You know the Chinese saying: The longest journey starts with a single step.”
Mom: “It’s like there’s an invisible process going on all the time that we never noticed before.”
Dr. Rick: “Yep, and we must be aware of this invisible interactional process of circles if we are going to help Jacob become solid in his interactions. Circles are like bricks in a wall. We want lots of bricks to build a solid wall.”

Parallel Play: Imitating What the Child Does.
Dr. Rick: “OK, Dad, let’s do the next Rabbit Hole technique called ‘parallel play’. Imitate him and make it fun. Move the beads he’s NOT moving.”

Dad takes some beads on the other side from Jacob and says (with a lot of animation): “Up, up, up, and down, down, down.” Jacob stops what he’s doing and gives dad a look.

Dad: “See that? He opened another circle.”
Dr. Rick: “Right. He wants to see what you’re going to do next. Push them all the way over to his side, then stop, and let’s wait and see what he does.”

When dad does this, we lose Jacob. He goes back to visually stimming on the beads, back in his Comfort Zone.

Theme and Variation: Introducing OUR ideas.
Dr. Rick: “We lost him. No circles. That’s OK. You’re not going to keep him engaged all the time—yet. Let’s try the fifth technique. Let’s do some ‘theme and variation’ (see below). You’ve already done several variations just by following Jacob’s lead, but let’s think of some more.

Theme and Variation
- Block them in a playful way
- Count the beads as they drop down
- Push the beads with an object (Thomas)
- Spin the beads instead of push them
- Gently wiggle the wires as he pushes them
- Sing a song about beads as he pushes them
- Have the beads talk to each other (too high for now)

Mom: “Can I take a turn?”
Dr. Rick: “Sure, why don’t you both join him?”

I explain that ‘theme and variation’ answers the question: What are five or more ways we can do this activity, these beads, that would be fun for Jacob? This is the beginning of introducing our ideas so we have to be careful here, not to play too high. We still have to read Jacob’s subtle cues to see if he likes our ideas or not.

Note: For example, variations 1-6 are at the right level but variation 7, having the beads ‘talk’ to each other, is too high.
Dr. Rick: “Let’s try blocking the beads in a playful way. It’s got to be playful, not frustrating. Let’s take turns. Mom, you go first. Try holding the wire where he’s going and when he gets to your hand, say ‘Ouch’ and pull your hand away. He won’t understand the word ‘ouch’, but it helps to be dramatic, silly, and surprising in a fun way that will insert yourself to keep and hold his engagement.”

Jacob pushes the beads toward mom’s hand and when it gets there, she shouts “Ouch” and jerks her hand away (opening a circle). Jacob thinks this is hilarious and starts laughing out loud (closing a circle). He looks to his mom to do it again (opening a second circle!). Dad steps in, Jacob runs the beads into his dad’s hand (opening a third circle); dad yells “Ouch” (closing the third circle), and Jacob laughs so hard he gets the hiccups (closing another circle). We do this (opening and closing several more circles) until the joke grows old and we lose him again.

Mom: “That was the most fun!”
Dr. Rick: “What a tag team! You can really see Jacob’s potential to engage. We probably opened and closed close to seven or eight circles with him. And it’s only going to get better.”

Changing the Sensory Mode.
Dr. Rick: “OK. You two up for one last technique?”
Dad: “Changing the mode?”
Dr. Rick: “You’re learning fast, dad! I’ve found that the worst sensory mode for engagement for most children with ASD is the visual mode. You can see for yourselves how absorbed Jacob gets when he watches objects. It can become very addicting. So when you can’t get circles because the child is too absorbed in their visual Comfort Zone, then it’s time to change the sensory mode from the visual to touch, or sound or movement or swinging or roughhousing or tickling or jumping.

Sensory Modalities
- Visual
- Auditory: songs, animal sounds, onomatopoeia (buzz, boom, crash, etc.)
- Touch—light (tickling), deep (pressure, squeezing)
- Proprioception—feeling of the joints in motion, jumping, shaking of arms and legs
- Vestibular—movement in space
- Motor planning—getting your muscles to do what you want
- Space—the closer you are, the more connected you are

“In fact, you did change the sensory mode, mom, to auditory when you made the sound ‘boink’. And dad, you changed the sensory mode to touch when you held Jacob’s hand and helped him move the beads along the wire. In general, it’s best to stay with the child’s interest if he or she will let you in.”

“But let’s say that you’ve tried the Rabbit Hole Techniques, and Jacob is not letting you in. You’ve really tried to follow him and engage him for a long while, but he’s so addicted to the visual activity that he’s stuck.

“So, we want to change the modality by introducing our idea. There is a danger here. This technique, like Theme and Variation, is about our idea of fun and is not truly following the child’s lead—at least not at first. So be careful. Don’t take over and open all the circles. Still, changing the sensory mode is a good technique when you can’t connect especially through the visual mode.
“So let’s change the mode to movement and we’ll start with shaking Jacob’s arm in a fun way. If he likes that, then dad and I will swing him by his arms and legs into mommy’s lap and we’ll wait and see if he likes it, if he cues us for more.”

Mom: “So, we’re really not following his lead anymore.”
Dr. Rick: “Well, that’s a very good point. We’re staying with his interests in sensory-motor play, even though we aren’t technically following his lead.”

I go over to Jacob who is still visually absorbed, pushing the beads. I take his hand (I open a circle) and give it a little shake while also saying; “Shaky shake shake!” This use of sounds that sound like what you are doing is called ‘onomatopoeia’. I wait expectantly gesturing with my hands out (opening another circle) and, sure enough, he gives me a smile (closes the circle) and holds his hand out (closes another circle).

Mom: “I think he likes it.”
Dr. Rick: “It’s OK to introduce our idea as long as he likes it.”

I gesture for him to give me both hands (open), and he does (close). I “shaky shake shake” both hands, and he likes it.

So, I grab his hands and dad grabs his legs and we swing three times while counting, “1...2...3...SWING!”—into mom’s lap. When he lands in her lap, mom gives him a big hug and sets him back on the floor.

Dr. Rick: “Now, wait. Let’s see if he wants to do it again.” He gives us ‘the look’ (opening a circle) and holds his legs and arms up for swinging (opening another circle). “See what waiting does?! OK, Jacob. 1-2-3-SWING! Here we go!”

We do it again. And again. And again. We get lots of circles. Hand circles. Foot circles. Eye contact circles. Big, little, and micro gestural circles. We vary it (Theme and Variation) by changing the height of the swing, by me taking his feet and dad taking his hands. He loves it so much that he throws a little tantrum when we get tired and have to stop!

Dr. Rick: “I’m sorry, Jacob. Now, you don’t want to stop engaging us!”

We all get a good laugh. The child with autism won’t leave us alone!

Dad: “Can we bring you home with us?”
Dr. Rick: “Hey, I’m only the coach. You guys were amazing in your play.”

Then, I explained that in a way, they will be taking me home by doing the PLAY Project, where a home consultant will come to their home every month, teach them about the PLAY Project approach (See Chapter 9: The 7 Circles of the PLAY Project), videotape their play interactions, and give them a video review report that will guide them on what to do next. Most children with autism don’t change day-to-day or even week-to-week. Usually every month or two, the parents will need to keep up with Jacob’s changes as he climbs up the developmental ladder.
Dr. Rick (I reach into my file box and give them a handout): “Here, let me give you this checklist for playing with Jacob (See PLAY Project Checklist at the end of this chapter). It summarizes a lot of what we’ve been talking about. So, how was this session for you two?”

Mom: “Really fun. A lot to learn but fun.”

Dad: “He’s made progress already!”

Dr. Rick: “Jacob has tremendous potential. And you are wonderful parents who can definitely do the work of play.”

We all laugh at my unintended pun.

**Jacob’s Functional Developmental Levels**

Dr. Rick: “So, let me send you home with a quick sketch of Jacob’s Functional Developmental Levels. These levels are based on the wonderful work of Stanley Greenspan, MD, and Serena Weider, PhD. I highly recommend their book called ‘Engaging Autism’ (See Resources & Websites), where they go into the levels in detail. We’ll teach the FDLs to you as part of the PLAY Project.”

“Here’s a quick set of ‘thumbnails’ for each of the six FDLs (See Appendices D&E). You’ll get a more detailed description of the FDLs from your PLAY Consultant (See Chapter 10)”

**Functional Developmental Levels**

- FDL I: Self-regulation and Shared Attention
- FDL II: Engagement
- FDL III: Two-way Communication
- FDL IV: Complex two-way Communication
- FDL V: Shared Meanings & Symbolic Play
- FDL VI: Emotional Thinking

“I don’t mean to get too technical, but I do want to document Jacob’s progress over time. Jacob is what I call a ‘I, II, III guy’.”

Dad: “Is that good?”

Dr. Rick: “That’s where most children with autism start. Take a look at that checklist I gave you.” (See The PLAY Project Checklist at the end of this chapter).

FDL I: Self-Regulation and Shared Attention.

I explain to mom and dad that at FDL I, Jacob shuts himself down, and disappears into his Rabbit Hole quite a bit. So he’s not ‘with us’; he’s in his Comfort Zone—doing his own thing. His problem is that he’s shut down (See Chapter 7 Visit 3: Part 2 OT & Sensory Integration), which prevents him from sharing attention with us most of the time. He’s only ‘with us’ some of the time throughout the day right now.

Dad: “I can totally see that.”

Mom: “He ignores a lot.”

Dr. Rick: “Using a scale of:

- 25% for some of the time;
- 50% for half the time;
• 75% for most of the time; and
• 100% for all the time,
“Jacob’s is 25% solid at FDL I. He’s ‘with us’ some of the time.”

Dad: “I get it.”
Dr. Rick: “By doing the Rabbit Hole techniques, he’s already opening circles and wants to play. If we can get in about two hours per day of PLAY Project play, Jacob should really improve in his shared attention and engagement and move more solidly into FDL II and III.”
Dad: “So we have to go after him to get him engaged more of the time.”
Dr. Rick: “Yes. If you work hard, I predict that soon, Jacob will love being with you. Then, his FDL I will increase to being with us ‘most of the time’.”
Dad: “That would be 75%.”
Mom: “I would love that.”

FDL II: Engagement.

Dr. Rick: “So, our main goal for Jacob right now is to get engagement. I call this the sweat level. You will have to work hard (i.e., sweat) and not leave Jacob alone too much. I advise limiting TV, videos, and/or computer time (i.e., all screen time) to one hour per day. Even if you invent fun games based on your ideas, make sure you have his attention and engagement. Really pay attention to his attention. Where is it? What is he paying attention to? I thought he was engaged at least half the time when we made the effort (i.e., when we were ‘sweating’. So I give him a rating of 50% for FDL II.”
Dad: “You call it ‘sweating’ when we open most of the circles.”
Dr. Rick: “Right, that’s what I call ‘sweating’. You do a lot of the work of interaction.”
Mom: “But you have to wait too.”
Dr. Rick: “Right, you must wait to give Jacob. . .”
Dad: “. . . a chance to respond.”
Mom: “And a chance to open his own circles.”
Dr. Rick: “You guys are really getting this stuff!”

FDL III: Two-way Communication.

Once we share attention and get engagement, then we’re on our way to FDL III, two-way communication. This means that Jacob not only responds when we open the first circle, but he also initiates and opens his own circles (which we know he can do). If FDL II is the sweat level, where you have to do most of the work of engagement, then FDL III is the wait level where you have to slow down your pace to see if the child wants to respond and/or initiate. And when Jacob is working at both FDL II and III, you have to do both—sweat and wait—depending on what he’s doing in the moment.

Dr. Rick: “So, if you are always opening the first circle, what FDL is that?”
Dad: “II?”
Dr. Rick: “Right! If you do all the work, then Jacob won’t ‘exercise his initiation muscle’, so to speak. If you don’t wait, he can’t initiate. So slow your pace and wait for him. It will also take some of the pressure off you to DO, DO, DO. If he doesn’t initiate, though, then you will have to sweat and go after him. But always give him a chance to close and open circles. I rated Jacob as having 25% of FDL III because he initiates only some of the time. So his current FDL profile is 25% FDL I, 50% FDL II and 25% FDL III.”
Dad: “So, when is he going to talk? You told us before but now I can’t remember.”
Dr. Rick: “Right now and for the next several months, we have to work on his gestural communication to solidify FDLs I, II and III. We want to start helping Jacob make connections with words that mean ‘fun’. Words like: ‘1-2-3-Go’, ‘juice’, ‘daddy’s home’, ‘time to eat’, ‘up up up’, ‘shaky shake shake’, ‘swing’, ‘more’, etc.”

Dad: “Can we make a list?”

Dr. Rick: “Great idea. But they have to be Jacob’s list, not your list.”

Mom: “Didn’t you say that we have to get Jakey to FDL IV before we can expect him to talk.”

Dr. Rick: “Great memory, mom. That’s right. FDL IV (complex two-way communication). So, first comes attention (FDL I), engagement (FDL II) and two-way communication (FDL III). At first, Jacob’s communication will be gestural—looks, a hand reaching out, moving closer indicating more—THEN comes understanding what you’re saying (receptive language), THEN comes words.

Dad: “I’m looking forward to that day.”

Dr. Rick: “I know. Me too, but please, for now, don’t worry too much about words. If you try to ‘push that river’, you will waste your time and probably slow Jacob’s progress down. We have to finish up, but let’s summarize for you.”

“We’ll know he’s making progress if:

• He is more with us,
• He’s able to open and close 3-5 circles of interaction consistently, and
• He’s initiating (opening circles) more.

“I hope this was helpful for you.”

Mom: “Very helpful.”

Dad: “A lot to take in.”

Dr. Rick: “I’ll send you the audio file. Plus, your PLAY Consultant will go over all this with you at the home visit. I strongly recommend that you get the PLAY Project DVD (See Resources & Websites). It will save you a visit and orient you to the model. What I’d like to propose is that I meet with you every 3-4 months once you get started with the PLAY Project.”

Mom: “We’re excited. Our consultant is coming over next week. This was a fun visit.”

Dad: “It was so great to see Jacob laughing.”

Mom: “He’s never done that in a doctor’s office.”

Dr. Rick: “It helps that I don’t give shots!” (We all laugh). “It was great to see you again. Call me with any questions. Bye-bye, Jacob (he ignores me).”

Mom: “He’s in his Comfort Zone again.”

Dad: “We’ve got work to do, and we’re going to do it.”

Dr. Rick: “That’s the right attitude, dad. I am so high on this boy. I think he’s going to do great.”

Conclusion. I hope I haven’t loaded the family up with too much information, but it’s information that will be revisited again and again in the home visits with the PLAY Home Consultant, who will videotape the play interactions and go over the PLAY principles and methods at the first home visit (See Chapter 10). I have a really good feeling that Jacob is going to do well, but he has a ways to go.

Summary
In this visit, I introduced the Grant family to:

• What it means to ‘follow the child’s lead’
• How to get ‘circles’ of interaction
• What techniques to use (Rabbit Hole Techniques, slowing the pace, Theme and Variation) when engagement is difficult (See Checklist below)
• How to understand the first three Functional Developmental Levels (FDLs), and how they apply to Jacob

References & Websites
  http://www.hanen.org/Guidebooks---DVDs/Parents/More-Than-Words.aspx
• *Giggle Time*, Susan Aud Sonders, Jessica Kingsley Publishing, 2002

Coming Up Next
• The Grants learn about the principles, methods, activities, and techniques of the PLAY Project approach (See Chapter 9: The 7 Circles of the PLAY Project).
PLAY Project Checklist
For Functional Developmental Levels I, II, III

FDL I: Self-Regulation and Shared Attention
- How is your positioning? Are you being with the child near them or on the floor or facing them or following them around the room?
- Are you paying attention to the child’s attention? Where is he/she looking? What is his/her attention focused on?
- Are you paying attention to the child’s true intention? What is he/she interested in right now?
- Are you able to interpret your child’s subtle cues to understand what he/she wants? Are you ‘reading’ them right?
- When your child shows his/her intention, are you responding in a supportive way, encouraging your child to do what they want? Can you accept your child right where he/she is at?
- Whose play idea is it? Yours or your child’s?
- Are you using the ‘Rabbit Hole Techniques’?
- Can you define ‘circle’ of communication? What does it mean to ‘open’ a circle? Close a circle? Do you know how to count circles?
- Are you having fun together?

FDL II: Engagement
- Are you playing at the right level? Too high (child not getting it)? Too low (not engaging the child)?
- Can you engage your child by following his/her lead?
- Are you enthusiastic, animated, silly, fun? Using voice, gestures, and actions to make it fun?
- Are you in the right sensory mode to engage your child? You might have to change it up (i.e., avoid visually absorbing activities) to get better engagement.
- Are you getting 3-4 circles of communication going? Do you know how to count circles?
- How long can you keep the engagement going by being dramatic, silly, fun, sensitive to their interests (are you sweating yet)?
- Are you having fun together?

FDL III: Two-way Communication
- Are you slowing down your pace and waiting long enough to get responses from your child?
- Are you getting 6-10 circles of communication going?
- Are you ‘thinking circles’ as you play and going for longer chains of interactions?
- Who’s opening the first circle? Are you waiting for him or her to initiate?
- Are you using Theme and Variation to be inventive with your play?
- Are you connecting words to routines and fun events? Does he/she understand routines when you refer to them? Does he/she turn to his/her name?
- Are you seeing any imitation yet?
- Any word-gestures yet? Like signing for ‘more’, waving bye, pointing?
- Are you still having fun together?
Chapter 9
The 7 Circles of the PLAY Project

The 7 Circles of PLAY: The PLAY Project Approach
Jim and Julie Grant were beginning to learn the essential principles and methods of the PLAY Project model during their last visit. Soon, Amber, a master’s level social worker and the Grant’s PLAY consultant, will:

- Make her first monthly, two to three hour visit to the Grant’s home (involvement with the PLAY Project typically lasts one to two years)
- Get to know the Grant family and collect a set of assessments on Jacob
- Videotape Jim and Julie’s play interactions with Jacob for 10-15 minutes
- Give the family verbal feedback (coaching) during the visits, and
- Written feedback (video analysis) after the visits on ways to implement the PLAY Plan on a daily basis (See Appendix G: Jacob’s Video Review)

In this way, the Grants will learn to help Jacob march up the ladder of functional development and reach the potential within himself.

In this chapter, I’d like to go behind the scenes, so to speak, and describe what the PLAY Consultant will be saying to Jacob’s parents as she walks the family through the 7 Circles of PLAY.

1st Circle: Ready, Set, PLAY! An Introduction to Principles and Methods
In this first ‘circle’, the PLAY Consultant will introduce the Grants to the principles and methods of the PLAY Project that will help them understand the program goals as well as gain skills to improve engagement with Jacob and improve his functioning. Here are the 7 Circles of the PLAY Project:

- **Have fun with people**. Play should be one-on-one to start and must be engaging.
- **The ‘dose’ matters**—two hours per day (broken up into 10-20 minute PLAY sessions) for a total of 15 hours per week.
- **Accurately profile the child** in terms of his or her Comfort Zone, Sensory-Motor Profile (SMP) and Functional Developmental Levels (FDLs) in order to
- **Play at the right level**

1. **Have fun with people.** When you are having fun and the child is having fun, then you are probably playing the right way. When you do what the child loves, he or she will love being with you. In the beginning, play should be one on one—one adult playing with the child—and should be engaging. Over time, as the child moves up, he or she will want to play with siblings and then peers.

We were able to have fun with Jacob (See Chapter 8) and made him laugh a few times throughout the visit by using some sensory-motor activities, especially swinging. But the fun was short-lived, as he was not easy to engage. So putting in the time will be important for Jim and Julie Grant.
2. *The 'dose' matters:* Jacob has true autism, so Jim and Julie should try to get in the full two hours per day of PLAY. We don’t want parents to put in two straight hours. That would be unrealistic. Instead the play should be broken up into short 10-20 minute sessions throughout the day. Also, we encourage families to *make every interaction a good interaction* by being playful and engaging throughout *all daily routines* of waking up, getting dressed, eating, going out, etc. Intensive play, starting with one on one engagement, makes stronger neurological connections in the child’s brain. After a while, parents tell me that they enjoy PLAYing and don’t even worry about getting in the time.

3. **Accurately profile the child in terms of:**
   - Comfort Zone
   - Sensory Motor Profile
   - Functional Developmental Levels

   In the 2nd Circle of PLAY, we will go into more depth on assessing Jacob’s profile. Here are the elements we consider:
   - *Comfort Zone* (See Glossary) is what the child does when you let the child do whatever he wants to do. These are the repetitive, autistic behaviors and interests of the child that isolate them from relationships.
   - The *Sensory Motor Profile* includes which senses (visual, touch, movement, etc.) are favored by the child, which sensory-motor modalities make it easy to engage the child, and which modalities are to be avoided (like watching videos). These issues were described in detail in Chapter 7 on occupational therapy.
   - Finally, by now you should be able to list Greenspan’s six *Functional Developmental Levels* by heart (See below in case you can’t). These levels are like a ‘developmental ladder’ that your child will climb up as you have fun, put in the time, and play at the *just right level*. If you are still a little shaky on the milestones within each of these levels check out Appendices D & E. We’ll analyze Jacob’s FDLs in the 2nd Circle of PLAY.

   **Greenspan’s Six Functional Developmental Levels**
   (See also Appendices D & E)
   - Self-regulation and shared attention (FDL I)
   - Engagement (FDL II)
   - Two-way Communication (FDL III)
   - Complex Two-way Communication (FDL IV)
   - Shared Meanings & Symbolic PLAY (FDL V)
   - Emotional Thinking (FDL VI)

4. **Play at the right level.** When you profile the child accurately you will be much more likely to play at the *right level*. This means not playing too high (over the child’s head) or too low. When you are playing at the right level the child is much more likely to stay engaged with you. Insert yourself into their world by being dramatic, funny, surprising! When you have fun at the right level, the child will automatically make progress and reach the *potential within* themselves!

   During the last visit with the Grants, I had to coach them to play at the *right level* because they naturally wanted to play too high. They wanted to play at a *symbolic* level (mom played ‘choo choo"
Why do parents tend to play at too high of a level? Answer: Because all parents want their children to talk and be social, that’s why! They want so much for their child that they try to ‘push the river’, instead of just going with the flow. I have to remind parents frequently that first we must build the foundation of the house (interaction), so to speak, before we build the walls (receptive language and gestures), let alone the roof (talking and social skills). Talking and social skills are the crowning glory, the final achievement of development. And if parents want their child to climb this ladder of development, they MUST play at the right level (See Chapter 6: The Language Mountain).

It was Lev Vygotsky, the famous Russian psychologist, who said that we have to teach and play at the ‘just right’ level, which he called the ‘Zone of Proximal Development’.

Proximal means ‘near’ or ‘where the child is at’ developmentally. If we play too low in Jacob’s Comfort Zone, he will not make progress because we are not challenging him enough and he will isolate himself. If we play too high—which Vygotsky called the Zone of Potential Development—Jacob won’t understand what we are doing and he’ll disconnect. The best way to help Jacob make the fastest progress is to play at the ‘just right’ level—the Zone of Proximal Development.

For Jacob, this meant joining his visual stimming, his lining up, squeezing his hands/fingers, and swinging him. For Jim and Julie, joining Jacob’s ‘autistic behavior’ was emotionally hard but when they did, they got engagement and smiles and laughs.

The Essential Methods of PLAY

If PLAY principles are like a map that guides the overall direction of engagement, PLAY methods are the parents’ constant companion on the road that tell you what to do to keep engagement going. These methods should be used during every interaction (to see examples of parents using PLAY methods, get our DVD or watch the online videos at www.playproject.org).

Methods. The methods involve getting down at the child’s level, following the child’s lead, meeting them where they are at, and taking them where they need to go. In other words, methods lead to fun and playing at the right level—two main principles of PLAY!

The Five Basic PLAY Methods

1. Read the child’s cues/intentions accurately.
2. Follow the child’s lead. Be responsive to what the child wants. Honor the child’s ideas.
3. Slow down your pace. Observe. Wait!
5. Build on the child’s ideas. What would be fun?

Cues Help You Understand the Child’s Intentions. Cues are hints, based on the child’s behaviors and subtle gestures that tell you what the child is thinking or intending. The child with autism is not going to look up at you and say, “Oh, by the way mom, I just love the way these trains look all lined up by color.” By seeing where the child’s attention is, you can interpret their cues and very often figure out what the child’s intention is, i.e., what the child wants.
Follow the Child’s Lead. Once you have read the child’s cues and understand the child’s intention you need to respond and follow the child’s lead. This means being responsive to the child’s cues, intentions, behaviors, and ideas. In the beginning, the child’s lead/idea may be so simple (like ‘lining up’) that you’ll miss it if you aren’t paying attention, especially if you are too focused on your own adult ideas. So pay attention to the child’s intention and pay attention to the child’s intentions. In the beginning, this is probably the most challenging method for parents.

Pacing and Waiting. In order to ‘read’ the child’s cues, parents have to slow down their pace of interaction, observe the child closely, and wait to see what the child wants; wait for the child’s idea. This allows you to get responses and initiations, better known as ‘circles of interaction’.

In the beginning, it’s natural for the adults to open most of the circles by being engaging, fun, and high energy (but not too over-stimulating!). We have to go for the smile, the laugh, the gleam in the eye to capture the child’s attention and engagement. BUT, we must be constantly aware of those moments when the child responds to us and closes circles, or better yet, when the child shows their idea and opens (i.e., initiates/starts) their circles. These first ideas and initiations by the child are like gold.

For young children with lower functioning autism, the first ‘ideas’ (intentions) will be based on seeking sensations (e.g., deep pressure, lining up, watching spinning objects, running) or looking for cause and effect experiences (e.g., opening/closing doors, flipping pages, turning on and off lights). Only much later will the children have more complicated ideas. I will discuss these when I talk about the hierarchy of activities later in this chapter.

The Interactional Process: Go for Circles. By reading the child’s cues, understanding their intentions, following their lead, and responding to them at the right level, we will get them engaged with us in a fun way. Engagement means interacting and interacting means opening and closing circles.

We are constantly opening (initiating or starting) and closing (responding or completing) circles of communication defined as the back and forth—the ping-pong—of communication. I talked about this with the Grants at the last visit (See Chapter 8). There are so many back and forth interactions (what we call a ‘continuous flow’) going on in a typical social encounter that it’s hard to count circles. Usually we aren’t even aware of this interactional process. It happens automatically and naturally.

For children with lower functioning autism, though, circles are few and far between. They will completely ignore people, not opening even one circle! They will not even turn to their name. Even for many higher functioning children with autism, their ability to carry on a rich interactional conversation is limited.

In the PLAY Project, we pay very close attention to this interactional process because it is the foundation of future social skills and must be established early in order for the child with ASD to become functionally social in the future.

So, in this first circle of PLAY, we must become aware of the interactional process. We must start counting circles, thinking circles, going for circles.
Expanding the Play. Once we tune in to the child’s ideas, actions, and interests, we can add our own ideas and extend theirs. We can challenge them AND follow them at the same time. Exactly how we do that leads us to activities and techniques, which will be described later in the 3rd Circle of PLAY.

2nd Circle of PLAY: Understanding Your Child: Creating a Unique Profile

In order to help Jacob reach his full potential, Amber will need to discover Jacob’s unique developmental profile. In the PLAY Project our approach is completely individualized because each child is unique and has a different profile. During the first visit, Amber will administer a number of assessments that look at language, functional development, autism severity, and play interactions. She will help the Grants understand Jacob’s profile so the work of PLAY with Jacob will be at the right developmental level.

Let’s briefly (See also Chapter 8) review Jacob’s profile according to his:
- Comfort Zone
- Sensory motor profile
- Functional Developmental Levels (FDL)

Comfort Zone. Jacob is still quite stuck in his own world, doing his own thing, which is largely a sensory-motor world. His connection to people is still weak. As children become more connected to people over time, their Comfort Zone activities will naturally decrease. To help the hard-to-engage child we used the Rabbit Hole Techniques with Jacob (See Chapter 8).

Sensory-motor Profile (SMP). We went over Jacob’s SMP in detail in Chapter 7 and Chapter 8. A good occupational therapy evaluation is very helpful here. The figure below provides a quick summary of the most important features. Here, too, as Jacob makes progress, his sensory-motor system will become more integrated into his functional development and not derail his social connection.

Functional Developmental Levels (FDLs). As you can see, Jacob’s Functional Developmental Levels include characteristics from his Comfort Zone and SMP:

Jacob’s Comfort Zone and Sensory Profile

Comfort Zone
- Lining up, visually ‘stimming’, watching doors open and close, flipping pages of books, watching Sesame Street, wandering.

Sensory Motor Profile
- Under-reactive (bump on a log), loves visual but also deep pressure, movement, tickling, music.
- Picky about food textures, prefers crunchy to soft.

Jacob’s Functional Developmental Levels

FDL I: Self Regulations & Shared Attention
- Not solid. Still in his own world most of the time.
- Shuts down and avoids people.
• Likes his Comfort Zone activities.

FDL II: Engagement
• Not solid. Engagement is brief.
• Parents have to work hard (‘sweat’) with high energy to get Jacob engaged.

FDL III: Two-way Communication
• Just emerging. Jacob will only occasionally initiate.
• Has trouble even closing circles.

‘Solid’, ‘Holes’, and ‘Capacities’. You’ll notice that as I discuss a child’s profile, I will use terms that measure how well the child is progressing in his or her profile. These terms include:
• Being ‘solid’ at developmental levels, meaning that this FDL level is achieved
• Having ‘holes’ at those levels, meaning that this FDL is not yet achieved
• Having ‘capacities’ at higher levels, meaning that the child has untapped potential

So, for instance, Jacob is still struggling to function at the lower three FDLs, with difficulty sharing attention (FDL I), staying engaged (FDL II), and interacting in a two-way fashion (FDL III). In other words, he is not ‘solid’; he has ‘holes’ at the lower three levels. But he seems bright and he has nice capacities at FDL III and maybe even a little at FDL IV. We know he has potential. The Grant’s PLAY Consultant Amber will rate these FDLs on a scale and chart them for the family.

Also, in regard to Functional Developmental Levels, it is critical to understand that children do not function at one level only. They function on all the levels they are capable of. Once again, it’s helpful to think of the child as climbing a ‘developmental ladder’ with their ‘feet’, so to speak, on their lowest FDLs, their ‘body’ on their middle FDLs and their ‘hands’ reaching up to climb to their highest FDLs. So, where should we be working with Jacob? What FDL do we play at?

Where is the Work of PLAY? Jacob has his ‘feet’ in his Comfort Zone, i.e., he’s not ‘solid’, only sharing attention some of the time, at FDL I. His ‘body’ is at FDL II, which means his parents have to work hard to engage him (that’s why we call FDL II the ‘sweat’ level). When they work hard, they can engage him some to half of the time. And his ‘hands are reaching up’ to FDL III, which means he only has some two-way communication and doesn’t open and close many circles of communication.

So, the work is primarily going to focus on FDL I (getting his attention) and FDL II (keeping him engaged). But we will be promoting FDL III (noticing when he opens and closes circles to create two-way communication) as much as we can. Yay! Now we have a basic plan!

Once we have profiled the child and understand his or her Comfort Zone, Sensory-Motor Profile, and range of Functional Developmental Levels, then we can usually figure out what types of techniques to use and which activities to introduce. Welcome to the 3rd Circle of PLAY.

3rd Circle of PLAY: Individualized Techniques and Activities
From the initial assessment, we know Jacob’s unique strengths and needs. Amber will work with Jim and Julie to design an individualized plan of techniques and activities designed to help them ‘woo’ Jacob into a playful, fun relationship that will help him make progress. Being connected to people is the most important thing in the PLAY Project. Parents want to know ‘what to do’ when they are
with their child. The 3rd Circle of PLAY empowers the family to build their skills as players while supporting their child through the stages of development.

*Techniques.* Let’s start with techniques. In order to build on the child’s intentions, actions, feelings, interests, and ideas, we have to either be naturally playful or we have to have a plan. Techniques provide a plan that answers the question: *What do I do next?* Techniques may be used one at a time, but typically, they are used in combination with *methods* to produce a smooth interactional flow (See *Appendix F: PLAY Techniques*).

Let’s begin with some basic techniques. Then, I’ll show you how you can combine techniques to create engaging variations for your child that will be fun.

**Basic PLAY Project Techniques**

- *Being With*
- *Taffy Pulling*
- *Suspense & Surprise*
- *Playful Obstruction*
- *Salient Language*
- *Theme & Variation*
- *Cause & Effect*

**Being With.** This is the most fundamental technique. Just simply *being with* the child in his space, at his level, face to face, with no ideas of your own (i.e., putting on your ‘Zen head’) allows you to observe your child and really see what his intentions, feelings, and ideas are (e.g., lining up trains, seeking deep pressure by flopping on the couch, wanting more rough and tumble play). This technique brings you into the present moment with your child, gets you tuned in to cues, and allows you to see your child exactly where they’re at so you can follow your child’s lead.

*Note:* For very hard to engage children, however, you can’t wait too much or you will lose them. For these children, I recommend the *Rabbit Hole Techniques* (See *Chapter 8*) and fun activities. For hard to engage children, you have to work hard at getting engagement. You have to *sweat*!

**Taffy Pulling.** When you have the child’s engagement—like good eye contact—don’t let it go! Dwell in that eye contact. Stay right there. Make engagement last and s-t-r-e-t-c-h it out like *pulling taffy* by doing what you are doing more slowly, or . . . by adding a slight variation, or . . . by creating a little suspense, or . . . setting the child up for a little surprise, or . . . who knows what will happen next? Did I ‘taffy pull’ you into wondering what I was going to say next?

**Suspense and Surprise.** This is a kind of ‘taffy pulling’. By creating suspense followed by a surprise, the child will stay engaged.

- Examples include counting with the dramatic tension rising as you count each number: “1-2-3-4-5 Tickle, Tickle, Tickle!”
- I also love ‘The Claw’ where you hold your hand in a claw shape above the child (who is usually lying down) and say, “Here comes the claw. Here comes the claw!” And then ‘The Claw’ comes down into the child's belly.
- Ready-set-go games also create suspense and surprise.
• Peek-a-boo has suspense and surprise built into it. Try stretching it out (‘taffy pulling’) by pacing your voice a little bit slower (but not so slow that you lose the fun!).

**Playful Obstruction.** This technique of making the child work for what they want can be used throughout the day in many situations.

  + **Example 1:** You stand in the doorway of the room your child is trying to get into, playfully obstructing their entrance, and make your child push you out of the way to get into the room. When they push you, be dramatic and fall down. Children love slapstick.
  + **Example 2:** You hold an object the child wants in your closed fist and make the child open your hand finger by finger to get it. Count as the child opens each finger. Then, say “There it is!” when they get the object. Just remember, it’s supposed to be more playful than obstructive.

Remember: **Fun always trumps any technique.** Don’t be too obstructive. Don’t stretch things out too long. Don’t keep doing an activity if the child doesn’t like it.

**Salient Language.** *Salient* means ‘stands out’. In this technique, we want the language to stand out. The words that mean the most to the child should be emphasized throughout the day. The most common words are going to be the ones that make the child laugh, that motivate the child (like food), names of loved ones (including the family pet!), and routines. Make a list of your child’s 20 most meaningful words and have everyone use these words consistently throughout the day.

**Theme and Variation.** One of the most important techniques—**Theme and Variation**—can be used for both lower and higher functioning children.

When the child is engaged in an activity that they love, like swinging in a blanket, and they want to do the same activity over and over (and over!) again, it’s time for the ‘Theme and Variation’ techniques. The **theme** is the current (repetitive) activity. To create **variations** ask yourself this question: *What are five to ten things I can do with this activity in a way that is fun?* Here are some variations on ‘swinging’:

  + Go slow and wait for the child to initiate that he wants more swinging
  + Use words to express his gestures: “Oh, you want to swing!”
  + Play dumb and make him ask you twice or three times
  + Count 1-2-3 while you swing. Stop at 2 and see if he will say “3”
  + Sing a song about ‘swinging’ and let him join you
  + Swing him to the couch and change locations
  + Move him in an up and down motion instead of a swinging motion

**Cause and Effect.** For example, as children move up functional developmental levels from FDL I (sharing attention and being more ‘with us’) to II (being fairly easy to engage) to III (starting to respond to us consistently and initiating more and more), they become more purposeful and develop the capacity to understand cause and effect. So parents need to introduce cause and effect games as a play technique. By doing so, parents will ‘woo’ the child to develop this emerging capacity.
Flip the light switch and the lights go on. Say “1-2-3” and the child knows something fun will happen. Play peek-a-boo and she knows that your face is coming from behind the blanket. And they ‘get it’. They might even imitate. They look; they smile; they want more. Repetition is the key.

The ability to make this cause and effect connection begins at FDL III (two-way communication) and gets more solid at FDL IV (complex two-way communication/problem solving skills) until, through much repetition, the child goes beyond simple cause and effect and begins to recognize routines. When you have repeatedly, over days and weeks and sometimes months, said “Let’s go bye-bye”, eventually, the child gets excited and moves toward the door. This marks the beginning of true receptive language, a big milestone in functional development and leads to the higher level techniques.

**Higher Level Techniques.** Techniques (and activities) vary depending on the child’s Functional Developmental Level. In Appendix F, you'll notice that techniques are divided into FDLs I-IV and FDLs IV-VI. Makes sense, right? The higher the child’s FDLs are, the more complex the play will be and the more complex the techniques will be too.

**WARNING!** Children on the autism spectrum must first build the foundation of attention, engagement, and two-way communication (the first three Functional Developmental Levels) before they will be able to move to the higher levels. The higher levels grow out of the lower levels like a leaf grows out of a stem and a flower emerges from a bud. Not until the child becomes ready do these new functional abilities happen. And then, amazingly, when the child is ready, these abilities emerge naturally, so don’t pull the plant to make it grow. PLAY techniques become more complex as your child becomes more functional and marches up the developmental ladder (FDLs IV, V, and VI).

**Higher Level PLAY Techniques**
- Rhythm and Music
- Mirroring/Reflecting
- One Step Commands
- Pretend Play
- Simple/Imitative Pretend:
  - Phone to ear, bottle to baby’s mouth
- One Theme Pretend:
  - pretend eating, pretending with the doctor’s kit
- Two Theme Pretend:
  - good guys/bad Guys, playing ‘house’

**Rhythm and music.** Likewise, the repetition of songs like ‘Ring around the Rosie’ or story songs like ‘The Eensy Weensy Spider’ leads to an understanding of meaningful sequences that are fun. Saying “I’m. . .gonna. . .get you!” repeatedly and rhythmically, especially if followed by rough housing or tickling, will be quickly understood by a child at FDL III-IV. There’s a part of the child’s brain that seems particularly receptive to rhythm and music. I will often recommend that parents sing what they want to say to the child using the ‘London Bridge’ song: “Now it’s time to take a bath, take a bath, take a bath. Now it’s time to take a bath, my dear Jacob.”
Mirroring/reflecting. This next technique may be the technique I personally use the most. As the child comes to understand more and more (i.e., receptive language is improving), it’s important that parents use language to mirror the child’s experience. You can mirror: behavior, feelings, and/or language.

- **A behavior** reflection would be: “Jacob is climbing up, climbing up.”
- **A feeling** reflection—for the child making a face of disgust at getting his hands muddy—might be: “Yuck, no dirt!”
- **A language** reflection—after the child says “Juice”—would be: “OK, more juice.”

In this technique, you must use statements, not questions. The child is experiencing the world in the form of statements. He’s not thinking “Am I climbing? Do I hate this dirt on my hands? Do I want juice?” No. These aren’t questions in the child’s mind. Use statements!

One step commands. At later FDL IV (complex two-way communication/problem solving skills), the child will move from understanding simple cause and effect and repeated routines to understanding one step commands. At first, these commands will be simple like “Sit down, please.” Or “Come here, Jacob.” But eventually, the child will be able to follow the ‘spontaneous give and get’ commands: “Jacob, give the ball to daddy.” It helps to be close when you start to use this 1-step command and to use gestures (i.e., wide open hands) so the child can get the idea. By the way, at this stage most children will start using single words and have a vocabulary of 20-50 words. *Most children with ASD start talking when they are at a solid FDL IV!*

Pretend. The last set of techniques I will present here are the pretend techniques. Pretend and imagination are central to child development, yet very few interventions for children with ASD emphasize pretend play. In the PLAY Project (thanks to Serena Weidler, PhD and Stanley Greenspan, MD), we identify three forms of pretend, which vary by functional developmental level: Simple pretend, One thematic pretend, and Two thematic pretend play.

**Simple imitative pretend**, beginning at FDL IV, happens when the child puts a phone up to his ear in imitation of mommy or daddy doing it; or feeds a baby doll or a big mouth puppet in simple imitation of his parents’ actions.

**One thematic pretend play** emerges at late FDL IV and early FDL V (shared meanings). An example is when the child plays doctor by using each instrument of his pretend doctor’s kit—a stethoscope, an otoscope, a shot—in turn. He doesn’t really pretend to be the doctor. He has one idea, which he repeats over and over using a different instrument. As we play with him (as you’ll see in later visits with Jacob), we can expand on his one thematic play to make it richer, more varied, and more complex. This will lead him into the more complex, two thematic play.

**Two thematic pretend play** emerges at FDL VI (emotional thinking). These children are usually talking in at least short sentences. These children can really play the role of ‘doctor’ and say, “Are you sick? I can help you.” Then, give you medicine because you are sick. This is true emotional thinking. Here, there is more than one idea or theme; two ideas are being connected logically. Other examples of two thematic play include ‘good guys and bad guys’, playing ‘house’, or playing ‘school’.

Pretend play is very rich. No other form of intervention is as effective in helping all aspects of development. As children move from simple through one thematic to two thematic play, they are gaining language, social skills, and robust problem solving skills. Pretend play is the path to true social relationships. In the PLAY Project we love pretend play!
Combining and Creating Techniques. Once you have the basics, then you can combine techniques. Altogether, there are nearly 50 different techniques (See Appendix F), so you have plenty to choose from. And you can also make up new ones!

WARNING: To end this section on techniques, it’s important to note again that techniques are not used mechanically, in isolation from the flow of play. You would not say, “OK, I’m going to use the technique of playful obstruction now” without first seeing what the child is doing. Techniques should be used smoothly and naturally within play.

Activities
The 3rd Circle of PLAY includes activities. Here, again, I must warn you that activities should be based on the child’s interests and functional level. Activities are secondary to our methods. Why? Because activities are usually based on the adult’s ideas.

Whose Idea Is It? In Jacob’s case, as you may recall, we did a swinging activity that Jacob loved. This was not Jacob’s idea. It was mine. So, it is OK for parents/adults to have their own play ideas. It is OK to introduce and initiate activities. Just be aware that it is your idea and not the child’s. And give the child every chance to lead by waiting and slowing your pace. Remember: one of our ultimate goals is to help the child become as independent and functional as possible. This means that the child must come up with his or her own ideas. This is why we value and emphasize ‘following the child’s lead’ so much. Over time, the child WILL initiate lots of his/her own ideas (as you will see in Jacob’s next visit).

In the beginning, however, many of our children, like Jacob, don’t give us much of a lead to follow, and their ‘lead’ often takes us into their Comfort Zones, which can be a dead end developmentally. Sometimes, especially in the early engagement stages, we have to provide ideas and activities.

Watch for the Child’s Ideas. While the 3rd Circle is all about activities that we, the adults, introduce to the child, we still have to watch for the child’s lead. As soon as the child has an idea of his or her own, we must be able to recognize it and follow it. Even though we start the activity, we can still follow Jacob’s lead by waiting and watching for his ideas/initiations. For example, after we swung him, we waited. What did he do? He gestured for more (his idea!) by putting his hands out (he completed a circle!), so our idea became his idea! Then, we could follow his lead. Interesting, eh?

The Hierarchy of Activities. So, what kind of activities should we introduce? We know that the activities have to be at the ‘just right’ level (or Vygotsky will be upset with us!). How do we know which ones are just right?

Do nothing and see what the child does!!

What you will discover is that there is a clear hierarchy of what children love to do based on their unique profile and Functional Developmental Levels (FDLs).

The Hierarchy of Activities
1. Pure sensation (FDL I and II)
2. Cause and Effect (two step sequences) (FDL II and III)
3. Sequences (more than two steps) (FDL III)
4. Game like activities (FDL III and IV)
5. Simple imitative pretend (FDL IV)
6. One theme pretend (FDL V)
7. Two theme pretend (FDL VI)

In other words, if you leave the child alone, a lower functioning child will gravitate to sensory based play (e.g., visually stimming on lining up—a pure sensory delight). A slightly higher functioning child will like cause and effect (e.g., turning on and off a light switch).

What is exciting to me is that, as we play at the right level and the child makes true progress in their profile, their interests evolve. They naturally, spontaneously, and with prompting want to play at higher and higher levels, and they want to play with you. So, let’s make a list of activities that are associated with each level of the hierarchy.

Activities for FDL I and II. For the lower FDLs I-II, you will notice that the activities involve sensation, deep pressure, light touch, and movement.

**PLAY Activities for FDL I and II**
- Gently shaking or squeezing arms or legs
- Rolling and unrolling child up in a rug or blanket
- Swinging in a blanket
- ‘Squooshing’ to give them a feeling of pressure
- Tickling (not too much!)
- Gentle wrestling
- Water play of all kinds (bath, sink, hose, etc.)
- Bubble play
- Opening and closing a door and playing peek a boo from the other side
- Spinning the child on a swivel chair, stopping and saying “Stop”, spinning it and saying “Go”

I tend to avoid the visual activities like playing with trains/cars or electronic toys, books, and puzzles—though bubbles are great visual fun. So, moms, get rough and tumble!

Activities for FDL III and IV. For the next levels, notice that we are moving into the realm of simple cause and effect and sequences of three to five actions in a row that are meaningful. Here, it’s not just about sensation or movement alone. There is a ‘little story’ here, something that the child can anticipate, where they have to ‘get the joke’.

**PLAY Activities for FDL III and IV**
- Peek-a-boo. Hide under a blanket.
- Use: “1-2-3” or “Ready-set-go” language
- Chase/Monster: “I’m gonna get you (tickle)”
- Ball or balloon play (back and forth games)
- Very simple pretend (phone to ear, feed dolly, cars crash and make a crashing sound)
Activities for FDL V and VI. Here, at FDLs V and VI, we start to become truly symbolic in our activities. Words have more meaning. This is more than sensation or movement, more than cause and effect. This is the beginning of imagination, where words have abstract meaning. “Let’s pretend that you’re the bad guy and I’m the good guy”, can you see the developmental ladder of activities moving from sensory-motor to simple cause and effect to the symbolic?

PLAY Activities for FDL V and VI

- One theme pretend (FDL V): doctor, feed the puppets, tea party with stuffed animals, sword fight
- Two theme pretend (FDL VI): good guys/bad guys, playing ‘school’, playing ‘house’
- ‘Reading’ books—mostly looking at pictures and telling a simple story (don’t READ the book, explain what’s happening) (FDLs V & VI)
- Real hide and seek, not just peek-a-boo (FDLs V & VI)
- More complex song/music games (FDLs V & VI)
- Board games/sports (FDL VI)
- Play dates with peers (FDL VI)

Jacob’s Activities? So what activities would you recommend for Jacob? Since he still spends a lot of time in his Comfort Zone and it is hard to engage him, I would recommend the list of activities for FDLs I and II that are sensory, touch and movement based.

Even though Jacob’s parents have a set of activities that should be fun and engaging for Jacob, on some days, the activities THEY choose won’t engage him. Engagement can be an elusive butterfly and will be affected by Jacob’s mood, time of day, level of frustration, who is playing with him, the location of play, and the type of play. So his parents might have to give up their ideas and activities and go back to methods by ‘following Jacob’s lead’.

As you can see, play is work and can be complicated, especially if your child has a more complex profile. Over the next several visits, as you will see, Jacob’s profile evolves and becomes more and more challenging. This is why families need the PLAY Consultant to provide guidance, which leads us to the 4th Circle of PLAY.

4th Circle of PLAY: Family Guidance: Coaching, Modeling, and Feedback
Families view the (usually monthly) home visits with expectation and a certain amount of anxiety. It’s a big deal to let someone new into your home! For families, there are all kinds of questions and issues: Will it work? How does it work? Are we going to like the consultant? Will we be able to do it right?
We are very familiar with these concerns. Our PLAY Consultants are well trained, master's level child development experts and really good at supporting the family in their role as their child's best PLAY partner. The PLAY Projects around the country and internationally have served a whole range of families in terms of number of children, marital status, education, income, and location. It is our foundational belief that every parent no matter what their circumstances wants to have a close and rich relationship with their child. The consultant answers questions, coaches the parents as they play, models the techniques and activities and provides written or verbal feedback. Video footage is taken of both the parents and the consultant to be used as part of the visit review. Hopefully, the PLAY Consultant will become a trusted member of the team that helps the child reach their full potential. Here are the key elements of family support.

Coaching. Coaching is the primary job of the PLAY Consultant. The consultants know family systems, human psychology and child development. They are certified in the PLAY Project and know how to help children move up the developmental ladder by gently guiding the parents to effectively use PLAY Project principles, methods, techniques, and activities with their child.

Coaching is a two way process, which recognizes that parents are expert on most aspects of their child’s life. Some parents, like the Grants, are totally committed to implementing PLAY and ready to go. Other parents are more skeptical and have a 'show me that it works' attitude. Still others are anxious about performing. Coaches understand adult learning and how to ‘follow the lead’ of the parents to find the best way to transmit the complex information of the PLAY Project.

An important part of coaching is videotaping and giving feedback ‘in the moment’ that PLAY is happening. There is no escape from the videotape! Typically, the consultant takes 10 minutes of the parents PLAYing and the parents take a three to five minute video of the consultant modeling PLAY. The detailed analysis that comes from watching the parents play is described in the 6th Circle of PLAY.

Modeling. During the home visits, PLAY Consultants play with the child in order to model methods, techniques, and activities. As mentioned, a three to five minute sample of the consultant's play episode is also recorded on videotape. The consultant then critiques her or himself during the video analysis (See 6th Circle). (No one escapes the videotape!)

Modeling may be a powerful way to demonstrate the PLAY methods, but it is fraught with potential danger. If the PLAY Consultant plays too well, the parents can feel sad and/or inhibited because a ‘stranger’ can play better with their child than they can. If the consultant doesn’t play well enough, then parents may question the consultant’s competence. These issues become a matter for open discussion between parent and consultant. In the PLAY Project, we welcome parents sharing their observations, feelings and concerns.

Support and Feedback. Over time, hopefully, a trusting relationship will grow between parents and consultant and, within the bounds of a professional relationship, they will get to know each other better.

Social Support. Parents who have a young child with ASD face daunting challenges: therapy issues, pre-school issues, sibling issues, scheduling issues. . .the list is unending it seems. Parents’ feelings run the gamut from the anxiety and guilt of not doing enough, to feeling overwhelmed for having to do so much. It’s so nice to have someone in your corner who cares and understands.
Resources and Referrals. One of the important roles of the consultant is to help families find resources. For parents with mental health needs, those dealing with marital conflict, families struggling with keeping their financial heads above water, etc., the consultants may help with emotional support and referrals to appropriate agencies in the community.

Hopefully, with appropriate support and guidance, parents will be motivated and available to PLAY with their child. This leads to the 5th Circle of PLAY: Engagement.

5th Circle of PLAY: Engagement: PLAY Time Between Parent and Child

Typically, PLAY Consultants come once a month, sometimes as often as once a week. But unlike services that are provided in a medical model, where you send your child for physical, speech and language, or occupational therapy one time per week, the PLAY Project is a parent-coaching model, a parent implemented model. We teach you. Between visits, you work with your child by putting in the time and following the program.

While the PLAY Project is inexpensive money-wise compared to most other therapies, it appears to be highly expensive time-wise. At least, most parents feel that way in the beginning. Julie Grant felt pressured and overwhelmed at the thought of having to get two hours per day of engaging PLAY with Jacob, and she’s a stay at home mom! What about families with two working parents? What about single parents with other young children?

In our research, however, we found that instead of increasing stress or producing overwhelming feelings of depression, families who started the PLAY Project experienced less stress over time and depression was significantly reduced (See Appendix B: PLAY Project References, Article and Abstract). How is this possible?

Three Secrets.

• First: Start slowly and build up the time of PLAY. You have weeks to develop a plan. No giant hurry. Do what you can. Just get started. Your consultant will support you no matter what.

• Second: There is plenty of time. At twelve waking hours per day times seven days per week, a two to five year old child is awake about 140 hours (plus or minus naps!) per week. We’re just asking for 10% of that—two mealy hours per day. And guess what? Families in our research study, who came from every walk of life, reported putting in on average 1½ to 2 hours per day. How did they do it? (See below)

• Third: Don’t leave things up to chance. Make a plan.

Every Engagement Counts. Time can be counted if your child is engaged with any person. I strongly advise families to turn off the TV, video, iPhone, iPad, Wii and computer. Do not let the child play in isolation. Include him or her in family events. Do not spend all your time driving to multiple therapies. And finally, encourage engagement from all family members: mother, father, siblings and/or the extended family. Cha-ching! Time in the bank!

Don‘t Make Routines Routine! From the moment your child wakes up until the moment your child goes to sleep, you have many, many opportunities to engage with him or her through daily routines.
Don't make routines routine! Remember: Make every interaction a good interaction. Think 'circles' all day long during every routine.

When you go into the child's room to wake them up, think about techniques like 'taffy pulling': 'I'm going to stretch out this interaction until he gets out of bed. I'm going to wait for eye contact and see what he does. Then, I'm going to follow his lead. I'll go slowly, step-by-step into his room while calling his name and create some suspense and surprise. I'm going to get me some circles from this guy.' It's not about time; it's about being mindful and making each moment count.

For each and every routine, you have engagement opportunities. Waking up, getting each item of clothes on, brushing teeth and washing up, getting silverware and plates...well, you get the idea.

Planning. Finally, plan your time. Get a calendar and make a schedule of PLAY time. For instance, ask dad to get just a half hour in when he comes home from work at least two to three days per week. Talk about it together and put it on the schedule. You're shooting for a few 15-20 minute sessions where you do nothing but just be with your child. And you can include the other child or children too. Make it a 15-minute family play session. Make sure you use your weekends wisely.

One of the things that a two to three hour home visit from your PLAY Consultant does is show you that you can make the time. A lot of families these days, in all their busyness, have simply forgotten to play. So, it may feel a little strange at first to do nothing but wait and see what your child wants to do. But with your first successes at engaging your child, you realize how nice it is to just be with your kids and do whatever they want and have fun. It’s fun! And we’ll help you all the way. So try to plan for a few short 15-minute play sessions per day and voilà! Before you know it, you have gotten your time in without even trying. Most of our families tell us that in the beginning they counted the hours, but as they became used to PLAYing, they just PLAYed all the time.

6th Circle of PLAY: Visit Review: Video and Written Feedback

So your PLAY Consultant leaves; you’re excited to use the PLAY Project approach; you plan to make time for PLAYing, and you think ‘It would be nice to have some guidance until my PLAY Consultant comes back the next time.’

Visit Suggestion Report. When she’s done with the home visit, your consultant will give you three written suggestions to help you direct your play in the short run. (See Appendix G: Jacob’s Suggestions and Video Review Report. This report is from a later visit when Jacob was higher functioning.)

Video Analysis and PLAY Plan. Then, in one to two weeks, you’ll get a package in the mail (or email). Your PLAY Consultant will send you the 15-minute video she took at the last visit, along with a PLAY Plan on exactly what to do with your child. Welcome to the 6th Circle of PLAY.

The consultant will study the videotape and give you a detailed written analysis of the play (See Appendix G: Jacob’s Suggestions and Video Review Report).

• There will be a real time review, literally a minute by minute written commentary that emphasizes the positives and points out when you are accurately reading your child’s cues, following your child’s intentions, and getting circles of interaction. You will be able to study yourself and notice your pacing, methods, and techniques.
• The home consultant will also include observations about your child's Functional Developmental Levels, and she'll make suggestions about methods and techniques that you might incorporate into your play the next time.
• At the end of the write up is a PLAY analysis and plan that goes over:
  • Your child’s profile (Comfort Zone, Sensory-Motor Profile and Functional Developmental Levels)
  • Rates your child’s progress
  • Offers suggestions for techniques
  • And recommends new activities that might be fun to try

In the next several chapters, I do this type of analysis for Jacob’s parents as he progresses through the six Functional Developmental Levels.

**The 7th Circle of PLAY: Change and Growth: Revising the Plan as the Child Develops**
As your child changes, the whole PLAY Plan changes as we reassess and adjust the activities, methods and techniques. This is the 7th Circle of PLAY: Since most children make gains over months, not days or weeks, the monthly (typically three hour) home visits make sense. We commonly follow children over one to three years in the PLAY Project offering families ongoing support as their child hopefully marches up the Functional Developmental Levels. Each year we reduce the number of visits because parents don’t need as much support. We teach you, the parents, to become your child’s best play partner. This way, every interaction becomes a good interaction promoting your child’s development.

**Summary**
• The 7 Circles of PLAY form the basis of the PLAY Project approach (see a description of the 7 Circles at the end of this chapter)
• A PLAY Consultant guides the family through the PLAY Plan by helping to describe the child’s unique profile, coaching parents, modeling, and giving feedback
• Parents then learn to play in an engaging fun way, throughout the day by employing key methods like reading their child’s subtle cues, following the child’s lead, and getting ‘circles’ of interaction
• Techniques and activities help the parents know what to do next
• By following the PLAY Plan, parents help their child march up the developmental ladder

**Resources & Websites**

Websites

Books
• Visual/Spatial Portals to Thinking, Feeling, and Movement, Serena Weider, Profectum (2012)
• *Autism Solutions* by Ricki Robinson

Coming up Next
• We help Jacob’s parents learn how to help Jacob move up the developmental ladder from Functional Developmental Level III to Functional Developmental Level IV
7 Circles of the PLAY Project

The PLAY Project is a play-based early intervention program that can improve social interaction, communication, and functional development in children with autism spectrum disorder.

1. **Ready, Set, PLAY! An Introduction to Principles and Methods** To begin, the PLAY Project Consultant (PPC) introduces the family to the principles and methods that will help parents understand the program's goals as well as gain skills to strengthen engagement and improve child functioning.

2. **Understanding Your Child: Creating a Unique Profile** Next, the PPC invites the family to share their knowledge about their child. This parent-professional partnership helps to create a program for the individual child. Assessment tools identify the child's Neurological Comfort Zone, Sensory Motor Profile, and Functional Developmental Level. The goal is to create a child profile that supports the child through each stage of social and emotional development.

3. **The PLAY Plan: Individualized Techniques and Activities** Guided by the child's unique strengths and needs identified during assessment, the PPC collaborates with the family to design an individualized plan of PLAY Project activities and techniques. The PLAY Plan empowers the family to build their skills as players while supporting their child through the stages of development. [The plan changes/is updated as child makes progress]

4. **Family Guidance: Coaching, Modeling, and Feedback** During each home or clinic visit, the PPC supports the family in their role of play partner with their child. The PPC answers questions, coaches the parents as they play, models the activities and techniques, and provides written feedback. Video footage is taken of both the parent and the PPC, to be used as part of the visit review.

5. **Engagement: PLAY Time between Parent and Child** Between visits, the family follows the PLAY Plan’s activities and techniques as they interact with their child during daily routines and short play sessions throughout the day. The family is encouraged to playfully engage their child 15-20 hours per week. The goal is to make every interaction a good interaction, providing the intensity needed to help the child grow in their social-emotional development.

6. **Visit Review: Video and Written Feedback during PLAY Visits** Video captures the child playing with the family and the PPC. After the visit, the PPC reviews the video to assess the child's progress and the family's engagement in PLAY Project activities. The PPC provides the family with the video recording and an updated Profile and PLAY Plan that include helpful observations and suggestions.

7. **Change and Growth: Revising the Plan as the Child Develops** Children are dynamic and so is the PLAY Plan. On an ongoing basis and at scheduled intervals, the PPC will reassess the child's progress, adjusting the PLAY Plan's recommended techniques and activities to best meet the changing needs of the child and family.
Chapter 10
Visit 5
Moving On Up?

After the last visit with Jacob, I was hopeful but worried. Jacob was still in his own world too much of the time. He was hard to engage and was initiating toward his parents mostly to get what he needed or wanted. He would take them by the hand to the refrigerator for juice or yogurt (which indicated some good problem solving skills), but he didn’t seem to enjoy playing with them or his two-year old brother, Charlie, who he mostly ignored. He was arriving at a critical moment. Would he move up into the higher functional levels or would he stagnate?

PLAY Project Home Visits
‘Jacob Grant’ was on my schedule for an 11 a.m. appointment. It had been about four months since I’d seen the family and the Grants were enrolled in the PLAY Project (See Chapter 8: Starting the PLAY Project Autism Intervention). Their home consultant, Amber, had been going to the home once a month to video interactions and coach the family. Amber would then analyze the video and give the family written feedback between visits.

Typically, I review the videos and supervise the home consultants. I record my comments on an audio file for the family. Amber confirmed that Jacob’s parents were committed to putting in the time and trying to use the methods. But as I watched the video, I could see that they were anxious players, trying too hard. They were taking over the play by offering too many of their own ideas and playing way too fast, not giving Jacob enough time to respond. I wanted them to ‘slow down and have fun’ and not put so much pressure on themselves. But this is the way it is for new PLAY Project families. They’re anxious to get going; they’re anxious to see progress; they’re anxious to hear words!

As I recall Jacob’s history, I’m getting anxious about Jacob’s progress when I hear him fretting in the waiting room. They’re here.

I go out to greet everyone, shake hands with mom and dad, and hold up my hand to slap five with Charlie, who’s two year old now and he gives me a robust high five. Then, I hold up my hand to Jacob and instead of giving me a high five, he reaches for my hand. Then, he hides behind his mom’s legs. I look at Jacob’s parents and say, “That’s a good sign. At least he’s closing a circle.” They smile but looked a little worried. I learn a lot just by saying hello.

Once in the playroom, the boys quickly find toys they like. They play in parallel, quietly and let us talk—for a while.

**Dr. Rick:** “Well, it’s been about four months since I saw you last, though I watched a couple of videos since then. Did you get my audio files?”

**Dad:** “You don’t pull any punches on those tapes, do you?”

**Dr. Rick:** “Was I too hard on you guys?”

**Mom:** “Not really. We were playing too fast and taking over. It was actually a relief for me to hear that I could wait and not have to fill in every second engaging Jacob. That felt like so much pressure.”
Dad: “But then, we wondered if we weren’t doing enough.”

Dr. Rick: “It’s a delicate balance. But as long as you are working on the process of engagement, then you’re doing enough. In the beginning, you have to ‘sweat’ but as Jacob improves you have to ‘wait’ and do less. It sounds like you’re putting in the time.”

Mom: “Once I get two hours a day in, I relax and... then I have more fun.”

She realizes what she was saying and we all laugh.

Dr. Rick: “Mom, no! (I mock yell at her) You’re supposed to have fun all the time.”

Mom: “But it feels like work.”

Dr. Rick: “Going for ‘circles’ is like building a brick wall. It’s time consuming.”

Dad: “I hope all those ‘circles’ are paying off.”

When there’s so much anxiety and expectation, how can a parent relax and have fun? It’s not until their child is making really good progress that most parents can relax—a little. My veteran PLAY Project families tell me that after a while they do settle in and stop worrying as much about the hours because they use every opportunity throughout the day—not just separate PLAY sessions—to interact with their children. Until then, though, ‘it feels like work’.

At this point, Charlie notices Jacob playing with ‘Mac’, the big semi-trailer from Cars, the movie. Jacob is putting cars inside the trailer (not in a pretend way but in an ‘in and out’ way), and it looks like fun. As Charlie gets closer and reaches for the toy, Jacob whines and nudges Charlie out of the way. Charlie’s feelings get hurt; he starts crying and runs to mom. She skillfully redirects him to the Buzz Lightyear action figure, which says ‘To infinity and beyond’ when you push his buttons, and he’s happy again.

Mom: “There’s a bit more of that going on now. Previously, Jacob would just leave.”

Dad: “He’s protecting his turf. Isn’t that a good thing?”

Dr. Rick: “Absolutely. I’m a big fan of the dark side. (They laugh.) Possessiveness is normal. It shows that he’s aware of his brother. How’s Charlie doing?”

Mom: “He’s a blessing, easy going. He totally looks up to Jacob. Follows him all over the house. They’re buddies. I think Charlie in his own way gets more circles from Jacob than we do.”

Dad: “Seems to me that Charlie is passing his brother by. Even though he’s 18 months younger, he’s got tons of words. He listens to us when we ask him to do things.”

Mom: “I know we shouldn’t compare, but Jacob looks like he’s going backward compared to Charlie. Despite all the work we’re putting into therapy.”

Dr. Rick: “You’re saying Charlie’s passing his older brother developmentally?”

Mom: “It makes me sad.”

Dad: “We’re just not sure Jacob is making progress fast enough.”

In this conversation, there are three emotional themes I’m hearing. First, there is the question of Jacob’s progress. Is he really making progress? Second, Charlie is bypassing his brother. This is a source of reassurance about Charlie and a source of sadness and grief about Jacob. Younger siblings are not supposed to pass their older siblings. And finally, there is a doubt about whether this is the right intervention. Should they be doing more?

Mom: “I read on the internet about B12 shots really helping these kids.”
Dr. Rick: “I know this is an uncertain time. And it’s so hard to see Charlie going faster than Jacob. It’s natural to worry about whether you’re doing enough, but one thing I’ve learned is that when children are making good to very good progress month to month you should stay the course. The so-called ‘biomedical’ treatments may help Jacob’s health, but as we discussed way back in the beginning (See Chapter 4), they are not a cure for autism. Hard work is the right intervention and you are putting in the hard work. Don’t get distracted now. Let me find out from you about Jacob’s progress and then we’ll talk about whether to change direction, OK?”

**Progress?**

Often, the families are working with their child so closely day to day that they can’t be sure there has been progress. It is one of the main reasons they come to see me. They want my opinion as to whether their child is reaching his or her milestones. But before I can give my view, I have to get a detailed history as well as use my office observations.

At the beginning of follow up visits I always ask parents to rate their child’s progress:

Dr. Rick: “So given all this ‘work’, I’d like each of you separately to honestly rate Jacob’s progress over the last four months: poor, fair, good, very good or excellent progress.”

There is always a moment of drama. The parents look at each other for a few seconds, and then at the same time, dad says “Fair” and mom says “Good”.

Dr. Rick: “So, dad, why ‘fair’?”

Dad: “I just thought he’d be doing better. He’s not talking at all.”

Mom: “But he’s saying some words. When I say ‘1-2-3’ he seems to be saying ‘go’, and then, I tickle him and he loves it. He’s got a number of other sounds like that.”

Dad: “He hardly ever plays with Charlie. Look at him, he’s still a loner.”

Mom: “But when you come home, he comes to find you.”

Dad: “Yeah, that is new, but maybe that’s because Charlie comes running too. Plus, I throw Jake around a lot and wrestle which he loves. I’m still not sure he cares that it’s me or that he just likes what I do with him.”

Dr. Rick: “If you keep doing what Jacob loves, dad, he’ll love being with you. I think he does already.”

Dad looks doubtful. I could hear the heartbroken worry and self-protection in dad’s responses, the hope in mom’s. It is a very sad thought that your own child might not ever talk and not be able to express special feelings for you. There is so much at stake! Love, happiness and long-term success are all wrapped up in the idea of ‘progress’.

**Big Milestones**

Parents judge progress according to the *big* developmental milestones:

- When will he talk in sentences?
- Why won’t he play with his brother?
- When will he have friends?
- When will he be able to tell me he loves me?

In the long run, these milestones must be achieved for the child to be truly functional in the family and society.
Little Milestones

In the short run, though, there are less dramatic, smaller developmental milestones—more important to me—that will build a bridge to those bigger milestones. It is no coincidence that these milestones are related to Greenspan’s first four functional developmental levels. You cannot leap from ‘autism’ to ‘functional in society’ without accomplishing the following little milestones:

- Ability to calmly pay attention to a task or to people
- Ease of engagement (e.g., turning to his name, getting his attention)
- How long interactions last (i.e., how many back and forth interactions in one social encounter)
- How often the child starts or initiates an interaction, and
- Whether the child is showing some ability to problem solve

While I hear dad’s longing and mom’s hopeful optimism, I need to find out how Jacob is doing in terms of these little functional developmental gains before I either commiserate with them or reassure them. These milestones are often invisible to the family, just as the foundation of a house is invisible and below ground but crucial to the stability of the house.

I explain all this to mom and dad. I want them to understand the difference between the big and little milestones.

As I watch Jacob play, I notice that he is turning the handle on my Curious George jack-in-the-box. He is persistent and keeps turning it until it pops up. Then, he puts his hands over his ears as if to show that he’s a little scared but excited too. I say to him: “Watch out! Here comes George!” He quickly looks at me and then averts his eyes. His head goes down in embarrassment; then, he runs to his mom for cover.

To me, this is all very telling and good news. First, it shows Jacob’s ability to sustain attention. He kept turning the handle when he could have lost interest and stopped. It shows that Jacob has his own idea to achieve a goal by understanding cause (turning the handle) and effect (getting it to pop up). This is a form of problem solving too. The problem is ‘How do I get this Jack-in-the-box’ to pop up?’ He had two organized emotional responses: he was a little afraid of Curious George, and he got embarrassed when I said something to him. He reacted to me and then ran to his mom for protection. These are important signs that he is indeed making progress. He is engaged, initiating, and at least problem solving a little. He has his own ideas!

The Child’s First Ideas

It is the most magical time when, after hours, days and months of engaging interaction, the child with autism begins to truly have his or her own ideas. These very first ideas, however, are so subtle or simple that parents often miss them. As I mentioned in Chapter 8: Visit 4, there is a hierarchy of activities that starts with pure sensory-motor experiences (e.g., visual stimming) without true ideas, to simple cause and effect (e.g., turn the handle and make Curious George jump up), to longer sequences and then on up the developmental ladder in a predictable step-wise fashion until the child enjoys games, pretend and play with peers.

I was getting excited, checking off Jacob’s accomplishments since I had seen him last. He was showing an understanding of simple cause and effect (with Curious George), but more than that, he knew...
that a surprise was coming. This is what I call ‘a little story’—a sequence of events that are connected with a beginning, middle, and end with a little pay off. I love jack-in-the-boxes for this reason. First, you turn the handle, then there is a song, then the top pops up, and the monkey comes out. It’s a little story. This is kind of exciting and scary. Other examples include song games like ‘Ring around the rosie’, where the child ‘gets’ that first, we hold hands, then we sing, then we go around, and THEN everyone will ‘fall down’; or the game Monster where the child ‘gets’ the sequence that the monster will tickle him.

Mom reported that Jacob said ‘Go’ when she said ‘Go’, so he could imitate. He was able to understand common routines, e.g., when dad comes home, it’s time to play. By the parents’ report, Jacob was enjoying song games. He was also taking his parents by the hand (gesturing) to the fridge for food, suggesting simple problem solving. Finally, he had a few first words. As I mentally check off Jacob’s progress, I contain my excitement and take more history.

Dr. Rick: “OK. I’m seeing real progress here, but I want to make sure that what I’m seeing is consistently happening at home. How easy is it to engage him in play activities?”

Mom: “That’s much better, don’t you think hun?”

Dad: “Huge. When I wrestle and roughhouse, he won’t leave me alone. He loves it when I ‘fly’ him like an airplane and crash him into the couch. And we can play for a pretty long time.”

Mom: “He loves swinging in a blanket while we sing songs and will even take turns with Charlie.”

Dr. Rick: “So he’s able to have longer and longer interactions with you when it’s your idea. What about when it’s his idea?”

Mom: “You mean like stacking blocks in a certain order of color?”

Dad: “. . .or turning lights on and off?”

Dr. Rick: “Yep.”

Mom: “When we follow his lead and I name the colors and say ‘up, up, up’, he likes it, and we can go for a long time.”

Dad: “I play this game with him where he starts to go for the lights, and I block him and say ‘No you don’t’. He totally gets it, laughs, and gives me a look like ‘O yes I will’. And he goes after that switch again, with me pushing him away, until he finally flicks the switch. He looks at me like ‘Let’s do that again’.”

Dr. Rick: “Brilliant, you guys! You’ve turned into master players. You can woo him with your ideas, but you can also follow his ideas. What about turning to his name?”

Mom: “When he’s lining up his cars and trains, he can still get stuck.”

Dad: “That’s still 50/50 I think.”

Dr. Rick: “OK, Dad. Call him, please.”

By this time, Jacob is back playing with the toys. He’s pulled out the Thomas the Tank Engine and is lining up the trains by connecting the magnets (a nice simple idea). He’s not putting them on the tracks, however. Dad calls him once and Jacob ignores him. Dad calls him again—this time with a little more force—and Jacob gives a brief glance up. Not bad!

Moving Up!

Dr. Rick: “So, he’s much easier to engage; he’s initiating; he’s having longer interactions. I saw him problem solving with Curious George.”

Mom: “Amber, our home consultant, told me to play dumb when we’re in the kitchen and you won’t believe how this guy can problem solve when he wants something badly enough. I pretend I don’t know what to do next and he’ll keep pulling and pushing me to take me to the fridge for his
milk. You’d be proud of him, Dr. Solomon. He opens so many circles. I’ll pretend I don’t know where we’re going and go the wrong way and he’ll keep pushing me in the right direction. He must think I’m a real dummy.”

Dr. Rick: “Dumb like a fox! He wasn’t talking with words, but he was ‘talking’ with gestures (See Chapter 6: Climbing the Language Mountain). Next time, make him take out the milk, make him find his bowl. Nice work! Get little circles too. When he pulls you, pull back a little and make a joke or game of pulling. Okay, Jacob seemed to get the routine of ‘Dad comes home and we play’, so let me ask you about other routines like ‘Time for a bath’ or ‘Let’s go outside’ or ‘Get your shoes’. How’s that going?”

Dad: “He’s definitely quicker now. When I say ‘Want to go out?’ He’ll get his shoes in a quick second if he knows we’re going in the car. He loves to go for a ride.”

Mom: “And he’ll throw his diaper in the garbage when I tell him to.”

Dr. Rick: “That’s a definite improvement. OK, what about the more spontaneous ‘give and get’ commands like ‘Give that train to daddy.’”

Mom: “I don’t think so yet.”

Dr. Rick: “Let’s try it now. Dad, would you get down on the floor and give Jacob a few more trains to add to his line? Then, ask for one back with no gestures, just words, and let’s see if he’ll follow a pure verbal ‘give’ command.”

Dad totally gets it. He gives Jacob more trains which Jacob takes and lines up and then asks (without any gestures): “Hey Jake, give me that caboose.” No response; he repeats, “Hey Jake, would you give me that caboose?” Jacob ignores him again.

Dr. Rick: “OK, dad, let’s add a gesture.”

I coach dad to put the caboose in Jacob’s hand; then, I ask dad to stretch his hand out with an open palm and ask for the caboose again. Jacob gives it to him.

Dr. Rick: ‘Well, he needed some help, but this is the next big developmental step—spontaneous one step commands like ‘give’, ‘get’, ‘go get’. I didn’t really expect that yet. First, comes routines, then a few single words, then one step commands.”

Mom: “I think he’s saying some words.”

Dr. Rick: “What do you mean you ‘think’ he’s saying some words.”

Mom: “Well, I told you about ‘1-2-3 go’. He says ‘go’ for sure. He makes an ‘uh’ sound for ‘up’ and ‘d’ sound for down when I’m playing the up and down game. He’s signing for ‘more’.”

Dr. Rick: “That counts as language. Language is an intentional communication that uses a symbol and signing is a symbol.”

Mom: “I heard him yell ‘mama’ once when he fell outside and scraped his knee. But only once.”

Dad: “I heard him say ‘Uh oh’ when Charlie spilled his milk, and we said ‘Uh oh.’ But I think he was just echoing us.”

Dr. Rick: “That’s a good sign too. It means he can imitate a little. Do you think he’s looking at pictures when you name them?”

Mom: “Definitely. But he doesn’t point.”

Dr. Rick: “I’d bet he likes it when you point and name the pictures.”

Mom: “He loves it, especially things with wheels and animals. Then, he gives me great eye contact. Should we work on ‘eye contact’?”

Dr. Rick: “Eye contact happens naturally when he’s engaged. Same with words, words come when he’s ready.”

Dad: “But when is he going to be ready to talk?”
Dr. Rick: “He is talking.”
Dad: “I mean carry on a conversation.”
Dr. Rick: “I want him to carry on long conversations too. But remember our conversation a while ago about the Language Mountain?

“First, comes interaction (attention, interaction & two way communication), which is getting better. Then, comes gestural communication and then, receptive language, i.e., the ability to understand, like those routines we talked about which includes problem solving. Mom was seeing Jacob problem solve in the kitchen when Jacob wanted to eat. Now that these little milestones are in place, two to three word sentences should happen next.”

Dad: “How soon?”
Dr. Rick: “I don’t have a crystal ball, but I’m hoping within the next four to six months or so. And I wouldn’t tell you this unless the evidence supported it. I am very happy with Jacob’s progress. He’s having his own ideas! So I disagree with you both. I feel that Jacob has made good to very good progress over the last four months.”

I look at them warmly, happy myself with the good news, and pause to give mom and dad a chance to absorb what I am saying. They look very happy too, look at each other, and hold each other’s hands.

With a little more history taking, it turns out that Jacob is not only doing better with language and social interaction, but he is becoming less fixated and repetitive. He tunes out less and less, though he still ‘does his own thing’. In terms of his sensory/motor profile, Jacob is still ‘very visual’ and he gets irritable in loud, noisy, chaotic environments like restaurants and malls. He loves music and, of course, deep pressure, bouncing, and swinging.

Medical history revealed that he has been very healthy. He is sleeping pretty well but has occasional night waking; his food preferences are narrowing and he is still not toilet trained. Charlie is starting to go potty, which was disappointing to them as Charlie was again advancing more than Jacob. To keep up with Charlie, the Grants started to toilet train Jacob, and it wasn’t working. He was fighting all efforts to get him to sit on the toilet. He just didn’t seem to care if he was wet or dirty. I advise them to wait on the toilet training. It will be a lot easier when Jacob is more solidly into FDL IV (See Chapter 23: Visit 15 Toilet Training) and beginning to talk in two word sentences. He just isn’t there yet.

**Survival of the Tastiest**

Regarding food, I warned them not to let Jacob narrow his food choices by giving him tastier foods when he rejected the foods he used to like.

Mom: “But what if he won’t eat the old foods?”
Dr. Rick: “He should get hungry enough to eat it later in the day.”
Dad (pointing to mom): “She can’t let him go hungry.”
Dr. Rick: “He used to eat many more foods right?”
Mom: “Right.”
Dr. Rick: “Why did his range get narrower and narrower? Because he thought to himself: ‘Hmm this food is tastier than that food. If I reject this food, I’ll get something tastier.’ He rejects eggs and he gets pancakes. He rejects grilled cheese and he gets PB&J. He rejects chicken and he gets strawberry yogurt.”
Dad: “How did you know? That’s exactly what he’s eating for breakfast lunch and dinner.”
Dr. Rick: “What you are witnessing I call survival of the tastiest. Don’t let that happen. If you want him to eat a broader diet, then when he doesn’t eat what you put in front of him, save it for later. Don’t give him tastier foods. Remember, a habit in motion stays in motion. And once he has a habit of a narrower diet it will be much harder to change. The experts say that a child need up to 20 chances to try a new food!”

I don’t think mom is completely convinced, but it is time to finish up and we’ll have more time to talk about feeding issues in a later visit (See Chapter 21: Outings and Eating). At least I gave a word to the wise.

Jacob’s Profile
I explain that with all their hard work of engagement, they have been helping Jacob solidify his lower three functional levels. I turn on my voice recorder and started talking:

Dr. Rick: “So, let me go over Jacob’s Functional Developmental Levels, and then, we’ll talk about a plan for the next few months. I’ll record this for you.”

“FDL I—Shared Attention and Self-Regulation: 75% Solid. Jacob is more ‘with us’ and less in his own world most of the time, so I’ll give him 75% here. These are rough percentages: 25% means some of the time; 50% means about half the time; 75% means most of the time and 100% all the time. 75% is major progress! But there’s still a pretty big hole here. It means he’s NOT with us about a quarter of the time. We have to pay attention to his attention and wait for him to pay attention, but it’s getting better. I should warn you, though, that getting more solid at FDL I comes with a cost. Remember, FDL I is also about self-regulation which may get worse as Jacob gets better. I suspect that as he becomes more aware, as the ‘blinders come off’ and he becomes more aware of everything around him, he’ll get more anxious. This can lead to more moodiness, more difficulty with self-control, and more behavior issues (See Chapter 17: The Good, The Bad, and The Ugly). I noticed several episodes of anxiety today. For instance, you mentioned that he has been fretting and whining some when he doesn’t get his way. He’s had some night waking, which is new, and his eating has become pickier.

FDL II—Engagement: 75% Solid. I’m going to give Jacob 75% for FDL II also. You can engage him pretty much whenever you want to if you follow his lead. He enjoys rough housing, especially, and all kinds of sensory motor play like tickling and ‘get you’, ‘airplane’ where dad ‘flies’ him and ‘crashes’ him into the couch, and swinging in a blanket while you sing. He is even becoming more aware and engaged with Charlie. He joins in with Charlie during rough housing sessions with dad. He used to let Charlie take his trains and would just wander off. Now, he is getting upset, whines, and yells. We can talk about some of these behavioral issues later. For now, I’m just happy that his emotional life is emerging and he’s becoming easier to engage.

FDL III—Simple Two-way Communication: 50% Solid. There’s still a pretty big hole here, so I’m going to give him 50%. While Jacob is able to open and close more ‘circles’ in a given encounter, you still have to do a lot of the work and he still tends to ‘fragment’ i.e., break off relationships suddenly. This happens especially if the activity is either too exciting or not interesting enough. Now, sometimes, he’ll come back to finish a game. Mom and dad, you guys are definitely getting better at seeing Jacob’s ideas. For instance, he likes stacking the big LEGO blocks and putting them in the ‘right’ order by color. But, for FDL III, we have to ‘think circles’. You mentioned that when you joined his idea and labeled the colors, he’d look at you (opening a circle), smile (opening a
second circle), and wait for you (opening a third circle!) to put the ‘right’ color on the stack. He is enjoying simple cause and effect games like turning on and off the lights or having you point and, in a sing-song voice, name the pictures of animals or trains in a book.”

At this point, Dad searches his pocket and proudly shows me a picture on his cell phone of mom, Charlie, and Jacob all sitting on the couch reading together ‘like a normal family’.

Mom: “We’re learning to wait more. Amber (the PLAY home consultant) has really been coaching us on waiting. Jacob is actually seeking us out to play!”

Dr. Rick: “Waiting can be torturous.”

Dad: “We thought he’d just go into his Comfort Zone, but now, he’s coming after us more and more.”

Dr. Rick: “That called initiating! Way to wait.”

“FDL IV: Complex Two-way Communication: 25% Solid. I’m going to give Jacob a little credit for FDL IV—25%—because I’m seeing glimmers of problem solving, the potential for longer interactions, and a little more emotional organization. He still does not understand the all-important one- and two-step commands, but this is where he’s going. Keep waiting, keep going for circles, keep making him work and problem solve. I’ll lay out the plan for getting Jacob to Level IV. Here is his profile:

Jacob’s FDL Profile

- FDL I: Shared attention and self-regulation: 75%
  - Has Comfort Zone activities but less time in his own world.
  - ‘With us’ most of the time.
  - Still ‘fragments’ or breaks off relationships.
  - Getting a little more dysregulated emotionally.
- FDL II: Engagement: 75%
  - Now easy to engage in sensory motor play.
  - Parents still have to ‘sweat’ i.e., initiate and work hard
- FDL III: Two-way Communication: 50%
  - Interactions still short. On average three to five circles.
  - Not initiating consistently but seeks sensory/motor play
- FDL IV: Complex Two-way Communication: 25%

The Family System

Dr. Rick: ‘Well, you guys, this is good news, but it’s taken a lot of work. How are you two holding up?’

Mom: ‘To tell you the truth, I’m getting a little burned out. What with Charlie, who won’t leave us alone and wants attention, and doing all the housework, and playing with Jacob . . .’

Dad: ‘It’s been work doing play.’

We all laugh at dad’s unintended pun.

Dr. Rick: “You get any help? Like a cleaning person to help you once a week around the house? (They shake their heads) How about getting out to go on a date? (They shake their heads) Any one in the family helping out?”
Mom: “It’s his family that’s close. He won’t ask, and I’m sure not going to.”
Dad: “The kids are too hard.”
Mom: “Your sister has offered and she’s a special ed teacher.”
Dr. Rick: “No wonder you’re a little burned out. Now that Jacob’s doing better and Charlie’s getting older, maybe you can ask her to babysit just for a night out. It’s so important for you to stay connected as husband and wife and not just mom and dad.”
Mom: “It’s been so long since we had some ‘us’ time.
Dad: “Let’s do it.”
Dr. Rick: “Smart man!”

I think they heard me.

The Plan
Dr. Rick: “Jacob has made a lot of progress. We have to keep up with him, but we shouldn’t go too fast. Even though he’s showing capacities up to FDL IV, I’m strongly advising you to ‘stay with what he loves’—sensory motor, cause and effect play, and little stories—for now. It’s very tempting to want to move up to pretend play and/or focus on words (dad!), but I think it would be a mistake to move up too fast and play too high. He’s not ready to answer ‘What’ questions or even say the names of objects, though he probably could if we drilled him on it. I wouldn’t; I don’t want holes in Jacob’s lower levels. And don’t worry dad. We are going to get Jacob to talk, but I want to do it in a way that honors and respects where he’s at.”

Key Methods.
Dr. Rick: “So here is what I advise you to do:
• As always, pay attention to Jacob’s attention and to his intentions. What are HIS ideas? Follow him.
• If you introduce YOUR ideas, be aware that they are yours (See Activity Ideas below).
• LESS is MORE. Do less and let Jacob lead more. WAIT for him! Take the risk of losing him. He’ll come back.
• When you don’t know what to do—DO NOTHING. Then, FOLLOW his lead and ideas.
• You can ‘woo’ him upward (See Technique Ideas) by gently building on his idea or challenging him but . . .
• DON’T TAKE OVER.
• Once you have him engaged GO FOR MORE CIRCLES. Use the theme and variation technique. The best circles are the ones HE starts.
• Have FUN! Ask yourself: ‘What would be fun for Jacob?’
• DON’T WORRY ABOUT WORDS yet. Jacob is communicating through GESTURES.

Then, I went into my rant about gestures.

Gestures.
Dr. Rick: “It’s hard for me to over emphasize the importance of gestures. Eighty percent of human communication is gestural. If we don’t focus on gestural language, Jacob will not look natural as he progresses. Jacob’s primary language right now is gestures. When he takes your hand, he’s saying, ‘Come with me’. When he walks away, he’s saying, ‘This is too much for me’. When he frowns, he’s saying,
‘No!’ We must respect and honor these gestures as communications or we’ll miss so many opportunities to transform these gestures into words. That’s one of our main goals.

“The biggest mistake that parents make is ignoring, missing, or minimizing gestural communication and making the child say words. Let’s say he’s reaching his hand out for juice, and we want him to say “Juice.” So we ask him (over and over), “What do you want? What do you want?” It’s obvious what he wants. By dismissing or ignoring his gesture, he learns that his best way of communicating is not important. It changes the focus from interaction to therapy. It ruins the flow. I would really like the both of you to respond to Jacob’s gestures as if they were words. I’ll have more to say about the all-important gestures in the Technique Ideas below.

**Activity Ideas.**

**Dr. Rick:** “Below are some activities that Jacob might enjoy, but remember to follow his lead if he doesn’t feel like doing these activities:
- Chase, monster, ‘get you’ games
- Wrestling, rough housing
- Songs with a physical aspect like ‘Ring around the Rosie’, ‘Eensy Weensy Spider’, ‘Head, Shoulders, Knees and Toes’, ‘This Little Piggy’ etc.
- Percussion instruments
- Horsey back rides. And have him make you ‘go’ with some kind, any kind, of gesture. Don’t make him say ‘go’ unless he does so spontaneously.
- Swinging in a blanket. Make it last.
- Books with single pictures on the page. Be dramatic. ‘O look! Theeere’s Thomas!’
- Labeling objects in a sing-song rhythmic way: ‘Thomas, Henry, Percy, Sally!’ ‘One block, two blocks, three blocks, four blocks.’ ‘Horse, cow, pig, dog.’
- Balance visual activities—puzzles, movies, train sets—with sensory motor physical play.
- Opposites: up and down, round and round, on and off.
- Peek-a-boo games. Hide under a blanket and wait until he pulls it off; hide behind a door, then jump out and tickle him, then run back behind the door.

**Technique Ideas.**

**Dr. Rick:** “Try the following techniques to help Jacob move solidly from FDLs I-III into FDL IV:

- **Theme and Variation.** Probably the technique you’ll use the most while playing on the floor is theme and variation. When you’ve done the same activity the same way a few times, it’s time to change things up. Ask yourself: ‘What are five to ten different things we could do with: trains, books, blocks, swinging in the blanket, etc.?’ Let’s take swinging in a blanket:
  1. You could swing it faster or slower, higher or lower.
  2. Stop swinging and make Jacob gesture for more.
  3. Sing a different song and swing at a different pace.
  4. Bring in a doll and have the doll swing with Jacob.
  5. Have Charlie take a turn.
  6. Swing so it lands on the couch.
  7. Say, ‘I’m tired. All done.’ and let Jacob convince you to keep going.

Get the idea?

- **Building on Jacob’s Idea.** Related to theme and variation is building onto Jacob’s idea. Here, instead of bringing in your idea, you add to Jacob’s idea. For example, if he’s pushing his train
on the tracks (his idea), you can add to his idea by saying, ‘There it goes. Woo-woo.’ Or you could put another train on the track and see what he does. He might push it off. Then, you can label his gesture with words, ‘Bye-bye train. Get off my track.’

- **Label Jacob’s Gestures with Words.** This is a very important technique. When Jacob gestures— grunts, points, looks, cries, frets, etc.—label his gestures as if he could talk. I want you to speak for him and use statements. When he reaches for the juice, you could say ‘O, you want juice’. When he shakes his head as you offer him a new food, you could say, ‘No carrots, mom!’ Don’t overdo it but label his most important gestures.

- **Salient Language.** ‘Salient’ means ‘stands out’. Create a list of 20 words that will stand out, that Jacob will find meaningful. Use them consistently. They should be words he associates with fun. Words like: Go, 1-2-3, up, down, on, off, out, car, eat, cookie, juice, ice cream, get you, chase, wrestle, tickle, mom, dad, Charlie, bye-bye. That’s twenty.

- **Play Dumb.** Finally, make Jacob work by doing less yourself. This is especially effective to use throughout the day when he’s highly motivated. Mom, you’re getting good at this technique! If he wants to go out, make him get his shoes, hand them to you, put his foot out, etc. This is also called ‘playful obstruction’. Remember that it should be playful to the point of frustration but not beyond.

**Conclusion**

I speak into the voice recorder: “That’s a lot to consider, but it’s all on this tape. Besides, this little guy is moving on up, and we have to keep up with him! Of course, Amber and I are here to support you as we go forward. Here, let me end by giving you the key elements of FDL IV so you can see where we are going:

**Functional Developmental Level IV**

*Complex Two-Way Communication*

- Problem solver! Has his/her own ideas
- Gestural communication primarily with dozens of words
- Opening and closing of 10-30 circles in one interaction
- Simple pretend: phone to ear, cow says ‘moo’
- Much more ‘with us’ – continuous flow of interaction
- Imitation
- Follows spontaneous one-step commands: go, get, give to, etc.
- ‘Little stories’: ‘gets’ meaningful sequences
- Parallel play with peers/siblings
- Feelings more and more organized

“You’ll notice that Jacob is beginning to show these capacities. That’s why I rated him as having 25% FDL IV. But we want longer interactions, more organized gestural and verbal communication, and the beginning of pretend play. You’ll know he’s well into Level IV when he can answer the spontaneous one- and two-step commands. Those you can work on. I just don’t think he’s there yet, but he’s on his way. When Jacob gets solidly into this level, he’s leaving autism proper and heading towards high functioning autism. Let’s cross our fingers. See you in about four months and on video. Keep up the great work.”
We say our goodbyes and this time, as the family is walking out (along with everyone else), Jacob gives me a high five!

Summary
- Jacob is definitely ‘moving up’, but he still has ‘holes’ in his development including ‘fragmenting’ i.e., losing the social connection
- In order to close these holes, the parents have to focus on the little milestones of circles and gestural communication and not ‘push the river’ toward verbal language
- This was asking a lot because we all want Jacob to talk in sentences, but there is a definite progression with several milestones that lead from sensory motor play to short sentences
- If the Grants follow the milestones, then I feel quite confident that Jacob will talk more and more
- Mom and dad are getting a little burned out; I suggested getting a baby sitter and going out
- I also suggested ways to help Jacob eat a wider range of foods, but I’m not sure mom agrees
- I listed ideas for Activities and Techniques to help Jacob move up
- With any luck at all, Jacob will reach a turning point and move solidly into FDL IV; I was cautiously optimistic

Resources & Websites

Websites

Books

Coming Up Next
- Will Jacob move more solidly into FDL IV?
- How long can the family keep up the pace of intervention? What is the toll on the family?
- Behaviorally, Jacob has a few surprises for his family.
Chapter 11
Visit 6
The Turning Point!

The Turning Point
Before the last visit, I was worried; afterwards, I felt better. Jacob Grant was making very good progress. Now, four months later, I was positively excited to see Jacob and his family for a return visit in the office. If the videos I’d been watching were accurate, Jacob had made the most important advance in development that a child with autism can make; he moved solidly into Functional Developmental Level IV—the turning point!

As the four of them walked from the waiting room into my office playroom, I went over the last four months in my mind. Along with Amber, the family’s PLAY Project Consultant, I watched each of the monthly home visits that had been captured on 15 minutes of video, and as I watched, I recorded my observations and suggestions.

Last Video Review. Watching the last recording, I remember actually cheering ‘Yay!!’ as Jacob was playing a rolling game with his dad. Jacob was lying on a huge beanbag and dad was lying on the floor next to him. Jacob was telling dad: ‘Roll on you?’ (He meant ‘Roll on me’ but pronouns are always hard to learn.) Jim Grant, like a big steamroller, rolled on him, giving him deep pressure, which Jacob absolutely loved. He made his dad roll again and again back and forth. (Poor dad got a real work out and was sweating!) It wasn’t just that he was now using words (which was fantastic in itself), but he ‘got it’, he was having fun playing a game with his dad! It was a beautiful thing to see. The autistic veil was thinning.

The game of ‘don’t wake up mommy’ was hilarious. Jacob loved making mom mad when he woke her up from pretend sleeping. And the scenes of hide and seek were just as wonderful. I cheered into my recorder: “Look at that boy go!” when Jacob, who used to just grunt or cry, figures out (with dad’s help) that he had to go behind the curtain and wait, while mom kept saying ‘Is he here? Nope. Is he here? Nope.’ But Jacob came out of hiding before his mom could find him. Mom said, ‘Jacob you’re supposed to hide.’ But Jacob couldn’t stand the suspense anymore. Julie didn’t insist that Jacob ‘play the game the right way’. Instead she followed his gestures and lead and, when he came out of hiding, mother and son had a most wonderful reunion with lots of back and forth hugging and kissing.

As I watched the video, I rooted them on speaking into my recorder: “Way to go mom and dad. I can see that you guys are ‘thinking circles’ and playing at exactly the right level. Congratulations, you have made it to the turning point!”

The Current Visit
Now in my office playroom, as the parents settle into their chairs, Jacob, 4 ½ (had it already been over a year of intensive play-based intervention?), immediately goes for the basket of Thomas the Tank Engine trains and says ‘Choo choo’ while Charlie, now 2 ½ (those half years matter at this age!), grabs a couple of Matchbox Cars and, imitating his brother, says ‘Choo choo’ too. I say ‘Choo choo’ back to see what will happen, and they both look at me and smile.
Dr. Rick PLAYS. I take this as an invitation, so I quickly get down on the floor and start building a train track. As soon as I start connecting the little wooden tracks, Jacob and I exchange smiles and eye contact, and I can see that he ‘gets it’; he likes what I’m doing. I say to his parents, “I’m building on HIS idea to play trains, and I’m keeping my eye on him to see if he’s into it.”

He was into it! I put a train on the growing number of tracks and tell him to put another one behind mine, and he does it. Then another track, another train, another track, another train. I show him how the magnets connect. I say, “Choo choo, here we go!” I push the trains a little and tell him to “keep them going, Jacob! Push!” And he pushes the growing line of trains on the nearly completed track.

I’m building quickly to get the bridge built into the track so the trains can go ‘up up up and down down down’ as well as ‘around and around’. And he loves this idea (I’ve ‘wooed’ him!). He gives me a look like ‘Isn’t this cool—trains go on a track! Trains can go up and down, around and around!’

When Charlie starts to get jealous, I invite him to play, and in a split second, both boys are pushing the trains on the track, saying “choo choo” and having a great time together. There is a lot of looking back and forth throughout the play.

I put a little boy character on the track and say, “Watch out little boy! Here comes the train”. I knock the little boy off the track and say, “Ow!” (a little of my slapstick humor). Charlie laughs out loud and wants to put the little boy back on the track and do it again, but Jacob ignores this joke and just loves watching the trains go up and down, around and around. Mom and dad look so pleased.

Mom: “He’s never played trains like that before.”
Dad: “They look just like regular guys.”

**Characteristics of FDL IV**

This play interaction was very telling. It had all the elements of Functional Developmental IV (See Appendix D: FDL Summaries):

- Jacob was problem solving because he figured out what to do with the trains. He could have just ignored me and focused on his isolated train.
- He had some words (‘choo choo’) but communicated mostly with gestures—looking, smiling, putting his trains on the track, etc.
- He connected a train to its sound, i.e., ‘choo choo’ which shows simple pretend.
- He strung together a series of interactions, opening (initiating) and closing (responding) lots of circles in a continuous flow.
- He had his own ideas but also responded or imitated my ideas.
- He also listened to me and followed a command to put the trains on the track in a row. He ‘got’ the ‘little story’ about trains going ‘up and down, around and around’.

When I tried to move up to FDL V (Shared Meanings) by adding a story line about how dangerous it is for a little boy to be on the track, he didn’t ‘get it’. This was too high, and you could see right away that Charlie understood and laughed, but Jacob ignored it. Finally, Jacob enjoyed playing with his brother. Granted, it was mostly parallel play where the siblings were aware of each other though
not interacting a lot—yet. There was a clear sense that he was enjoying himself with us, i.e., he was showing sustained pleasure in interaction. His feeling life was getting more organized.

Then, just as we’re feeling so good, Jacob puts his head on the floor and starts to visually stimulate himself (i.e., ‘stim’) by lining up and running the trains in front of his eyes. His mom gives me that look that says: ‘He still has his ‘autisms’.’ I smile to her and to myself. This ability to talk about Jacob’s autistic behaviors with a sense of perspective and humor is a very good sign. It indicates to me that the Grants had come to a point of accepting Jacob’s condition even as they worked hard to help him outgrow it.

*The Return Visit: Interval History*

**Dr. Rick:** “I was just thinking about those last videos from the home visits. You guys must have thought I was a raving maniac.”

**Dad:** “Well, you are passionate about what you do.”

**Dr. Rick:** “Hope it was helpful.”

**Mom:** “We love getting the feedback from you and also from Amber. The video review tells us what to do right when it’s happening. She’s full of ideas. It’s wonderful to have that kind of support. You don’t feel alone.”

**Dad:** “And I have to say, because I know you’re going to ask, that Jacob has made amazing, I mean ‘very good to excellent’ progress. (He looked at me knowingly because I always start my visit by having the parents rate their child’s progress). My mom and dad were over for a visit the other week. They hadn’t seen Jakey for a couple of months and they were shocked that he played with them and that he was saying words.”

**Dr. Rick:** “After that last visit I was hopeful; now I’m really excited. I think Jacob may have ‘turned the corner’ on his autism. The autistic veil is thinning, but let’s be systematic here and cover some bases.”

So, I question Jacob’s parents and make notes in Jacob’s chart about current programming which still consists of special education preschool, four mornings a week. There, he’s receiving about a half hour each of speech/language and occupational therapy per week. He’s been in preschool now for almost a year and loves it. Otherwise, the only other program he has is the PLAY Project.

**Dr. Rick:** “Have you heard from the school about Jacob’s IEP for the coming year?”

**Mom:** “Not yet. After that last IEP, when we changed his classroom, I’m almost afraid to call the school.”

**Dr. Rick:** “Well, you better give them a call or, better yet, write an email to the principal asking when his IEP is going to be scheduled. It’s time.”

**Dad:** “We’ll do that right away.”

**Dr. Rick:** “What about other programs? Have you considered ABA? Now that Jacob’s making progress now might be the time.”

**Dad:** “For a while there, we did consider ABA but when Jake started making such good progress we didn’t want to change anything.”

**Dr. Rick:** “I’d at least visit an ABA program and see what you think.”

**Dad:** “We’ll look into it.”

**Mom:** “But we’ve got such a good program, Dr. Rick. Jacob loves going to preschool and we love doing the PLAY Project.”
The parents report playing one to two hours per day, broken up into 15-20 minute PLAY sessions. Dad comes home and spends an hour with the boys after dinner, including a bedtime routine of reading favorite books.

When I ask about health, the Grants report that Jacob has been ‘healthy as a horse’ but when I asked about sleeping, eating, toileting, and sibling issues there were some growing concerns (See Section 3: Daily Hassles Using Misbehavior to Promote Jacob’s Emotional Thinking). I decided not to focus on these issues because we had to keep up with Jacob’s developmental gains.

Language Milestones: From Gestures to Words

Jacob’s parents reported that he now had ‘dozens of words’ that he was using consistently, but not frequently, throughout the day. He was not putting words together yet, except for some phrases like ‘1-2-3-go’. But receptively, he understood a lot of routines, turned to his name consistently, and, most importantly, followed one-step, spontaneous (not routine) commands, like ‘Go get . . .’ and ‘Give me . . .’

I call Jacob, and he looks up. Check. I tell dad to ask for Thomas the Tank Engine with big hand gestures. Reluctantly, after a few repeated requests, Jacob gives it to dad. Check.

Gestural Language. Jacob was communicating mostly through gestures though the words were coming fast. He grabbed his parents’ hands and pulled them where he wanted to go. He pointed to cookies and said ‘Cookie’. He frowned, stomped, and yelled when angry (emotional gestures). He shook his head ‘No’. He glanced to acknowledge he heard (and purposefully ignored!). He made ‘vroom, vroom’ sounds (vocal gestures) when racing his cars. He knew what a cow, dog and cat said. In short, he was ‘talking’ through gestures. But this wasn’t good enough for dad.

Dad: “So when’s he going to talk?”
Dr. Rick (with mock frustration): “Dad! He is talking! You want full sentences and so do I, but first come gestures and single words, then come the sentences. Remember the Language Mountain. If you don’t honor his gestural communication, when he does ‘talk’, he might talk unnaturally (too loud, too flat, no song in his voice) or he’ll have immature sentence structure.”

Dad: “But the language therapist is telling us to make him talk in order to get what he wants.”
Dr. Rick: “What’s most important right now is the flow of the interaction. Doing therapy interrupts that flow and that will lead to holes in Level IV. Limit your therapy to specific times of day. Don’t do therapy all day long. It’s great when therapy generalizes into life, but it’s terrible when life becomes a form of therapy.

So let’s honor Jacob’s gestural intent. When he points to a cookie, don’t say: ‘What do you want?’ You know what he wants. Much better to label his gestural intent with your words and use a technique like Asked and Answered. ‘Oh Jacob. You want a cookie?’ (Asked). ‘OK, here’s the cookie.’ (Answered). We talked about this the last visit. If you act as if his gestures don’t mean anything, after a while, he’ll feel that his gestures are not important. And gestures are the most important form of human interaction accounting for 80% of human communication. Labeling his gestures with words is the single most important way to promote spoken language.”

Language Techniques

• Honor and label gestures as communication
• ‘Speak for’ the child’s gestures
Another important thing you should do is use normal tones and rhythms; don’t baby talk or oversimplify your language. Of course, you shouldn’t be too abstract or talk too fast. You have to talk at his level of understanding, but it’s good for Jacob to hear what real sentences sound like. Repeat yourself to make sure he understands and then, simplify as a last resort. We’ll talk more about language, but let me ask you how Jacob’s doing socially.

Social Interactions and Activities

Socially, at least with adults, Jacob had started to play simple social games and initiating activities (See chart below), like horsey back (he’d climb on dad’s back) and swinging in a blanket (he’d bring the blanket over unprompted). In fact, he was becoming a pest, wanting to play all the time! He loved ‘monster’, where dad would hide under a blanket and then when Jacob and his brother pulled the blanket off, the ‘monster’ chased them around the house, caught them, and tickled them. Jacob was starting to make car sounds and animal sounds. He was putting a toy phone up to his ear and gibbering into the mouthpiece. He would listen to grandma talk on the phone but wouldn’t say anything to her.

PLAY Activities for FDL III & IV

- Peek-a-boo; hide under a blanket
- Use ‘1-2-3’ or ‘Ready-set-go’ language
- Chase/Monster: ‘I’m...gonna...get you (tickle)’
- Ball or balloon play (back & forth games)
- Very simple pretend (phone to ear, feed dolly, crash cars)
- Animal, car, and/or train sounds
- Puzzles
- Naming animals, objects in books
- Opposites (up/down, on/off, go/stop)
- Songs/music games (‘Ring around the Rosie’, ‘March, march, march’)

Socially, with his brother, he played side by side a lot in parallel play, although they were starting to fight more and more over toys (which I considered to be a good sign). Before, Jacob could just take Charlie’s toys whenever he wanted to, which Charlie used to allow. Now that Charlie was older, he fought back. When the parents gave the toy (that Jacob had taken) back to Charlie, Jacob was now throwing little temper tantrums.

At first, these fits didn’t last too long, but lately, they were not only lasting longer, they were gaining in intensity with louder cries and some hitting of his brother and parents. This was really worrying mom and dad (not to mention Charlie). I saw it as a sign of real progress and mentioned that we would discuss the Six Rules for Sharing later (See Chapter 24: Siblings WITH Rivalry).
But, overall, I was very pleased with Jacob’s advances in social interactions. Even his aggression was a sign of emotional intelligence! (Did I mention that I am a fan of the ‘dark side’?).

Fewer Repetitive Interests and Comfort Zone Activities. While Jacob’s play was becoming more social, he still ‘fragmented’ frequently, i.e., he broke off social encounters without warning and then wandered off to do his own thing.

There were times, especially after coming home from preschool, when he seemed ‘pretty out of it’ and hard to engage. He still lined up toy cars, trains and trucks; he still played with puzzles and Legos or flipped through his favorite books of trains or trucks. He’d watch *Dora the Explorer* or his favorite DVD *Cars* (the Pixar movie) over and over for hours if his parents let him (which they didn’t).

In short, Jacob still had his Comfort Zone interests, but his parents reported that he spent much less time doing repetitive and stereotyped behaviors.

**Dr. Rick:** “It’s real progress when a child’s interests evolve from simple sensory motor play in his Comfort Zone to wanting to rough house with people. I say that his ‘affect’, his feeling life, has progressed.”

As if on cue, Jacob who had been playing with the trains for a long time, gets up and starts wandering around the office. He notices *The Big Book of Trucks* on my shelf—one of his Comfort Zone activities. I decide to join in his Comfort Zone.

**Dr. Rick:** (dramatically in a loud voice): “Whoa, *The Big Book of Trucks*!”

I pick it up and show it to Jacob, who immediately gets absorbed looking at the big trucks on the glossy cover. I wait. He opens up the book and starts eyeing each truck on the page. I use the technique called narrating and rhythmically label and point to the trucks.

**Dr. Rick:** “Backhoe! Dump truck! Tractor! Semi-truck.”

**Jacob:** “Truck.”

It all seems so interesting that Charlie joins us.

**Dr. Rick** (to Mom and Dad): “It doesn’t matter what the names are. I don’t expect him to understand the meaning of the words (that’s for FDL V and VI). He loves the labeling process, the rhythm, the sound, and the pointing.”

**Mom:** “I’ve been actually reading the books, and he never stays very long. Now I see why.”

**Dr. Rick:** “I rarely ‘read’ to a Level IV kid unless the book is very simple and rhythmic. I watch their eyes and see what THEY are interested in.”

I can see that Jacob wants to turn the page, scan the pictures, turn the page, scan the pictures, turn the page, scan the pictures. I want to test the parents a little.

**Dr. Rick:** “He’s not interested in the story or the words. What’s his intention?”

**Dad:** “He wants to keep going.”

**Dr. Rick:** “Right. So how do we join him?”
Mom: “Say ‘turn the page?’”
Dr. Rick: “Right! (I join Jacob). “Turn the page. . . See the trucks. . . Turn the page. . . Oh look at those trucks.”

**What to Do With ‘Fragmenting’** Then, in a flash, he is done with the book, lies down on the floor, and starts pushing a toy school bus back and forth in front of his eyes.

Dad: “What do you do when he does that?”
Dr. Rick: “Exactly the right question, dad. What should we do when he does that?”
Mom: “Follow his lead?”
Dr. Rick: “That’s an option, but now that he’s higher functioning, there are more options. When Jacob breaks off the relationship and does Comfort Zone activities, I call this *fragmenting*. He’s here and then he’s gone. The important thing is to notice it.

“Then you have three choices:
1. Wait to see if he comes back from ‘fragmenting’;
2. Follow his lead, re-engage him, and *stretch* out the interaction. I call this ‘Follow and Stretch’;
or
3. Prompt and make demands/call him back.

*Wait.* If Jacob, for example, were to come back and give me the truck book, that would be the best because he would be initiating. It would be *his* idea and his ideas are best. *We wait, just sit there and do nothing to see if he comes back.* But let’s say he doesn’t.

*Follow and Stretch.* “If we lose him, i.e., he fragments and doesn’t come back, then we can go after him, follow his lead, re-engage him, and go for circles/stretch out the interaction. And this is important—wherever his lead takes you, that’s where you go. *When he goes up (to higher functional levels), you go up, but when he goes down, you go down.*

Dr. Rick: “So here he is ‘stimming’ on the bus. What should we do? He’s in his Comfort Zone.”
Dad: “I would do the *Rabbit Hole Techniques.*”

### Rabbit Hole Techniques

1. Being with
2. Narrate (with feeling) the child’s behavior/intention
3. Help him do it better
4. Parallel play (i.e., do what he is doing)
5. Theme & Variation
6. Change the sensory mode

Dr. Rick: “Dad, you’re a genius. When he goes down, you go down.”

For many parents, joining their child at the lower FDLs is not an easy thing to do. They don’t want to see their child’s ‘autisms’. But experienced PLAYers know that when they join their child *exactly* where he’s at, it has the paradoxical effect of bringing him up to the higher levels. He may start in his Comfort Zone (FDL I), but then by using the Rabbit Hole Techniques, you get engagement (FDL II), initiation (FDL III), and now that Jacob is at FDL IV, he’ll start playing at his highest level naturally.
Dr. Rick: “OK dad. Let’s see what happens if you join Jacob (who is still pushing the bus in front of his eyes).”

Dad (getting down on the floor—being with Jacob in his Comfort Zone—says quietly): “Bus, Jakey, bus.” (Narrating)

Jacob looks up and sits up. He pushes the bus over to dad. Dad pushes it back to Jacob, and they are playing a game of catch!

Dr. Rick: “I love it. You went from Comfort Zone to Level IV play in less than a minute. This boy is really making progress. And so is Jacob.” (We all laugh).

Prompt and Make Demands.

Dr. Rick: “Finally, there will be times when waiting for him to come back on his own and/or following his lead and stretching out the interaction are not demanding enough. Now that Jacob is into FDL IV, you can prompt him and make demands and call him back (from his fragmenting). This is the philosophy of ‘can’. Ask yourselves: ‘Can he do it?’ If the answer is ‘Yes he can’, then we should expect him to finish what he started.”

“For instance, Jacob should clean up after himself. We shouldn’t wait for him or follow his lead. We should insist that he clean up. We could sing the ‘Barney clean up song’: ‘Clean up, clean up
Everybody clean up
Everybody, everywhere
Clean up do your share’

“We can make demands and still have fun. Examples of other demands we should make on him include ‘giving five’ for greetings and waving ‘bye-bye’ for partings, maybe teaching him to say ‘thank you’ for manners. He should be taking turns with Charlie. Listen, if he can follow commands and he can imitate, then these demands are possible for him to accomplish.

“Let me see if I can demonstrate this for you. Does Jacob give five yet? I remember the last visit, he reached for my hand but didn’t give me five.”

Mom: “We haven’t worked on that.”
Dad: “I don’t think he can do it. I tried but he didn’t give me five.”
Dr. Rick: “Hey Jacob. Jacob.”
Jacob: (looks at me)
Dr. Rick: “Come here buddy. Let’s practice ‘giving five’. Come here,” I wave him over and he comes over. To his parents, “I’m making demands. Let’s all circle up. Charlie, come over here,” Charlie comes. “Mommy, give me five,” she slaps high five. “Daddy, give me five,” he slaps me five), “Charlie, give me five,” he does it. “Jacob, slap me five,” Jacob gives me a high five like he’s been doing it all his life.
Dad: “That was just so cool.”
Dr. Rick: “I thought he could do it. I used a technique called ‘Three-way Modeling’ using you guys as the models. You can make demands, but it should still be fun.”
**Sensory Profile**

Finally, I wanted to see how Jacob was doing with his sensory and motor issues. Turns out that noises still bothered him, especially when the family went out to noisy restaurants and malls. He was getting worse about this and the Grants were going out as a family less and less. Jacob was starting to notice tags on his shirts and hated getting his hair washed and teeth brushed. I could see behavioral problems, based on sensory issues, in Jacob’s future.

He also didn’t do well with transitions and had a hard time with sequences that were new. Stopping activities he liked made him mad, and his parents noticed that it took a while for him to process what they said to him. It was almost like there was a five second delay in his auditory processing. I noted these important observations in his chart and made a mental note to discuss this in one of our next visits (See *Section III: Chapter 17: The Good, The Bad, & The Ugly*).

**Medical History and Review of Systems**

Jacob had been very healthy except for one ear infection. He had had no injuries, hospitalizations or surgeries, but he had a couple of cavities because he refused to let his parents brush his teeth. Overall, his health was fairly good.

When, however, I asked, as I always do, about the medical ‘Review of (Physiologic) Systems’—eating, sleeping, urination, defecation, hearing, and vision—I hit the jackpot.

Here was the litany of concerns: Jacob had narrowed what he would eat so much now that he was down to a handful of foods (they didn’t heed my warning about ‘the survival of the tastiest’, See *Chapter 10: Moving on Up?*). He refused to even sit on the potty even though ‘he knows’. He fought baths because all of a sudden, he hates getting water in his eyes. Besides not cooperating any more about brushing his teeth, he was fighting getting dressed in the morning (See *Chapter 20: Jacob’s Terrible, Horrible, No Good, Very Bad Mornings*) and would undress himself in defiance when he was ‘in his mood’. He wouldn’t go to bed without coming out of his room ‘20 times’ (See *Chapter 19: The Stone in Your Shoe: Sleep*). He was waking up in the middle of the night more and more and going in to his parent’s bed to sleep.

**Dr. Rick:** “Unless you want him sleeping with you all the time, you might have to ‘Ferberize’ him or at least take him back to his room and help him get back to sleep in his own bed. Just sit there in his room in a chair until he falls asleep on his own. Do that for three nights and he'll get used to sleeping back in his own bed.”

**Mom:** “I can’t wait to try that.”

**Dad:** “What’s ‘Ferberizing’?”

**Dr. Rick:** “A method of helping children fall asleep developed by Dr. Ferber, a pediatrician. But, knowing mom as I do (I smile), let’s just try sitting with him while he falls asleep. Ferberizing is much harder. We’ll get to that if we have to (See *Chapter 19*).

**Dad:** “That sounds good, but what’s happening to the good boy we used to have?”

**Dr. Rick:** “Well, I’ve good news and I’ve bad news. The good news is that this misbehavior is a sign of real developmental progress. The bad news is that it’s likely to get worse before it gets better.”

**Dad:** “Oh great.”

**Mom:** “And Charlie is starting to give us trouble too. He’s imitating his older brother.”

**Dr. Rick:** “I think we should get together soon to discuss these issues. If we nip them in the bud, it will be a lot easier and we can deal with both of the boys’ behaviors.”

**Dad:** “That would be great.”
Mom: “It’s getting pretty bad. And Jim and I are starting to argue about what to do.”

I could sense the tension in mom’s voice. The boys’ behavioral issues were starting to take a toll on the family system.

**The Family Dynamic**

Dr. Rick: “You two doing OK? Did you ever make it out on that date?”

Dad: “I asked my sister to baby-sit, and we went out to dinner and a movie.”

Mom: “Finally. It was wonderful to feel like a couple again.”

Dr. Rick: “How did the boys do?”

Dad: “My sister said they were ‘angels’. Went to sleep for her without a problem, and we had the night to ourselves too.”

Dr. Rick: “Good for you guys!”

Mom: “Last time I was feeling a little burned out but with Jacob’s progress, I feel better. Jim’s been wonderful to me.”

Dad: “Julie and I are doing good, but I’m not so happy with the disrespect the boys are showing to their mother. When I was a kid, all my dad or mom had to do was give us a look and we shaped up. Spare the rod, spoil the child type of thing.”

Mom: “I don’t think Jim really appreciates how hard it is for Jacob to understand what he’s supposed to do.”

Dr. Rick: “So, dad, you think the boys need to toe the line more…”

Dad: “I don’t like the ignoring and the nasty looks.”

Dr. Rick: “…and mom you think that’s asking too much?”

Mom: (nods).

Dr. Rick: “That’s a big difference. Maybe at some point we should talk about this so you are both on the same parenting page. I can’t tell you how important it is for each of you to feel supported in your view of parenting especially when you have a child on the spectrum. You don’t want to be too tough or too soft. These kids think differently, and it might be good to talk about it. Would you be open to discussing this at one of the next visits?” (See Chapter 14: Visit 7).

**Jacob’s FDL Profile**

Dr. Rick: “So even though there are some behavioral issues, the fact is: Jacob’s doing **fantastic!** I’ll record this. Let me summarize Jacob’s profile and emphasize some new techniques. Of course, Amber will help you with all of this too when she sees you for your next PLAY Project visit.”

“**FDL I—Shared Attention and Self-Regulation: 75% Solid.** He’s ‘with us’ most of the time. He still **fragments and still has his Comfort Zone activities**, but this is happening less and less. He wants to be with people and can **share attention** with easy engagement. The autistic veil is thinning you guys. I can’t tell you how important this is, but he’s starting to have behavioral issues because of his poor impulse control. He can’t **regulate** his feelings very well yet. This is very common. We’re going work on this at the next visit.

**FDL II—Engagement: 100% Solid.** Jacob is **easy to engage**, turns to his name readily, and he’s solidly attached to you two and Charlie.

**FDL III—Simple Two-way Communication: 75-100% Solid.** Here, he’s made great gains. He won’t leave you alone! He **initiates** all the time, opens and closes lots of circles, and enjoys cause and effect play and simple games. This is huge because it paves the way to Level IV. You guys have worked so hard!! And it’s paying off.”
FDL IV: Complex Two-way Communication: 50-75% Solid. Now, he's able to sustain continuous play for dozens of circles. He's got all the characteristics of FDL IV, but he's not 100% yet, so DONT PUSH THE RIVER. When he goes down into his Comfort Zone, go down with him. And don't make him talk by doing language therapy with him all day long. Honor and label his gestures. Do more simple pretend like feeding a big mouth puppet. And make sure you recognize his feelings. This is very important.

FDL V: Shared Meanings: 25% Solid. Jacobs reaching up into FDL V. He's understanding the 'meaning' of what you are saying to him more and more. But don't play too high. Stay with FDL IV activities."

“I know it’s hard, but we need to stay here for a while even though we are all chomping at the bit to move into Level V with more verbal language. I think he's just entering FDL V.”

**Technique Ideas**

Dr. Rick: “OK. Let me finish up here by giving you some technique ideas for FDL IV:

- **Big, little, and micro circles.** Don't settle just for big circles like looking your way or taking something from you or doing things you ask. Get some little circles like eye contact when you call him to take something, like a toy, and he looks at you and you look back and smile and he smiles. Then insert yourself—he silly or surprising—by moving the object over your head to see if he looks up at the toy and you say with a little tease in your voice: ‘Here, Jacob you want it?’ and then tease him a little with playful obstruction: ‘No, you can't have it. You want it? No, you can't have it.’ See if he gets the joke. Keep a continuous flow of interactions going and get another micro circle even to the point of handing it to him very slowly with suspense saying ‘Here it comes. Here... It... Comes.’ Then, hide it in your pocket and make him find it. Don't do this to the point of frustration. This should be playful, as a kind of gestural joke.

- **Speak for his gestures.** We've talked a lot about this already. I think I mentioned it the last visit, but it bears repeating. Whenever he shows you how he feels or what he wants gesturally, you will reflect back to him verbally what he intends. Use statements, not questions. ‘Let’s go out dad!’ Or ‘Hey Charlie, give me back my train!!’ This is one of the best ways to kick-start words and phrases.

- **Reflecting his feelings, words, and behaviors.** This is a closely related technique where you tell him (don't ask!) what he is feeling or doing as if you were a mirror that could talk. I use this technique more than all the others combined. So if he's pushing the trains, you say ‘He's pushing the trains!’ Or when he's putting on his pants you say ‘Pants on.’ If he's mad, you can say, ‘You're mad, Jacob; you don't want to stop watching TV.’

- **Everything comes alive.** Congratulations, Jacob is now beginning to play simple pretend. You can pretend that everything has a life of its own. The fork can dance over to the plate and say, ‘Here I go. I'm going to eat my hot dog. Num-num-num’. You can attribute life to any object this way.

- **Simple pretend.** If we're right in our profile, Jacob is going to love simple pretend. When the jack-in-the-box pops up, say, ‘Bye-bye jack-in-the-box’ as you push him down. When he played with trains, you'll notice that I spoke for the trains: ‘Choo choo, here I go’. Make sure the cars make car sounds; the animals make animal sounds; and make sure that you give songs like ‘Eensy Weensy Spider’ a full rendition with gestures. Even get a pretend spider. He's ready, and he'll love it. Get a pretend phone, a baby doll, some puppets, some pretend plastic food, and some long pipe insulators for swords. Pound on pots and pans and make music.
“This is going to be a fun time. I am so excited about Jacob’s progress I can hardly contain myself. His diagnosis is changing from ‘autistic disorder’ proper to high functioning autism. He has reached a critical turning point, and you should be very happy. I am very optimistic about him going to a regular kindergarten program.”

With these words, mom starts to cry outright. I hand her the Kleenex box. Dad wells up too. Of course, being the sentimentalist that I am, I join them and we all celebrate with a cry of joy and a round of high fives. The boys must think we’re nuts. I live for these moments.

I tell the boys it’s time to clean up and start singing the clean up song, “Clean up clean up everybody everywhere. . . .” but Jacob just stands there totally still. He puts his little hands up, still holding the two Thomas trains in them, over his eyes and has a very sad looking face.

Dad (in a stern voice): “Jacob, it's time to go. Time to clean up.”
Dr. Rick: “Do you see that? He’s sad to go. Let’s use the techniques of speaking for him and reflecting his feelings for a moment.” I speak for him, “‘No bye-bye, mom. No bye-bye, daddy.’”

He looks so forlorn standing there, frozen still, holding the trains up by his eyes.

Dr. Rick (to mom and dad): “Let’s stay with him. Don’t rush by these feelings.” To Jacob sympathetically, “I know Jacob. You want to stay and play.” I pause. He looks at me through his little hands, “I know it was fun, but we have to clean up. Come on buddy. Time to go.”

His hands come down. I think he truly felt understood. He relaxes a little and lets his mom pick him up with just a little whimper.

Conclusion
Dr. Rick (speaking into the recorder): “I know you’re itching to move into the language level, so let me give you a handout on FDL V so you can see where we’re going.” (See Appendix D: FDL Thumbnails).
Mom (looking over the sheet): “He’s not there yet.”
Dad: “But this is next right?”
Dr. Rick: “I think he’s got a little toe in FDL V. Pretty soon he’ll understand more and more of what you say, pretty soon! Keep putting in the time of interaction. Keep talking, playing, and using the techniques, and he’s going to get there. I know it. He’s on a roll and it’s because you guys have done such an amazing job. See you in about four months. Keep up the great work.”

Summary
• Jacob is much more ‘with us’ and can now open and close lots of circles in a row. The autistic veil is thinning! He fragments less; he goes into his Comfort Zone less. He wants to play with people! He is at the ‘turning point’!
• He communicates mostly with gestures but has a bunch of single words with occasional phrases AND he is following one-step spontaneous commands like ‘Get me that ball, Jacob’. That’s huge.
• I talk to the parents about how to ‘not read’ the book so that it’s fun for Jacob.
• Simple pretend is emerging too, which is a great sign that his ‘feeling life’ is progressing too. He’s not happy just doing repetitive behaviors any more.
• He’s now smarter socially, more aware, and starting to have more organized feelings. He’s starting to complain and whine. He’s pushing Charlie around and won’t share. We’ll need to talk about this soon, as the parents don’t agree about the rules.
• I listed a few techniques to help Jacob solidify his functioning from Levels I through IV.
• I am now optimistic that Jacob has reached a turning point and will understand shared meanings and start talking in short sentences (FDL V!).

Resources & Websites

Websites

Books
• Engaging Autism, Stanley Greenspan and Serena Weider, Da Capo Press (2006)
• Autism Solutions by Ricki Robinson, Harlequin Press (2011)

Coming Up Next
• Will Jacob move into FDL V?
• Problems with behavior get worse, including sleep issues, toileting, and aggression.
• The school has been calling too.
Chapter 12
Kindergarten: Ready or Not Here We Come

IEP Time

It may be spring, but parents of children with autism have fall on their minds as they plan for the upcoming school year. Thousands of IEP (Individualized Education Plan) meetings that will determine children’s future school placements and educational goals are being scheduled all over the country (See Chapter 5: Early Intervention and Special Education Preschool and Resources & Websites: Know Your Child’s Educational Rights). That’s when my office phone starts ringing off the hook. Amy, my assistant, says “Everybody's freaking out.” For five and six year old children with autism, the transition from preschool to kindergarten has begun!

So I wasn’t surprised when Jacob Grant’s chart appeared on my desk with an urgent telephone note: ‘4/15. Julie Grant called. She has to decide about Jacob’s school placement for the fall. Please call.’

During our last visit earlier in April, I had advised Julie Grant to get in touch with the school (See Visit 6: The Turning Point). At that time she hadn’t heard anything yet about his IEP meeting (Individualized Education Plan) and so didn’t know what the school district’s plans were for Jacob in the fall. He would be six in October but five when school started in September), and, even though he had made wonderful progress over the last year and half, I didn’t think he was ready to leave his special education preschool program yet and move on to kindergarten. I returned Julie’s phone call.

Age Does Not Equal Readiness

Dr. Rick: “Hello, Julie? Rick Solomon here.”

Mom: “Oh, Dr. Rick, I am so sorry to bother you so soon after we saw you, but I did what you said, and Jacob’s preschool teacher said the team is going to recommend that Jacob go to a full day kindergarten in the fall!”

Dr. Rick: “I’m glad you called. This is an important discussion.”

Mom: “If Jacob could go to a regular kindergarten in the fall that would be a dream come true. I remember you said when we first came to see you that you thought Jacob could be in a regular kindergarten program with regular kids.”

Dr. Rick: “That would be great, but we just have to make sure he’s ready.”

Mom: “I’m really torn. In a way, I’m excited that they think he’s ready for kindergarten, but I’m also scared that he’s not really ready.”

As I talk to Julie, I'm having the following considerations: Many of the children I see with higher functioning autism are truly ready for kindergarten. Others with more severe forms of autism clearly will not be ready to function well in a regular elementary school classroom and will need to go to special education programming within the elementary school.

Jacob is somewhere between these two extremes. Even though he has made major gains, he is not quite ready yet for kindergarten. For a child like him, I almost always recommend waiting as long as legally possible—this means turning age six before September in most states—before starting kindergarten. But I don’t want to upset Julie Grant; she is so hopeful about Jacob going to kindergarten. If worse comes to worst and a child, like Jacob, goes to kindergarten but doesn’t do well, I will recommend repeating kindergarten for reasons I’ll explain below.
Dr. Rick (looking at Jacob’s chart): “Well, I see that Jacob will still be five in September, thank goodness. So if we want to keep him in preschool we can. Our options are still open.”

Mom: “But doesn’t he have to go if that’s what the school decides?”

Dr. Rick: “Not if it doesn’t make sense. Remember that discussion we had way back in the beginning about the IDEA laws (See Chapter 5)?”

Mom: “You said parents have a lot of power.”

Dr. Rick: “Exactly Julie. Sometimes, the schools just move the children on because of their age, and at five years of age, Jacob could go to kindergarten. He’s old enough but age does not equal readiness. What matters is that he’s ready, not how old he is! In other words, he has the legal right to one more year in preschool. If he’s not ready, kindergarten—especially a full day of kindergarten—could be very stressful for him, and it could hurt his progress.”

Stress! As if the rushed early morning routines, the bus rides, the new (and noisy!) classrooms, and the new teachers students aren’t enough stress, there are also major new demands on the child to comply socially and perform academically in a kindergarten setting (See Chapter 16: The Seven Habits of Highly Effective Kindergarteners). And since children with autism want to ‘keep the world the same’, all these demands are all the more stressful.

Mom: “I’m glad we’re talking about this. I was feeling anxious about Jacob going to kindergarten. I have to let the school know what we want to do.”

Dr. Rick: “I would trust your gut. Julie, you’ve got great intuition. I’ve seen far too many kids develop major mood changes, sleeplessness, anxiety and even aggression when they go to kindergarten too soon.”

Mom: “So what should we do?”

Dr. Rick: “Let’s just go through this systematically, Julie, and then we’ll make a decision.

- The first issue is functional readiness. Has Jacob accomplished his preschool goals? I’ve got a handy dandy checklist of functional skills that Jacob needs to have accomplished first (See below).
- Then, we’ll talk about whether Jacob can achieve key kindergarten milestones—I call them the ‘Seven Habits of Highly Effective Kindergarteners’.
- Finally, I have a list of basic supports that Jacob (or any child for that matter) would need to function in a demanding school setting.

“And these checklists can serve as key IEP goals for Jacob (See also Appendix H: IEP Goals), whether he stays in preschool or goes to kindergarten.”

Children Who Are Not Ready

Dr. Rick: “I know you’re excited about Jacob going to a regular kindergarten, but Julie, there are very few times in a child’s life when he can gain a year of development on his peers.”

Mom: “But then he’d be older than the other kids.”

Dr. Rick: “Just a little. But what difference does it make to his friends if he’s five or six? I’ll say it again: What matters is that he’s ready, not how old he is!”

Mom: “True.”

Dr. Rick: “But let’s discuss it, and we’ll decide. You’re the boss. I’ll support whatever you want to do.”

Mom: “I want to do what’s right for Jacob.”
So what does ‘ready’ really mean? As I explain to Julie Grant, there are three forms of readiness: behavioral, academic, and functional readiness.

**Dr. Rick:** “If you don’t mind, I’d like to give you two extreme examples of children; one who is behaviorally ready and one who is academically ready, but neither of them is functionally ready.”

**Mom:** “Okay.”

**Dr. Rick:** “**Behavioral readiness** is the least demanding on the child (though not necessarily easy!) and simply means that the child can behave for two to three hours for a half day or five to six hours for a full day in the kindergarten setting without repeatedly disturbing or disrupting the class routine.

“I had a patient I’ll call Johnny whose parents came to me when he was already six. He had pretty severe autism—no words and little ability to interact, but his family wanted him fully included in kindergarten, which meant in his case that he stays in the regular classroom all day with a paraprofessional helper (sometimes called a parapro, para, and/or aide) at all times.

“I didn’t really think it was a good idea, but that’s what the family wanted. Johnny would sit, but he rocked and occasionally hummed throughout the two to three hours of the morning kindergarten class. He moved wherever his parapro took him without really participating; didn’t acknowledge the other children. He left class for occupational therapy and speech therapy, went out to the playground where he wandered around alone. If he became anxious and his humming got too loud, he was allowed to flip through office equipment catalogues page by page, which was one of his favorite repetitive, Comfort Zone behaviors. Outside of reminders to keep his humming down and sit down when he began to wander, he behaved himself for the whole year—almost.”

**Mom:** “What do you mean almost?”

**Dr. Rick:** “Toward the end of the year, he started misbehaving, and the parents finally agreed to move him to a more restrictive, self-contained classroom.”

**Mom:** “Do you think Jacob is behaviorally ready? He sounds higher functioning.”

**Dr. Rick:** “Well, Jacob is a lot higher functioning, but if the classroom demands are too high, if he doesn’t understand what’s going on, he could get bored and have trouble sitting. It might not be fun or meaningful for him. Then he might misbehave and not be behaviorally ready.”

**Mom:** “I see what you mean, and Jacob is not one to take things lying down.”

**Dr. Rick:** “Right, so behaviorally he might be a problem. OK. Let me tell you about another type of kid, I’ll call him Joey.

“Joey seemed to be academically ready. At age five, he had been reading for two years! He could count, knew his name, and could recite his address and telephone number on command. He knew his colors, numbers, and shapes.

“But Joey, despite his apparent academic readiness, was often in his own world. He ‘scripted’ (repeated, memorized songs and dialog) from his favorite TV show—The Wiggles—and had to be prompted to go along with the group by his parapro.”

**Mom:** “He needed a parapro too?”

**Dr. Rick:** “Yep. He didn’t really find classroom activities very interesting, so he would just get up and wander off and go play with trains or cars in the back of the room. He was misbehaving; his para had to bring him back. And he was easily overwhelmed by the noise and chaos of his
classmates and would occasionally bolt for the door, so you could say that Joey was *academically* ready but not *behaviorally* or *functionally* ready.”

Mom: “I think Jacob falls somewhere in between. Both those kids sounded like they weren’t as connected as Jacob.”

Dr. Rick: “I agree. And that gets us to ‘functional’ readiness. In order to truly succeed in kindergarten—which is, by the way, becoming much more demanding (it’s like the new first grade)—a child has to be ready behaviorally, academically, and functionally.”

**Functional Readiness**

Dr. Rick: “Functional means able to relate to people (i.e., teachers, school personnel, and peers) in a developmentally and socially appropriate way. A child can behave by sitting quietly; a child can perform academic skills. But if the child cannot connect to the teacher and other children, if the child cannot understand how to communicate, then he or she isn’t going to *function* very well in a school classroom. That’s why we’ve been working so hard with Jacob on the Functional Developmental Levels.

“From the school’s perspective, sending a child to kindergarten based on age alone can turn out to be a big mistake. *In order for children to really learn, kindergarten activities must be interesting and meaningful to them.* The typical child finds school fun and not too hard. One of the teacher's main jobs is to challenge the children at just the right level. Classroom activities should not be too demanding or too easy or boring for the child. When the challenge is just right, this is called being in The Zone of Proximal Development.”

Mom: “I think you mentioned this to me before, but honestly I don’t remember what it was about. I’m sorry.”

**The Zones of Development**

Dr. Rick: “You remember the *Comfort Zone*?”

Mom: “That term I know. Amber talks about Jacob’s *Comfort Zone* a lot during home visits. That’s when Jacob goes into his own world, right?”

Dr. Rick: “Right. Well there was a brilliant Russian developmental psychologist by the name of Vygotsky who developed a theory of learning at the turn of the last century that’s still influential today. What he said is that there are three *zones of development*, which can guide us to understand *school readiness*.

“The first zone is the *Comfort Zone*, where the child is comfortable doing what he already knows. For children with autism this is *what the child will do when you let them do whatever they want to do*. For example, Jacob loves to line up cars or watching the same video or flip through the same books.”

Mom: “He used to love to watch the door open and close. Drove us crazy. But he’s doing all those things a lot less now.”

Dr. Rick: “Yep, that’s *Comfort Zone* behavior. When children with autism are in their *Comfort Zones*, they are not learning very much. Two *preschool indications of functional readiness* for children on the spectrum are:

- That they turn consistently to their names
- And they are connected with the social environment most of the time
If your child is ‘stuck’ inside their Comfort Zone and is not paying attention to the environment, or not easily engaged, or not able to interact in a back and forth fashion, then your child is not going to be functionally ready for kindergarten.

“Vygotsky’s second zone is where the best learning happens—the Zone of Proximal Development. You know your child is in this zone when:

• They are attentive, engaged, excited, happy, and participating with others.

“When I am doing a classroom observation of a child on the spectrum, I am looking to see if the kindergarten setting is interesting and engaging to the child most of the time. If not, if the activities of the day—following a schedule of events, sitting attentively in circle time, cutting and pasting, following oral instructions—seem irrelevant, and the child is disconnected, then the curriculum is in the child’s Zone of Potential Development.

“This is Vygotsky’s third zone—the Zone of Potential Development. In one sense, it means that this is where the child has potential to learn, but it also means that the learning is too hard and ‘over the child’s head’. And I’m afraid there are way too many children who don’t ‘get’ school because they are in their Comfort Zones and the school activities are way over their heads, i.e., in their Zone of Potential Development.”

Mom: “And you’re thinking that kindergarten is going to be over Jakey’s head, in his...”

Dr. Rick: “Zone of Potential Development. Right. He’d need help in kindergarten. He’d need to be prompted to do this and that by aides in the classroom. I’m also worried that he’d just be ‘going along’ and not really learning a lot. In short, I don’t think he’d be in his Zone of Proximal Development.”

Mom: “Those concepts are very helpful. I’m beginning to see that buying another year for Jacob could give him a huge advantage developmentally.”

Dr. Rick: “I’m thinking that way too.”

Mom: “So what do we need to do to get Jacob truly ready for kindergarten?”

Dr. Rick: “We’re doing it. Jacob is getting ready by marching up the Functional Developmental Levels of the PLAY Project. And he is marching. I mean, look how far Jacob has come over the last year.”

Mom: “When I look back on it, it is amazing. Even my sister who hasn’t seen him since last Christmas noticed the huge change.”

Dr. Rick: “He used to be in his own world (FDL I) and now, he’s with us almost all the time. He used to be hard to engage (FDL II) and wouldn’t even turn to his name.”

Mom: “Now, he won’t leave us alone!”

Dr. Rick: “That’s great two-way communication (FDL III). And he used to have trouble understanding even the simplest requests.”

Mom: “And recently he’s been following more of those one-step commands you’ve been telling us about. And the number of words is really increasing.”

Dr. Rick: “Really? You didn’t tell me that! That’s like solid FDL IV!”

Mom: “The other day I told Jim I had to get some eggs and milk. Jacob overheard me and showed up at the door with his shoes on!”

Dr. Rick: “He wanted to go to the store too. That shows real problem solving abilities (FDL IV) and an ability to understand the meaning of what you said (that’s early FDL V)! Amazing.”

Mom: “I’m so proud of that boy.”

Dr. Rick: “I’m proud of you and Jim too.”
Mom: “So what FDL does Jacob have to get to in order to be truly ready for inclusion in a regular kindergarten program without aide support?”

Dr. Rick: “At a minimum he should be at a solid FDL V to early FDL VI. I'll send you a checklist I have for school readiness (see below). Let me read you off some of the items.”

Kindergarten Readiness Checklist for Children with Autism

- Turns to name consistently
- Can answer: ‘What are you doing?’ Or ‘What do you want for lunch?’
- Speaks in sentences of three to five words or more
- Follows two to three step commands
- Pretends: doctor, tea party, etc.
- Points to small body parts
- Plays simple games: hide and seek, Candyland
- Beginning to ask and answer ‘why’ questions
- Recalls two to three events from their day

Mom: “[Jacob can’t do most of these things except maybe turn to his name consistently.”

Dr. Rick: “I agree. These are mostly in his Zone of Potential Development. I believe he will be able to do all these things but not now. So I don’t think he’s likely to do well in kindergarten without substantial support.”

Mom: “You mean an aide.”

Dr. Rick: “An aide or even spending time in a resource room with a special ed teacher. I’m most concerned that the school could recommend a self-contained classroom (See *Note below.*)”

Mom: “And put Jacob in a classroom only with other kids with autism?”

Dr. Rick: “Yep.”

Mom: “I don’t want that at all.”

Dr. Rick: “Don’t worry. Remember, you have the power by law to have Jacob in the least restrictive environment.”

Mom: “I think we’ll keep him in preschool another year.”

Dr. Rick: “I think that’s smart, mom.”

Mom: “We’ve got an appointment coming up. Thanks for taking the time to explain all this.”

Dr. Rick: “This was an important discussion. Let me know if Jim has any questions.”

*Note: It is important to understand that different states in the U.S. have different approaches to the process called inclusion, i.e., how do we include a child with special educational needs in a classroom setting? In some states, all children are in a general education setting all the time. This is called full inclusion. In many states, however, this model is hard to achieve and very expensive so the special education school districts may opt for partial inclusion (i.e., some time in general education and some time in more restrictive environments like resource rooms (See also Chapter 5). In some states, children with special needs are placed in self-contained classrooms (the most restrictive environments) where the child is only with other children with disabilities. The child may be mainstreamed only for such things as lunch, recess and gym.

Summary

- It’s IEP time. The Grants are facing a choice: send Jacob to kindergarten or hold him back another year in preschool.
- Kindergarten may be too stressful for children with ASD if they are not ready.
- I argue that age does not equal readiness and define what I mean by functional readiness.
• Vygotsky’s three zones of learning and Greenspan’s Functional Developmental Levels help us decide where Jacob is at.
• I provide a Kindergarten Readiness Checklist.
• Guess what we decide to do?

Resources
• Know Your Child’s Educational Rights! Learn about the law: http://www.understandingspecialeducation.com/IEP-law.html

Coming Up Next
• Jacob Grant is moving up the path toward his potential. I summarize the journey he has made to this point.
• The focus of intervention shifts from an emphasis on interaction to Jacob’s language, imagination, and emotional thinking.
• We’re heading toward kindergarten!
Chapter 13
Visit 7: Part 1
The Path: Imagination and Meaning

The Path
Over the next five months, I follow Jacob’s progress by watching videotapes taken during PLAY Project home visits and witness the long awaited and much hoped for transformation: Jacob now understands most of what his parents are saying to him! He has developed simple pretend play, has too many words to count, and is now talking in two to three word sentences! In short, he has achieved Functional Developmental Level (FDL) V—Shared Meanings and Pretend Play—by age five!

How did this happen? As I watched Jacob’s videos with Amber, the Grants’ PLAY Project Consultant, I was acutely aware that for a child to go from autistic isolation—with almost no communication, no words, little interest in people, and nearly complete absorption in things—to a talking, relating, functional human being is a miracle of human potential (and a lot of work for the parents!). Amber and I were high-fiving and celebrating. This was a breakthrough.

For almost two years now, Jacob’s parents patiently watered, tended to, nurtured, and provided the light of love to their delicate flower. The flower slowly sprouted from seed, slowly popped its green stem from the soil, and painfully slowly developed leaves, deeper roots, and a longer stem. Many times they (especially dad!) felt like grabbing that growing stem and pulling it up to make it grow! But, with professional and family support, they gained faith that, if they persisted, Jacob would grow naturally, organically, and he would flower in his own time. How many hours, days, weeks, months, and years it took for this precious moment of blossoming!

The Path is clear. To become a truly functional human being, the child with autism must reach the milestones of each of Greenspan’s six functional developmental levels. Sometimes, this happens fast, sometimes slowly, and sometimes very slowly or, sadly, never. No matter what type of intervention a child has, he or she must gain the abilities to stay calm and pay attention (FDL I), sustain attention to become engaged with people (FDL II), develop the ability to have two-way communication (FDL III), and sustain that interaction with a rich gestural repertoire, simple words, the ability to problem solve, and the capacity to understand both routines and simple commands (FDL IV).

The next two steps—becoming symbolic (sharing meanings FDL V) and becoming a logical and emotional thinker (FDL VI)—complete The Path of early childhood development. The culminating achievement is the development of imagination! Not just the capacity for pretend, but the ability to imagine what others are thinking and feeling, the ability to imagine the future and recreate the past from memory. If this all happens by age six, the child is usually functional enough to go to kindergarten because the child’s autistic veil has thinned to the point where he is fully ‘with us’ and symbolic. He does not have ‘autistic disorder’ per se but has moved along the spectrum to ‘high functioning autism’ (and, in some cases, beyond). We have nurtured the potential within the child.

Don’t Push the River. Early on, Jim Grant asked me, ‘How do you know we are doing enough? If we do more, can’t Jacob do even better?’ I’m convinced that you can’t push the river, that the family’s job is
to stay in the ‘flow’ of optimal development and not get tangled, so to speak, in the tree branches on
the banks or get exhausted by paddling too hard. Doing too much can be as bad as not doing
enough. There is a point of balance that brings optimal development.

In my office, I ask families to make a judgment: ‘Please rate your child’s progress over the last six
months—poor progress, fair, good, very good, or excellent progress.’ I ask families to think about it
carefully and be as honest and accurate as possible. If families can honestly say that their child has
made very good or excellent progress, then usually there is nothing more they have to do beyond tweaking
what they are doing. I tell them: ‘Stay on The Path, do not push the river, don’t mess with success.’

If the family says ‘good progress’, then I evaluate to see if there are things we can add to their
program. Is the time of engagement optimal? Do we need another therapy? Do we have too many
therapies that are not all pulling in the same direction? Does the family need more support? Were
there stresses (moves, pregnancy, divorce, death in the family) that interfered with family
functioning and/or the child progress? Or, is ‘good progress’ as good as it is going to get?

The sad fact is that, no matter how much you do, some children move along The Path more slowly
than others. The child with more severe autism will take a longer time to get to the next functional
developmental milestone. You can’t push that river.

The Case of Connor.

Take Connor, for example, a four year old who I diagnosed at age three as having Fragile X, a genetic disorder affecting males, which causes cognitive impairments and autism. The
family implemented an intensive, comprehensive, developmental intervention program that included
the PLAY Project, special education pre-school five half days per week (which provided ABA
intervention (see Glossary), private speech and language therapy, and occupational therapy 1-2
times per week. The family worked hard, putting in 1-3 hours per day of engaging playful
interactions and Connor made progress.

After two years of very skillful intervention, however, he had moved from FDL I to FDL III with
perhaps a little of Level IV. When I asked his parents to rate his progress they answered ‘fair to
good’. I had to agree with them. But I couldn’t ask any more of them. He was reaching his potential;
he was doing as well as possible.

But it wasn’t fast enough for Connor’s grandparents. They paid $30,000 the next year for an
intensive ABA program, which used structured teaching and drills to help him gain language skills.
Connor, sadly, regressed. It was too much for him, and he lost many of the earlier functional skills
he had gained. The family returned to their previous program.

Over the next two years, Connor continued to make slow steady progress and reached FDL IV: He
was ‘with us’ and could stay engage for longer periods of time; he followed one-step commands; he
problem solved and began to talk in one word utterances. He even had a little bit of FDL V. He
became progressively more functional, but it took Connor four years, until age seven, to achieve
what Jacob has achieved in two years. The family tried to push the river, but more effort was not the
answer. Time, persistence, and patience furthered Connor’s development.

Sometimes The Path is even slower going, and the years unfold with little or no progress. This is
actually very uncommon, but when it happens, it is very disheartening. At some point, most families
feel a profound sadness. They must make a decision of the soul: To mourn the loss of the child they
wished for and love the child they have. Otherwise, and I have seen this too often, the families burn out, and spiral downward from grief to profound sadness to depression. This often leads to discord between the parents, neglect of the other children, and divorce. The cost of intervention was great, the benefit small.

The Cost-benefit Curve. When it comes to intensive intervention, there is a very real cost-benefit curve. The cost factors are time, effort, money and stress, and the benefit is the child’s developmental gains. When it comes to time and effort, I firmly believe in the National Research Council’s recommendations (see Chapter 3: When You Walk Out My Door: First Steps) that you have to put in 1-3 hours per day of engaging intervention. This can be done both formally through specific therapies and informally, using every interaction—waking, eating, and getting ready for bed—throughout the day.

I firmly believe that parents should not get tangled up in the time consuming and anxiety producing ‘biomedical’ approaches of diets, vitamin and mineral supplements, and/or alternative experimental therapies that have no evidence for them (see Chapter 4: Diet, Biomedical Treatments, Immunizations, and Autism). High cost, little to no benefit.

When it comes to the cost of effort and stress, I have seen too many families who paddled too hard—over-scheduling their child for 40 hours of different types of therapies per week, driving here, driving there—and burnt out as a result. I have seen the children burn out too, refusing to do the therapies, shutting down, and actually regressing. There are limits to a family’s and a child’s endurance.

Even large benefits in the short run for a child are not justified by the great cost—burnout, depression, and/or divorce—in the long run to the family. When there’s a child with autism in the family, divorce rates are higher. Often, the short-term gains for the child are lost. As the family goes, so goes the child.

But there is a skillful middle way that balances everyone’s needs, that works best in a harmonious way for the whole family and, in doing so, supports the child’s development. Families need to find that middle way to survive the challenge of autism.

The Family’s Path
For the parents, there is an emotional path that begins with grief being held back by hope that their child will succeed. There is an extraordinary anxiety that drives the parents to seek and implement an intensive intervention.

With luck, much hard work, and often at high emotional and financial cost, intervention brings results, a glimmer of progress and more hope. For families that are supportive and supported (by spouse, extended family, and friends), the burn out is less. The work is distributed. Depression is a constant threat. The parents support each other so they can each support the child with autism and his or her siblings.

The child with autism begins the long path upward. There are days, weeks and months of doubt alternating with growing hope as the child makes slow, steady gains. The child stays engaged longer. There are longer interactions. There is a real connection to people.
Direction and support from an experienced professional is like having a Sherpa guide who knows the mountainous roads and secret passageways that shorten the trek.

Then come the breakthroughs, the first words, the greetings at the door, the understanding of ‘get your shoes’, the first sentence, the unspoken and spoken celebrations. ‘This year he knew he was having a birthday party.’ Others outside the family notice it. It is amazing and the layers of grief give way slowly to more hope. There are tears of grief letting go and happiness arriving.

For the Grants, this family path has been long and hard. Luckily, Jim Grant is a good man. He loves his wife and supports her. He plays with Jacob and Charlie most evenings even though his job as IT consultant is stressful and demanding. He is ambitious for his son Jacob, unrelenting in his quest to get Jacob to talk, and, he can be as critical, difficult and demanding on others (namely me!) as he is on himself. But I really like him for this, even though his calls and emails—about this treatment or that supplement or whether we were doing enough—make me roll my eyes sometimes.

The perfect complement to her husband, Julie Grant is more accepting of Jacob but no less ambitious for him. She balances his husband’s ‘type A’ personality with a steady, calm commitment. She gets anxious at times, especially around Jacob’s emerging defiance and misbehavior, but she has good common sense, faith in Jacob and, at some level, seems to know that, as a family, they are doing about as well as can be expected. She also has good support from her parents, as well as her sister with whom she is close.

In short, this is a resilient family with a ‘high love charge’. The Grants know they are running a marathon that’s not over yet. They’ve learned, however, to pace themselves and avoid burnout, depression, and divorce by taking time for their marriage (they ‘go on a date’ once a month) and for their younger son Charlie. They stopped pressuring themselves to ‘get in the two hours a day’ and instead settled into a rhythm of PLAYing on the floor when they could and using all their daily interactions to keep engagement going.

Now that Jacob has emerged from his isolation, now that he is interested in people (because people are seen as safe and fun to be with), now that he has functional skills to tell them what he wants, ‘life itself’ has become Jacob’s PLAYground. As Julie said to me during this visit: “I just sit in amazement and watch the boys playing. Jacob wants to play with Charlie. He actually likes being with people.”

The Path of Affect
If there is a path of functional development where the child climbs up Greenspan’s six levels and if there is a path for the family where hope and grief battle their way to acceptance, there is one more path, which may be the most important—The Path of Affect. This, in my opinion, is Greenspan’s most important insight into human nature, which he calls the affect diathesis hypothesis.

Please note that the term ‘affect’ is also used to refer to the energy and feeling that the caregiver and/or child brings to an interaction in the moment. We would say a mom or dad has high positive affect if she or he shows lots of energy, is fun and funny and/or exudes an upbeat, positive attitude. We would say a child shows low affect if they are not interested in anything and tend to play repetitively without much enjoyment. These are children that don’t laugh much. They are passive and placid. This is an ‘in the moment’, situational affect.
Greenspan’s affect diathesis hypothesis is not about situational affect; it’s about the evolution of the child’s feeling life, their intentions. Let me simplify the meaning of this fancy sounding term. Here, ‘affect’ means the children’s overall feeling life: what children love to do, what makes them laugh, what excites them. Diathesis means ‘tendency’. It is the tendency of the flower to turn to the sun. Hypothesis means a theory, not yet proven. So the ‘affect diathesis hypothesis’ is Greenspan’s theory that the feeling life of the child drives the tendency to develop into a more and more complex human being.

In other words, what we are changing in our intensive play-based intervention is the child’s feeling life. We are helping the child along a path that starts with an absorption in things and ends with a love of people. Recent research has shown that very young children with autism, as young as six months of age, focus on objects not faces. This tendency to simplify, to keep the world the same, creates a vicious cycle that narrows experience, which in turn limits development, which in turn narrows experience. Autism is its own worst enemy.

To reverse this tendency, we introduce play. We ‘woo’ the child upward and show him that it’s fun to play with people. At first, of course, the parents follow the child’s lead, get the child’s attention and keep the child engaged. But after a while, he learns that engagement is fun, and then he wants to initiate interactions and actually seeks people. This is now FDL III—Two Way Communication. The child’s affect is tending upward. His intentions are changing. We are literally (through better and more complex brain connections) changing the feeling life of the child.

As we persist in our ‘wooing and waiting’, as we provide the ‘just right challenge’, the child’s affect rises even further, and he begin to like and want longer interactions that have a game-like quality. Then, he likes simple pretend play because it’s more fun than simple cause and effect play. Finally the child enjoys role-playing and can now talk in longer sentences. And what’s amazing, is that we no longer have to do anything to make him want to be with us. He just wants to.

**Jacob’s Path**

And what does Jacob want to do in my office playroom? He wants to play pretend with Mack, the cherry-red semi-trailer truck from the movie ‘Cars’. You must imagine this: Mack’s semi-trailer has plastic red sides that are hinged and open out, revealing a lavish interior with a gas pump, a grill brush, a refrigerator with oil, etc. just like in the movie. What’s more, there’s a ramp in the middle, with a bed made for Lightning McQueen, the heroic racing car in ‘Cars’. This bed can be controlled to go up and down and sideways by a ‘magic’ button built into the ramp (which Jacob has not discovered yet—shh, it’s a secret. You’ll soon see why I am telling you this.)

Jacob loves this toy and drives Lightning up the ramp onto the bed. This is a form of one thematic play. Then, he closes Mack’s sides, raises the back door and shuts Lightning snugly inside the semi-trailer truck. He looks at his dad to share his accomplishment, and dad says ‘Good job buddy, Lightning’s inside.’ He drives Mack around the floor of my playroom making gear-shifting noises. He’s pretending! His affect—what he wants and loves—has risen to Functional Developmental Level V—Shared Meanings! A key milestone of FDL V is one thematic play.

**Joining Jacob’s Play.** I sit down not too close to Jacob and quietly watch him play. I know he’s a bit shy at first so I give him time. I put on my Zen head (empty my mind of all expectations) and do nothing but observe. I follow his lead with words, only reflecting what he is doing:

**Dr. Rick:** “Wow. Mack opens up and closes!”
Jacob: Gives me a look (i.e., closes a circle) and opens up Mack again and looks admiringly at Lightning with his sleek red racecar lines.

Dr. Rick: “Lightning is so cool! He’s inside Mack.” Now I add a little pretend by talking to Lightning. “Hi Lightning.”

Jacob: Closes the hinges and hides Lightning.

Dr. Rick: “Bye Lightning (I act confused). Where’s Lightning?”

Jacob: Opens Mack up.

Dr. Rick: “Hi Lightning.”

Jacob ‘gets’ my humor and enjoys the game of opening and closing (as I, of course, become more and more dramatic). He laughs out loud as he repeatedly opens and closes the back of Mack and I repeatedly say ‘Hi’ and ‘Bye’.

Now, I decide to introduce Jacob to a new idea of my own—the secret magic button. I aim my finger, slowly point towards the magic button and as I actually push the button I say, “I push the ‘magic button’ and make Lightning jump.”

And Lightning jumps high and right off the ‘bed’. Jacob looks at me in amazement. We share a couple of seconds of eye contact and he smiles. I smile back. We are opening and closing little micro circles of communication. He looks like he wants to do what I just did. So I label what I think his intention is.

Dr. Rick: “Go ahead Jacob. Put Lightning on the bed and make him jump. Push the magic button.”

And he does! He laughs and thinks it’s very cool. I’ve made a friend! I joined his idea, expanded it in a way that I thought would be fun, and before long we were truly playing together.

Once you know ‘where the child is at’, it’s not hard to become a true partner in the play. But you should never take the play over. The child’s ideas are way more important than the adult’s. So I get a car of my own and wait to see what Jacob wants to do next. I keep eye contact and show him my car. He looks at it. I raise my eyebrows and tip my head down a little as if to ask if he wants to play cars. He looks at me as if to say, ‘OK I’ll play cars’. Then I put it into words.

Dr. Rick: “You wanna play cars?”

Jacob (smiling, nods): “Yes.” And he closes Mack’s sides like he did before.

Dr. Rick: “Bye-bye Lightning.”

Jacob: Starts driving Mack along the floor (his idea).

Dr. Rick (Making a “zoom zoom” sound with my black sedan matchbox car alongside Mack.): “Hey truck. Hey truck. Stop truck. Stop!!”

Jacob: Stops Mack and looks at me, a little confused.

No one had ever given him a command through pretend play before, and he was a little shocked at himself for actually listening to me/my car. But he stops. And I ‘talk’ for my car by wiggling it as it speaks.

Dr. Rick: “What should we do now, Mack?”

I note that Jacob hasn’t said many words, but he understands everything I’m saying to him. He understands my meaning. He is at FDL V—Shared Meanings and Symbolic Play. I know I’m
opening my share of the circles, but he’s responding to me and he’s got his own ideas too. We have a
nice balance of interaction with me leading some and him leading some. This type of play interaction
analysis is complicated but critical to helping the child along The Path.

Charlie’s been eyeing the action all along, and now he joins the play.

**Dr. Rick:** “Man, that is a fancy race car, Charlie. What’s his name?”

Here, I make a developmental mistake. Charlie looks blank. This is too tough of a question even for
Charlie, a typically developing three year old. It is an open-ended “wh-question” with two demands:
Charlie will not only have to know what it means to have a name for his car, but he’ll also have to
make up a name. It’s over his head; and after several seconds he still looks blank, so I help him out.

**Dr. Rick:** “Is his name **Racer**?”
**Charlie** (Relieved that I’ve answered the question): Nods enthusiastically.

I bring my black sedan Matchbox car into the conversation by wiggling him as he talks:

**Dr. Rick** (wiggling the car): “Hi. I’m **Black Sedan.** Who are you?”
**Charlie** (wiggling his car): “I **Racer.**”
**Dr. Rick** (Turning to Mack): “Hi. What’s your name?”
**Jacob** (alias Mack): Doesn’t answer.
**Dr. Rick** (aside: whispering to Jacob himself, pointing to Mack): “What’s his name?”
**Jacob** (whispering back): “Mack.”
**Dr. Rick**: “**Racer,** this is **Mack.**”
**Charlie** (wiggling his car at Mack): “I **Racer.**”
**Dr. Rick** (aside to Jacob): “Jacob, tell him who you are.”
**Jacob**: “**Mack.**”

So here we are, the three of us playing cars. I was so pleased that Jacob was able to stay with some
pretty complicated play around social introductions (with a lot of help from me!). He followed a
one-step command (‘. . .tell him who you are.’) and understood the meaning of the play situation.

Then, Charlie starts racing his car back and forth saying ‘vroom vroom’. I start racing my car around
saying ‘zoom zoom’. Jacob is watching but not joining. Instead of ‘vrooming’ like Charlie or
‘zooming’ like me, he makes the pulling action of a trucker blowing his horn and makes an “oo-oo”
horn sound.

**Dad:** “That’s a scene from **Cars**.”
**Dr. Rick** (to dad): “He added his own idea!”
**Dr. Rick:** (wiggling my car at **Racer** and then **Mack**): “OK guys, I have to go. See you later. Bye bye.”
**Charlie** (wiggling Racer): “Bye.”
**Dr. Rick** (to Mack): “Bye Mack.”
**Jacob** (wiggling Mack!!): “Bye.”
**Dr. Rick** (Climbing back in my chair at my table, I turn to mom and dad): “He imitated the
wiggling! That was fun!”
**Dad:** “It was fun to watch.”
**Mom:** “You made some tough demands on Jacob.”
Dr. Rick: “It’s time to expect more and more from him.”

The Path to Shared Meaning and Symbolic Play
This type of play and interaction is a huge achievement for Jacob. He has had a major leap in his receptive language. He knows what words *mean* without the need for gestures. Before, words disappeared into thin air and left no trace in Jacob’s mind. They meant nothing. They had to be connected to gestures (like an open hand that meant ‘give it to me’), specific repeated routines (‘time to eat, Jacob’), objects that got labeled (‘Where’s your diaper?’), or familiar people (‘Daddy’s home!’).

Now, words *mean* something by themselves. What used to be merely a sound has now become a *symbol*. You can say ‘Daddy’ ‘wants to eat’ ‘the banana’ and Jacob will have an internal representation for each of these things—he understands ‘subject-verb-object’ sentences. Below are the key milestones of FDL V, starting with an increase in receptive language.

**Functional Developmental Level V**

*Shared Meanings*

- Major increase in receptive language and understanding
- One thematic pretend play with adults
- Mostly one to two word phrases
- What, Where, Who, Actions, Yes/No
  - Not Why, When or Pronouns
- Continued parallel play with peers
- Follows one to three step commands
- Manners emerging
- Sense of humor emerging
- Compliance: Starting to do what other want them to
  - It is not following their lead to follow their lead

At this level, there is also a major increase in the number of words and the ability to answer simple questions like ‘what’, ‘where’, and ‘who’ questions. *Gestural language*, developed at FDL IV, still continues to be critical. It’s perhaps the most common mistake of parents to focus on expressive language i.e., spoken words, at the cost of ignoring gestures. But in my play with Mack, Racer, and Black Sedan, I was vigilant about gestural communication—eye contact, facial gestures, waiting, movement, etc.—and conscious about keeping longer gestural interaction going. This is complicated stuff!

A new capacity is emerging: Jacob ‘gets’ joking around (but he won’t understand actual jokes or how to tell jokes for at least another year). He understands slapstick; he knows when you are being silly, and he knows when you are saying one thing and meaning another (‘Don’t you wake me up! O you woke me up!’).

Social skills like greetings and manners are emerging. He understands that you say ‘hi, bye, please, and thank you’ at certain times (though he doesn’t really understand the idea of ‘manners’ yet). And, with support, he can play simple pretend with others. He is definitely into FDL V.
Jacob has followed a path developmentally that has taken him beyond his autistic disorder. He’s no longer locked in his own world, impaired in his language and communication, isolated even from his own family. He’s now living in a shared world where life has meaning. Jacob, in short, has changed his diagnostic category from low functioning autism to high functioning autism. He still has an autism spectrum disorder because he still gets stuck in his topics of interest and he is still impaired in his social thinking.

His parents are amazed with Jacob’s gains and eager to take the next step along The Path. They want to know what to do next to help Jacob reach his full potential. They’re ambitious for Jacob. So am I. It’s been a long and demanding path, but there is still a distance to go; Jacob has to finish solidifying FDL V and move through FDL VI before he will be ready for kindergarten, our next major milestone.

Dad (with a sheepish smile): “I hate to admit it, but you were right. We had to start low and go high. These last two years really tested my patience. I wasn’t sure we were going to make it to this point. Waiting for Jacob was tough.”

Dr. Rick: “It wasn’t easy. You guys worked hard and really supported each other! And this is complicated work.”

Mom: “I thought he was going to grunt and point forever, but then the words started coming and now he’s talking constantly. Looking back, it was pretty quick.”

Dr. Rick: “Well, he had a few words when I saw you last, and it’s been about six months now. But when he was ready, he made the leap. I’ve seen it so many times. You guys did good.”

Dad: “Now he’s learning his colors, numbers, and even letter sounds. Watch this. Hey Jacob?

Jacob: “Looks right away (Duly noted!).

Dad (pointing to his nose): “What’s this?”

Jacob: “Nose.”

Dad: “OK Jakey, Whose nose?”

Jacob: “Daddy’s nose.”

Dad (proudly): “Good boy, Jacob. That’s right, Daddy’s nose. We’ve been working on that one for a while. And we’ve got those refrigerator magnet letters that make the sound when you push them. He and Charlie love those. He’s really learning his letters.”

Mom: “And he loves it when I read books now. It’s like he’s memorizing the words.”

Dad: “Like a regular guy. He even gets it when we talk in long sentences. . .”

Mom: “. . .especially if it involves going to McDonald’s for chicken McNuggets.”

Jacob: “Looks up as if to say ‘McDonald’s? Did someone say McDonald’s?’ (We all laugh)

Dr. Rick: “Better watch out what you say! It always amazes me to see this level kicking in. Now, he’s going to help you all the way. Now, he wants to learn; he enjoys being with people. Congratulations you guys!” It was a happy moment. Jacob’s affect had risen to a new level!

Summary

• Jacob Grant is moving up the path toward his potential. I summarize the journey he has made to this point.

• He has arrived at FDL V: Shared Meanings, the ability to understand meaning and symbols, a huge achievement in receptive language.

• His feeling life (The Path of Affect) has changed too. He wants to be with people. He wants to play pretend. He has entered the world of true imagination.
• Dr. Rick, Jacob and Charlie play real pretend together!

Coming Up Next
• As the visit continues, we take a detailed look at Jacob’s current profile
• I give the Grants techniques to help Jacob make progress toward FDL VI
• Dr. Rick helps Jacob (and his parents) handle a ‘meltdown’
• The boys and Dr. Rick sword fight!!
Chapter 14
Visit 7: Part 2
Imagination and Meaning: Jacob’s Profile

Jacob’s Profile
So I take the history of the last five to six months and what stands out are the gains in language and social abilities, though his parents’ main concerns have to do with behavior and toilet training.

Language. Jacob is now talking in short sentences, mostly of one to three words (mostly still one to two words) on average, but he sometimes strings a longer sentence together like ‘Go outside, daddy. Mommy, go outside. Swing’. He understands (receptive language) most of what people say to him, that is, if we keep it simple.

At my earlier recommendation, the Grants, in addition to their weekly occupational therapy, added some additional speech and language therapy for Jacob one to two times more per month for an hour each session from a private, local therapy center. Their speech and language pathologist (SLP), Karen, was play-based and fun but demanding. She emphasized to the Grants that Jacob had to ‘work’ at home on key language milestones through daily interactions through talking and reading books.

So now, the Grants are making demands on Jacob to answer simple ‘wh-questions’ like ‘What is your name?’ ‘Where is Charlie?’ or ‘Who is this? Grandma. That’s right.’ He can even point in a book to the ‘doggy who’s sleeping’ and the ‘doggy who’s eating’ indicating an understanding of verbs/actions. He ‘jumps’ on command. He points to his smaller body parts like chin and elbow and knowingly plays song games like ‘Heads, shoulders, knees and toes’. I tested him on a couple of these.

Dr. Rick: “Hey Jacob. Jacob. What’s your name?”
Jacob (shyly tilting his head down and mumbling): “Jacob.”
Dr. Rick: “Where’s your chin?”
Dad: “Sometimes it’s like pulling teeth.”
Dr. Rick (firmly, demanding but with a smile): Jacob! Where is your chin? Show me your chin!”
Jacob: Reluctantly, touches his chin.
Dr. Rick: “Good job, big boy.”
Dr. Rick: (To his parents): “Now that Jacob has reached FDL V, it is not following Jacob’s lead just to follow his lead. (They look at me quizzically.) If all we do is follow what Jacob wants without making demands on him that would be babying him. We are not going to help him that way. So, his true lead is expecting him to comply with what we know he can do. But we can’t be too challenging or we will lose him.”
Dad: “I see what you mean. We’ve been ‘following his lead’ since we started the PLAY Project and now it’s time to challenge him more. I get it.”
Dr. Rick: Just be careful not to overdo it. For instance, he’s still not going to be able to answer or ask ‘why’ questions, and he can’t recall the immediate past (‘what did you eat for breakfast?’). These are FDL VI language skills. So, he’s not there yet but let me try something here because I could be wrong. (I turn to Jacob) Hey Jacob. What did you have for lunch? Hey buddy, what did you have for lunch?”
Jacob: (Silence)
Mom: “I don’t think he understands what happened earlier in the day.”
Dr. Rick: “He’s just not there yet, but he will be. I would like you to start talking about what just
happened in the immediate past. I’d even put pictures or drawings of his meals on a bulletin board
and say things like ‘For breakfast, you had cereal. Remember Jacob? Cheerios! For lunch, you had
grilled cheese’. I want him to get a sense of time. Do you guys use calendars and schedules at
home?”
Mom: “Not much.”
Dr. Rick: “Well, I think it’s about ‘time’. Get it?”

Social Interaction. Socially, Jacob is ‘with us’ almost all the time though he still occasionally ‘fragments’
or go into his Comfort Zone when he’s playing with his favorite Thomas the Tank Engine trains.
Recently, he’s begun to draw and write his letters, which absorbs him and makes him hard to engage
sometimes. He’s not a bad little artist. Of course, he still loves the ‘Wiggles’. When he jumps on his
little inside trampoline (which his OT suggested) or swings on the outside swing, he can ‘go into a
trance’. But when his mom or dad calls his name, he turns nearly every time (or he hears you and
ignores!), no matter what he’s doing.

Jacob is playing with Charlie a lot and luckily, there hasn’t been a lot of sibling rivalry issues (see
Chapter 24: Siblings With Rivalry!) yet because Charlie is very easy going. However, more and more
lately, he’s not been letting Jacob take his things without a fight. I don’t say anything, but I can see
some sibling rivalry on the horizon.

Mom and dad play with Jacob (and include Charlie) a lot and report that they can join Jacob at any
time. He likes for them to play. Of course, they have become sensitive and responsive players, truly
joining him and not taking over. They know how to follow his lead and play at the just-right level
(after all this time in the PLAY Project, they better be good at reading his cues and following his
lead!). They know how to distinguish between his ideas and their ideas. His interactions are getting
longer and longer, and he is initiating all the time. In fact, he can be a pest and won’t stop asking for
what he wants until he gets it!

Pretend & Sense of Humor. His sense of humor is developing too. He loves to ‘sword fight’ with daddy
and Charlie with the soft ‘swords’ (actually pipe insulators) and laughs when daddy falls down after
he’s been hit and/or stabbed. He gets it! Mum doesn’t like such ‘violent play’, but I assure her that
acting out aggression is one of the best ways of learning how to handle aggression. It also teaches
the all-important difference between what’s real and what’s pretend. The boys especially like to run
from dad when he pretends to be a ‘Frankenstein Monster’ with arms straight out, stiff waddling gait
and low, growly, voice and says ‘Me going to get you’. The boys control him by telling him to
‘Freeze’!

As another sign of his growing sense of humor, Jacob is becoming impish, purposefully testing to
see what he can get away with, e.g., he turns the TV on when he’s not supposed to and laughs when
he gets caught. He also knows when others are joking by their tone of voice. When dad says, ‘Don’t
you give me a kiss! No kisses!’ Jacob will purposefully disobey and give daddy a kiss. Then dad will
mock reprimand him: ‘Hey you. No kisses!’ And Jacob will do it again.

Behavior, His parents need their sense of humor as Jacob has become progressively more difficult to
deal with. The Grants have worked hard to help Jacob become more functional but (watch out what
you wish for!) increasing function means having desires, ideas, and expectations of one's own. Jacob definitely has his own ideas. When he doesn’t want something to happen, it’s NO! But he wants what he wants when he wants it—and he usually wants it NOW!

This has led to problems getting him dressed in the morning (see Chapter 20: Jacob’s Terrible, Horrible, No Good, Very Bad Mornings), tantrums in the public places (see Chapter 21: Outings and Eating) like the grocery store (he wanted three bags of Halloween candy) and in the mall (he wanted to play on the playscape instead of going shopping), and struggles with getting him away from the TV and computer. And just to add insult to injury he was not yet toilet trained (see Chapter 23: Toilet Training), and he was night waking (see Chapter 19: The Stone in Your Shoe: Sleep).

Mom: “Between the tantrums, the sleep problems, and the morning routine hassles every day, I’m getting frazzled.”

Dad: “It’s constant and getting worse.”

Dr. Rick: “We’ve created an Oscar the Grouch Monster! But this is the work of Levels V and VI. He’s getting more complicated. That’s a good thing.”

Dad: “Easy for you to say.”

Mom: “We need a plan.”

Dr. Rick: “And that’s what we’ll do, make a plan.” (See Section III: Daily Hassles: Using Misbehavior to Help Jacob’s Emotional Thinking)

Mom (half joking): “Sounds great. When can we start?”

Dr. Rick: “We’ll talk some today, but figuring out what to do for each and every difficult situation is going to take some time.”

Dad: “But this is a sign of progress isn’t it?”

Dr. Rick: “He’s outsmarting his parents, isn’t he? I take that as a good sign.” (We all laugh.)

Dr. Rick: “But, mom, I hear you. I’d feel frazzled too. Jacob is hitting you guys from every side. I just want to convince you that this too shall pass. We have to set up a structure at home so Jacob learns to manage his impulses better. It’ll take a visit or two to set it up, but we’ll show him how to get what he wants (at least some of the time) in a more mature way.”

Mom: “That makes sense. I feel a little better knowing that we’ll have a plan of action.”

Peers. When it comes to playing with other children in his special-education preschool program, he’s still standoffish. According to his teacher, he wants to play with the other children but doesn’t really know what to do, so he stands on the outside looking in. For his parents this is sad news.

Dad: “So how can we help Jacob improve his social skills?”

Dr. Rick: “He’s learning the most important social skills at home: how to interact for a long time in a back and forth fashion and how to play pretend (see below in Techniques). You saw what he can do if you work at it the right way.”

The art and skill of being social with peers is coming along, but at FDL V, there is no hurry right now. He’s learning a lot from Charlie. He’s getting enough exposure to other children at his preschool four half days per week. He’s learning wonderful skills there like listening, sitting with the other children, doing fun tasks, complying with rules, and being with others in a group.

In summary, Jacob reached Functional Developmental Level V before his fifth birthday. In fact, he knew what a birthday party was because his brother Charlie had his third birthday two months earlier and Jacob’s was coming up. He couldn’t stop talking about ‘presents’. He also knew what he wanted—Mack the semi-truck and Lightning McQueen, just like the ones in my office. He had
watched *Cars* the movie too many times to count and ‘got’ the story. Jacob has lots of ‘shared meanings’ now.

**Office Meltdown!**

Just as his parents finish telling me about his recent gains, Jacob begins to whine. He has been playing with ‘Mack’ the semi-truck all this time when finally, and suddenly, he notices that the back set of wheels on the (well-used) truck are gone!

*Jacob* (whining): “Wheels. Wheels.”  
*Dr. Rick*: “He’s whining because the back wheels are gone.”  
*Mom*: “He’s starting to whine all the time. It’s getting really bad.”  
*Dad*: “When something isn’t the way he thinks it ought to be—watch out.”  
*Mom*: “He’ll meltdown for an hour sometimes.”  
*Dad*: “And scream the whole time.”

*Dr. Rick* (to his parents): “Broken expectations trigger upsets.” (To Jacob): “The wheels are missing, Jacob. No wheels.”  
*Jacob* (getting louder): “Wheels! No wheels!”

*Dr. Rick* (to his parents): “This is common FDL V behavior. He understands the way things *should* be, and if they aren’t, then he gets upset.”

*Mom*: “A lot lately. We’re not sure what to do.”

*Dr. Rick*: “I use a five-step method for dealing with frustrations, but Jacob’s starting to escalate, so let me demonstrate with him first, and then I’ll go through the steps. The first step is to acknowledge his feelings. This is very important.”

*Dr. Rick* (to Jacob): “You want Mack’s wheels (statement). The wheels are gone! (statement). Where are the wheels? (me speaking for Jacob).”

*Jacob* (nodding, calming a little, his face looking very disappointed and sad): “Where wheels?” And he turns his hands over so his little palms are facing up and he shrugs his shoulders with a very cute gesture that means ‘where did they go?’

*Dr. Rick* (to his parents): “Step two is reasoning.” (To Jacob): “Bummer, Jacob. The wheels are broken. Broken.”

*Jacob* (upset, yells with dramatic sadness): “No wheels. Mack. No wheels.”

*Dr. Rick*: “Where are those darn wheels, Jacob? Should we find them? Wheels, where are you?”
Step three is distraction. Apparently reasoning isn’t going to work (yet), so we go on a hunt for the wheels and look in the drawers, on the shelves, and in the toy basket. (I whisper to his parents that the wheels are gone, but we can look for them anyway to distract him and maybe help Jacob calm down in the process) I point out that, in the process of distracting him, we are also getting lots of circles of communication: Jacob is looking back and forth at me, and mom and dad as we look in place after place. Even Charlie joins in the hunt. But no luck. The wheels are nowhere to be found.

Mom: “Now what do we do? This type of behavior is happening all the time at home.”

Dad: “And worse and worse lately. He can go on like this for a long time.”

And indeed he does. The crying and yelling are escalating, louder, and more piercing. My staff later told me they could hear Jacob throughout the office that day. It’s been going on for five minutes now and showing no sign of stopping. You would think we were torturing him. He’s distraught. Processing his feelings (step 1), reasoning with him (step 2), and distracting him (step 3) aren’t working.

Mom (anxious): “Jakey you’ll be OK. You’ll be OK.” Jacob runs to mom and dramatically collapses into her lap sobbing and screaming.

Dr. Rick (laughing at Jacob’s ‘if I can’t find my wheels it’s the end of the world’ drama): “OK mom, let’s just ignore him now. Don’t talk to him. When you pay attention to this behavior, you feed the fire.”

Dad: “That’s what I tell her, but she’s such a softy; she keeps trying to make him feel better, but it seems to make it worse.”

Dr. Rick: “It’s hard to watch. He’s your boy. And he’s come so far. It’s hard to see him suffer.”

Mom: “It really makes me sad.”

Dad: “Well it makes me mad. Look at him. Screaming over a dumb toy. Jacob, stop it!”

Jacob keeps screaming and screaming. Charlie, to his credit, is apparently used to this and blithely keeps playing as if nothing is happening.

Dr. Rick: “OK. I know it’s hard. You’re both right. It’s sad that he gets so upset over nothing, and he should just let it go. But let’s just ignore him. That’s step four, ignoring.”

Message of Competence. Then, I help them take the focus off Jacob and explain that, now that Jacob has reached FDL V, he is getting smarter, has a newfound sense of time and expectation, and can now experience frustration and disappointment. This is the beginning of the process of developing control over his emotions, but for the next several months, his emotions are going to have control over him, and it will take a while—several months at least—for him to get himself under control. It’s very important to have faith that he will figure this out. We will feel your faith in him and gain perspective from you. Through our five step process, we will give Jacob a message of competence that says ‘I know you’re upset and frustrated, but this is not the end of the world. You can get yourself under control.’

Ignoring him gives him a message that you are not worried. When you pay attention to upsets over minor issues (like Mack’s missing wheels) you are giving him a message of incompetence that says ‘Oh you poor little boy. I feel so sorry for you. You can’t handle minor upsets. You are so frustrated and disappointed. I’m so worried about you.’

On the other hand, there is no need to get angry or rejecting. That gives a message of rejection that says, ‘I’m mad at you for not behaving’. We need to understand that this is a necessary phase of emotional development. He can cry if he wants to, but you’re not going to give it a lot of attention because it’s not that important.
So we ignore him and guess what? He escalates and starts throwing things. He wings a Matchbox car into the wall and chips the plaster!

**Dr. Rick** (in a loud clear bass voice): “Jacob, no! You may not throw.” I get up (with a nod of permission from the parents) and stop him by taking his hands and walking him over to his dad. He’s hopping mad now and clearly getting out of control.

**Mom:** “Welcome to our Jacob.”

**Dr. Rick:** “Welcome to step five: controlling him. When all else fails, you have to stop him from breaking things or hurting himself or others.”

**Mom:** “I’m so embarrassed.”

**Dr. Rick:** “Don’t be. I see this all the time. It’s really common at this stage. It’s a version of the terrible twos and threes even though Jacob is five. Let’s just get him under control and see how long he goes. The record is the whole hour!”

**Dad** (holding a struggling, screaming Jacob in a straight-jacket hold, Jacob’s arms held across his chest, body pinned between dad’s legs): “Jacob, stop it. No throwing.”

**Dr. Rick:** “That’s it dad. You told him the rule ‘No throwing’ and now tell him that you will let him go when he calms down and gets himself under control.”

**Dad:** “Jacob, calm down and you can play.”

**Dr. Rick:** “Perfect. Now, let’s ignore him until he calms himself down.”

**Dad:** “A guy at work also has a kid with autism like Jacob. He was a wild man like Jacob too—wouldn’t listen to a thing, tantrumming all the time. He went to a child psychiatrist who gave him meds and his kid’s doing much better. Do you think he needs meds to control all these behaviors?”

**Dr. Rick:** “They can be helpful and I use meds as part of my practice, but I’d like to see if we can help Jacob without them.” (See Chapter 22: Medications?)

**Mom:** “Don’t the medications have side effects?”

**Dr. Rick:** “They do. So if we can help him without meds that would be better.”

**Mom:** “As long as we can help him soon. I really can’t stand all this screaming.”

**Dr. Rick:** “You’ve got a tender heart for him, but remember to give him a message of competence. He can get himself under control.”

Jacob screams continuously for the next several minutes at the top of his lungs totally out of control. We pretend we can’t hear him and talk about his health.

**Dr. Rick** (almost shouting over the crying): “So, how is Jacob sleeping?”

**Mom:** (laughing a little at the situation): “It’s better since we’ve insisted that he sleep in his own bed. I still have to sit in his room until he falls asleep, but at least he’s not sleeping with us.”

**Dad:** “That’s progress.”

**Dr. Rick:** “That is progress.” (But I make a mental note that mom has to get up one to two times per night a couple of days a week to sit in Jacob’s room).

Jacob’s screaming slows down some and alternates with whimpering until he gets mad that he’s being held and then he escalates again.

**Dr. Rick:** “Dad, just tell him again that when he stops screaming and gets himself under control, you’ll let him go.”

**Dad:** “Jacob. When you stop screaming, I’ll let you go.”

**Dr. Rick:** “Perfect. Now ignore.” (Loudly) “So let’s talk about toileting. Once you reach FDL V, children are ready to understand the toileting process.”

**Dad:** “This boy is definitely ready.”
Mom: “He knows what to do, but he absolutely refuses.”
Dr. Rick: “Uh oh. That’s a tough one. What have you tried so far?”
Mom: “Everything. Praising, bribing, getting him ‘big boy’ underpants…”
Dad: “He’ll sit on the toilet. He doesn’t mind it. But he’ll sit for ten minutes and nothing. As soon as we put his pull up on—bingo he goes.”
Dr. Rick: “This is common. He’s used to going in his pull up.”
Mom: “We even got him ‘Cars’ underwear, but he just peed and pooped in them and didn’t seem to care.”

By this time, Jacob was finally quieting down. It had been almost fifteen minutes altogether of crying and whimpering over Mack the Truck’s missing back wheels.

Dr. Rick: “OK dad, let him go.”

Jacob runs to mom for hugs, and then it’s over. He looks at Mack’s missing back wheels and looks at me.
Dr. Rick (at the risk of starting things all over again, in a sad voice I say): “Bye-bye wheels.”
Jacob: “Bye-bye wheels.” He starts to cry again, but it’s more of a sad cry than an angry cry.
Dr. Rick: “I’m helping him finish up the process of his feeling life. I want him to re-experience his frustration only this time with more control. And he’s doing it. This is progress.”

This time Jacob’s crying only lasts a minute, and then he’s OK and starts playing with a puzzle.
Mom: “Whew. I’m glad that’s over.”
Dr. Rick: “Well, the next time it will be shorter and the next ten times after that it will be even shorter hopefully. Eventually, he will be able to handle most of his impulses in a mature fashion.”
Mom: “I hope so. He is wearing me out.”
Dr. Rick: “With this five step approach, we should see improvement within a week or two. You’ll know you’ve arrived when you feel fairly neutral as you go through this behavior plan.”
Mom: “I’m not there yet. I feel stressed, not ‘neutral’.”
Dad: “But, honey, now we know what to do. I wrote it down:
• Tell him how he feels
• Reason with him
• If he doesn’t get it, try to distract him
• If he won’t be distracted, don’t give him attention
• If he acts out, control him”

Dr. Rick: “By George, I think he’s got it. The whole point is to not let him push your buttons but see this as an opportunity to help him be a better emotional thinker. Mom, you’ll get there. And dad, the benefit of doing this without meds is that this is more permanent. When he gets it, it will be imprinted in his brain. With the meds, it helps in the short run, but in my experience, when you stop the meds, the problems can start all over again.”
Mom: “Can we finish up about toileting?”
Dr. Rick: “I’ll tell you what. The natives are getting restless. I’ll give you some information now to look over. Then, please give me a call and we can nail down the specifics. Sound OK?”
Mom: “Sounds good.” (See Chapter 23: Toilet Training)
The boys are starting to argue and get bored. I ask them if they want a (sugarless) sucker. Of course they do. I send them out to Amy, the receptionist, and they come back with suckers. They are happy and quiet for the time being. I talk into the audio recorder.

**Working with the Child at FDL V**

**Dr. Rick:** “So Jacob has come a long, long way, you guys! Up ‘The Path’ of functional development. I truly believe Jacob can be fully included in kindergarten by the time he’s six.”

**Mom:** “The school tried to push me for kindergarten but after our discussion the other week (See Chapter 12: Kindergarten: Ready or Not Here We Come) I told them I wanted one more year of preschool.”

**Dad:** “And guess what? They caved! I was really proud of her.”

**Dr. Rick:** “Way to go Julie! There are very few times in life when you get a chance to gain a year on your peers. This is Jacob’s chance. Jacob’s not ready for a full day of kindergarten (See Chapter 16: The Seven Habits of Highly Effective Kindergarteners).”

**Dad:** “But how do we get him ready?”

**Dr. Rick:** “The short answer is: Help him move from FDL V to FDL VI. Jacob should be an emotional thinker (FDL VI) with the ability and desire to understand others. He’s still very self-centered and that’s to be expected of a child at FDL V. We have to keep connecting ideas for Jacob so he understands ‘why’ and ‘when’ questions. But this takes time and know-how. This is complicated territory. Let’s stay focused on FDL V. He’s not ready for kindergarten yet, but I’m confident that in a year he will be.

“Let’s make a plan for the next several months. I want to emphasize some new strategies and techniques. Of course, Amber will help you with all of this too when she sees you for your next PLAY visit, and I’ll be keeping an eye on you through the video tapes.”

For a transcript of my commentary on Jacob’s Functional Developmental Level profile see the ‘Addendum’ at the end of this chapter.

**Techniques** (See also: Appendix F)

**Dr. Rick:** “OK. Let me finish up here by giving you some specific technique ideas. This is complicated work but you guys are getting it! I’m glad to see you’re using the techniques we talked about the last time like Mirroring Feelings, Speaking for his Intentions, and Going for Big, Little and Micro Circles, etc. They still apply. In fact it is still very important that you continue to . . .

- **Follow His Lead and Ideas.** I know this is a familiar and fundamental PLAY Project method. But now that Jacob can understand you, follow directions, and imitate, you will be tempted to teach Jacob skills like his letters, colors, and numbers and prep him for school. Teaching is not really PLAY unless it’s fun for Jacob. Always ask yourselves: *Whose idea is this?* It is still critically important, perhaps more than ever now, to honor, respect, and follow Jacob’s idea. He has lots of ideas! *Do nothing for a full minute*; just **wait** and see what he wants to do. Then, follow and join his idea (be with him and narrate). You can build on his intentions once you know what they are, and then you can use the techniques of playful obstruction or making him work or theme and variation.”

**Mom:** “It is tempting to do more teaching now that he can learn.”

**Dr. Rick:** “Don’t get me wrong mom. Teaching is OK as long as he is having fun with it.”

**Dad:** “He likes learning new things.”
Dr. Rick: “Just be aware of Jacob’s feelings. If it looks like he doesn’t want to do something, then say ‘Hey Jakey, you all done?’ Give him permission to stop. Recognize his feelings. Then follow him. Here’s an important idea:

- **When Jacob goes up—go up, but when he goes down—go down.** This goes along with following his lead. Don’t just play at the highest level. Don’t be afraid to follow his lead even if he goes down to FDL I. He may need to go to his Comfort Zone to get regulated and calm down. We all do this when we’re stressed or when we just want to ‘veg out’. When you go down, not only do you help Jacob regulate, you help him close the little holes at the lower three levels. So, for example, when he’s visually absorbed looking at his trains, with the intention simply to ‘look’ and enjoy the visual scene—join him there: ‘Look at those trains Jacob!’ Use the old ‘Rabbit Hole Techniques’. Interestingly, now that Jacob has better receptive language (i.e., he understands so much), you can also talk to him about his stimming: ‘Hey Jacob, stop stimming on Thomas and come to dinner.’ I call this technique meta-cognitive thinking—reflecting on what you are doing. It’s using his higher levels to help with his lower levels.

- **One Thematic Pretend Play.** At his current highest level, Jacob will be interested in thematic pretend play. Whereas FDL IV play was very simple and more gestural—Jacob puts a bottle up to the baby’s mouth or puts a phone up to his ear—FDL V pretend play is truly symbolic. The ideas are not simple actions but representations of real life and involve repeating certain activities along one thematic line.”

“Here’s a list of thematic play ideas. I know you guys are already doing some of these in your PLAY Project home visits but it never hurts to review:

- Feeding puppets, dolls, animals
- Going places with cars, trains, trucks
- Home themes: Have your little dolls eat, sleep, poop, pee, go to bed
- Doctoring: Giving shots is the best!
- Monster: I’m going to EAT YOU UP
- Being ‘bad’: ‘Don’t you turn off that light!’ Or ‘Don’t you wake up mommy!"
- Sword fighting (I’m a fan of the ‘dark side’)

“Feeding is a classic type of thematic play. So, Jacob feeds the puppet a pretend plastic pretzel, and the puppet goes: ‘Yum, yum. I want juice’. Then, Jacob gives the puppet juice. The puppet says, ‘Can I have a cookie?’ It tends to be the same theme with variations over and over. If you’re playing ‘doctor’: first, he uses the stethoscope, then he’s using the otoscope, then he’ll use the blood pressure cuff. Then, he’ll give you a shot...”

Dad: “And he won’t stop when he likes something.”
Dr. Rick: “That’s when you need your theme and variation techniques. What are five things I can do with the feeding theme or doctor theme that would be fun for Jacob?”
Mom: “Jacob absolutely loves it when I do what you did the last time and spit out the food and say, ‘Yuck, I don’t like pretzels!’"
Dr. Rick: “You spit out the food?! Mom, are you coming over to ‘the dark side’?”
Mom (ignoring me): “He loves it when I’m afraid of shots. He comes after me with a certain evil gleam in his eyes.”
Dr. Rick: “Whether you know it or not, you’re adding some cause and effect. You’re connecting ideas—a shot hurts. There’s another game I love called ‘Don’t wake up Daddy (or Mommy)’ where you
pretend to sleep and then he wakes you up and you say in a mock angry voice: "Jacob! Don’t wake up daddy!"

**Dad:** “We play that one and he loves being bad.”

**Dr. Rick:** “But FDL V play should NOT have a dramatic story line with a beginning, middle, and end. Like playing restaurant or pretending to be a doctor who makes somebody better. It would be too high for Jacob, and I’d bet he wouldn’t find it as much fun. I just don’t think he would get it, but he will eventually. This move from FDL V pretend to FDL VI pretend is complicated (See Chapter 15: Rich Pretend Play). In FDL V thematic play, it’s one theme with little variations. You’ll know you are doing it right because it will be fun and Jacob will want to do it again and again. I’ll show you some expert, Level V, sword fighting if we get a chance before we leave today.

“The toys I like for thematic play include:
- Dolls, puppets and stuffed animals
- Tea party cups, plates, pretend stove
- Doll house and/or farm house
- Pretend food
- Doctor’s kit
- Simple wooden blocks. Legos are OK

“You probably have most of these. You should still limit TV, videos, and electronics of all kinds to an hour a day, two at the most. Jacob should love play with these types of toys. Make it fun; make it silly, but then wait for Jacob to see what he comes up with.

- *It’s not following his lead to always follow his lead.* I know it sounds like I’m talking out of both sides of my mouth here but not really. I mentioned this earlier. The first rule is still to ‘follow his lead’. The second rule is ‘challenge him’ to listen, comply, finish tasks, follow rules, take turns, have manners, greet people appropriately, use the toilet, etc. I call this the ‘philosophy of can’. Ask yourselves: ‘Can he do it?’ If the answer is ‘Yes, it’s within his ability’, then you should expect him to do it and support him. He should clean up his mess. He should greet Grandma and Grandpa at the door. He should listen to you when you ask him to do important daily activities (get dressed, brush your teeth, etc.). Kids at this level are still pretty independent and flighty. They still ‘do their own thing’. You will have to repeat and explain yourself. He may resist your demands. That’s OK. Turn the resistance into a discussion or friendly argument. Use the technique I call ‘tussling’.

- **Tussling.** This is a wonderful technique and given Jacob’s recent stubbornness, I’m afraid it’s a technique you’ll use a lot. You use tussling whenever Jacob doesn’t want to do something that he has to do—like brush his teeth or stop watching TV or clean up a mess. You know how a dog loves to growl and tug when you try to take away its balled up sock? It’s like enjoying an argument. ‘O yeah?’ ‘Yeah.’ ‘O yeah?’ ‘Yeah.’ This is what I call tussling, engaging in the tug of war itself and enjoying the process of arguing back and forth, but it has to be done right. There has to be a sense of humor about the process.

“You will always start with reflecting feelings (‘You don’t want to stop watching TV’) and then giving reason (‘But Jacob, it’s time for dinner so the TV has to be turned off’), but if those don’t work, then you get into the tussling. For example, just imagine this tussling scenario:

**Mom:** “Turn off the TV. Jacob, it’s time for dinner.”

**Jacob:** “TV on, Barney!” (‘Barney’ is the kids’ show with the purple dinosaur).
Mom: (using a statement, not a question): “You want to watch Barney.”

Jacob (firmly): “Watch Barney.”

Mom: “But, Jacob, it’s dinner time and Barney is all done.”

Jacob: “No dinner time.”

Mom: “Yes dinner time.”

Jacob: “Barney.”

Mom (jokingly grabs his hand and pulls firmly but without force): “Come on, Barney’s over.” In a silly voice, “All done, Barney. Bye-bye Barney.” (Pulls his hand and gives him a squeeze.)

Jacob: laughs.

Mom: “Come on. Let’s eat. Get on my back, and I’ll give you a horse back ride to dinner.”

Jacob relents, gets on mom’s back, and off they go into the sunset.”

“There are lots of benefits to *tussling*. First, it helps you keep a sense of humor. You don’t have to win (right away); you just have to keep the argument going. Second, you are generating a long interaction with lots of circles. And third, you are getting Jacob used to the idea that you are not going to let him ignore you, break a rule, or get away without finishing up an activity (you are getting him used to the *change* you want. See Chapter 18: Dr. Rick’s 20 Transition Tricks for examples).

• **Social Etiquette:** Negotiating the relationship. Closely related to tussling is ‘negotiating the relationship’. If I just got up and walked out of my office suddenly without saying a word, you would think something was wrong or that I was rude. You expect me to *negotiate the boundaries of my relationship* with you, to say something like ‘I’ll be right back’ or ‘Excuse me’. We expect that people will acknowledge our social bond by commenting on it. We always say ‘hello’ and ‘goodbye’. And yet we let Jacob get away without negotiating the relationship all the time. Now, it’s true that even typical children between ages two and three years old (FDL V) aren’t aware of social etiquette. But children with ASD need to work on this aspect of relationships more than typical kids. All I want you to do is *comment and insist on a response from Jacob*. When he walks into a room say, ‘Here comes Jacob. Hi Jacob’. And then insist that he says ‘Hi’, or at least gives you ‘five’. When he leaves, say, ‘Bye Jacob, see you later. Bye Jacob’ or ‘Where you going?’ And don’t forget to model for him by saying things like ‘I’ll be right back’ or ‘Wait, I have to get something’.

• **Modeling.** We now expect Jacob to be able to imitate or model after us, so let’s use this new ability of his. We will use a *doll to model toileting*. We will take turns by going around in a circle to model song games, music, or silly behavior. We will model social etiquette skills and skills of daily living (getting dressed, brushing teeth, eating with silverware). I just want you to be aware of how powerful imitation and modeling are. You can even videotape Jacob or Charlie doing something well so they can watch themselves and even model after themselves! Very powerful.

• **Language.** We need to get some extra language therapy to help with Jacob’s dramatically increasing language skills. I’m not an expert, but here are my main recommendations.
  o Jacob loves to *label* so label important objects and actions. Look Jacob, the *moon*.
  o Focus on the simpler *‘wh-questions’—What, Who, Where*—so he can label things.
  o Now that he’s into reading, let’s focus on *verbs*—‘Show me the cow who’s eating. Where’s the cow who’s sleeping. Nite-nite cow.’ Notice how we slip in some one-step commands?
  o When we’re reading, let’s focus on *the story on the page*—‘Oh no, Thomas the Tank Engine is going into the tunnel. It’s dark!’
Let’s talk about definitions. ‘It’s dark. Can he see? No! It’s dark’.
We slip in some ‘yes and no’ questions.
You should use examples to explain meanings. Turn off the lights and say ‘It’s dark’. Turn on the lights and say, ‘It’s light again’! Be dramatic. Use opposites.
A good SLP (Speech and Language Pathologist) will help you with prepositions, choices, plurals, pronouns, and higher level ‘wh-questions’.

**Sword Fight!!**

**Dr. Rick:** “OK. That’s it. Let’s finish up (I start singing the famous clean up song). Clean up, clean up, everybody clean up. Who wants another sucker?”

**Charlie:** “Me!”

**Jacob:** “Me.”

**Dr. Rick:** “OK. Let’s clean up, and then you can have a sucker. Jacob, you put the trains in the basket (I model). Charlie, you put the doctor stuff in the doctor’s box.”

The boys clean up nicely and head out to the front office to get their suckers. This is my chance to see how Jim and Julie are doing.

**Dr. Rick:** “So how are you two feeling?”

**Mom:** “Overwhelmed as usual. It’s like you get to one level and then there’s another and then another. And it’s getting more complicated at these higher levels. It’s like it never ends.”

**Dr. Rick:** “This is complicated work and it is never ending it seems…”

**Dad** (interrupting): “But it’s paying off. Jakey is doing so well! I love the detailed guidance and as long as we have a plan we’ll do it.”

The boys return. I whip out my ‘swords’—black, three-foot long, foam pipe insulators, which I got at the hardware store for 99 cents apiece.

**Dr. Rick** (to mom and dad): “Mind if I do a little sword fighting before we go?”

**Dad:** “Go for it.”

**Mom:** “Great. Get them all over-stimulated for the car ride.”

**Dr. Rick:** “En garde!”

I give Charlie a ‘sword’. He takes it. I offer Jacob one and he takes his. They are a little shy. So I stand there holding my ‘sword’ out and take a sword fighting stance. Then, I sing the *Raiders of the Lost Ark* theme song, and the boys look at me like I’m some kind of nut. I gently hit their swords with my sword.

**Dr. Rick:** “Ch-ch-ch.”

Charlie hits back. Jacob joins in next. We tap our swords against each other. Then I escalate a little and hit harder and say “boom” with each hit.

**Dr. Rick** (I hit Charlie on the shoulder): “Gotcha!”

**Charlie:** Hits me.

**Jacob:** Hits me.

**Dr. Rick:** “Ouch, ouch. O yeah?”
And that was it. They think this is the best game. There is a free for all of sword fighting that would have made Indiana Jones jealous. They smack me until they 'got me' and I collapse in the chair.

Dr. Rick: “Let’s get daddy.” And we all turn on dad and pepper him with harmless smacks of the sword. “We got him. OK. OK. You guys win. Go get your suckers.”

While the boys are running out, I congratulate mom and dad again for all of Jacob’s progress and encourage them to ‘Hang in there’.

Dr. Rick: “We’ll get Jacob’s behavior problems under control. Let’s plan on seeing you at the next available visit.”

What an intense visit! I feel like I’ve been beaten to death in a sword fight! But, as I walk out of my office playroom, I know Jacob is on The Path, and I get a little thrill just imagining how much progress Jacob will make over the next six months. This boy is going to be ready for kindergarten!

Summary
- Jacob is much more ‘with us’ and can now open and close lots of circles in a row to the point where, at least sometimes, there is a continuous flow of interactions. The autistic veil continues to thin. He fragments less; he goes into his Comfort Zone less. He wants to play with people!
- He communicates mostly with gestures but has a bunch of single words, AND he is following one step spontaneous commands like ‘Get me that ball, Jacob’. That’s huge.
- Simple pretend is emerging too, which is a great sign that his ‘feeling life’ is progressing too. He’s not happy just doing repetitive behaviors any more.
- He’s smarter socially, more aware, and starting to have more organized feelings. He’s starting to complain and whine. He’s pushing Charlie around and won’t share. We’ll need to talk about this soon, as the parents don’t agree about the rules.
- I give a 5-point plan to the Grants to help Jacob with his feelings.
- I listed a few techniques to help Jacob solidify his functioning from Levels I through IV.
- I am now optimistic that Jacob has turned the corner on FDL V, Shared Meanings, and FDL VI is emerging! (See Addendum below)

Resources & Websites

Websites

Books

Coming Up Next
• Will Jacob move more solidly into FDL V and move into FDL VI? Rich pretend play is the secret. Julie and I go through a detailed approach to working at the higher pretend levels.
• Problems with behavior get worse including not listening, aggression, sleep issues, toileting problems, and sibling rivalry.
• The Grants are thinking about next year’s school placement!
Addendum: Jacob’s FDL Profile

Hi Jim and Julie. This is Dr. Rick giving you some feedback on Jacob’s FDLs. Amber shared his video with me and here’s my take:

FDL I—Shared Attention and Self-Regulation: 75-100% Solid for Shared Attention but worsening Self-Regulation. The last time, Jacob was ‘with us’ most of the time, but now, he’s with us almost all the time. Now, his shared attention turns into long engagements and interactions. He still can lose the thread, but you guys are doing an awesome job of waiting for him to reconnect before you move on. He still has his Comfort Zone activities (trains and now books and letters, and jumping) and fragments (breaks off engagement) occasionally, but that hole is closing. He’s less rigid and the autistic veil has thinned to the point where he now chooses to tune us out—the little stinker!

By being tuned out or negative he is trying to control and regulate his world. But not only is getting upset immature, it doesn’t work very well. We want him to tell us (rather than yell, tantrum, hit, etc.) how he feels and what he wants. We want him to use symbolic solutions. I call it good negative behavior. There are ways to be negative that are good. We want him to start thinking more and reacting less. Using words is the high road to self-regulation and self-control (See Chapter 17: The Good, The Bad, & the Ugly). That’s what mature people do. We react emotionally, recognize our feelings, think about them, problem-solve, and resolve them. Then, we feel better without smacking people. You can go to jail for that!

Recognizing feelings is the first step to managing feelings. I love the way you are labeling Jacob’s feelings and recognizing his intentions. This will help Jacob’s behavior and self-regulation more than any other technique. It feels good to be understood, doesn’t it?

You are also explaining events and interactions; you are reasoning with him. You’ve still got to keep it simple, not over his head, but keep it up. Jacob needs to understand how he can get what he wants by talking and negotiating, not by crying and throwing a tantrum. This is the second most important method for helping Jacob control himself—explaining and reasoning.

Even if you do these things, in the short run, he’s still going to misbehave like he did in my office (remember Mack’s lost wheels?). He’s going to have poor emotional self-regulation for a while, which is to be expected. It’s the terrible twos at age five. It may be painful, but this is a sign of real progress. He understands so much more; his desires have become stronger; the blinders are off and the world, including his world of impulses, is overwhelming for him. This leads to poor impulse control and dysregulation. He now has true behavioral problems with hitting, disobeying, and throwing tantrums. I got to see this first hand. We’re going to get this boy regulated again, but it’s going to take a steady, consistent ‘iron fist in the velvet glove’ approach. That is, we have to be kind, sensitive, responsive and...tough. Clear about the rules, consistent in enforcement, and tough. We want to give him a ‘message of competence’. Over time, his impulsiveness and bad behavior will go down, and his understanding and good behavior will go up. We are going to talk a lot more about behavior in the next visits (See Section III).

FDL II—Engagement: 100% Solid. We can engage Jacob all the time when we want to. He may not like it and he’ll terminate engagement, but this is also engagement! In fact, this is the new challenge—can Jacob stay engaged even through strong emotions and when he’s challenged
intellectually? Can he use his words to disengage? Can he negotiate relationships rather than just break off or fragment? I hope those techniques we talked about are helpful—I don’t want him getting away with ignoring you when you talk to him about important things. Now, it’s not just about simple engagement but more about staying engaged for a long time in his relationships with others.

**FDL III—Simple Two-Way Communication: 75-100% Solid.** Jacob’s two-way back and forth abilities have really jumped here. You know he’s almost continuously aware, and he’s listening all the time (when it’s important to him!). As you say, he wants what he wants when he wants it—and he wants it NOW! This shows a lot of initiation. What I love about Jacob’s Level III is that he’s able to open a lot of circles (i.e., initiate interactions), and he closes most of the circles (if he wants to). As you saw in our play with Mack, and I can see in his home videos, he’s still having trouble initiating at higher levels of play, which is why I’m not giving him 100%. So, go slower when playing at higher levels (FDL IV and V) and give him time to process information, then he’ll initiate more.

**FDL IV: Complex Two-Way Communication: 75% Solid.** Now, here’s the big news. Since the last visit, Jacob has solidified Level IV, which is to say he’s becoming his own person in a world of people. He’s truly problem solving. For instance, he knows how to get your help to get what he wants. He hits Charlie and goes after him when Charlie takes his toys. Not that I like that kind of behavior, but you’ve got to admire his problem solving. We’ve got to teach him a better way, that’s all. He’s got his routines down solid and can follow one- and two-step commands like a champ. And much of the time, he can interact for many circles (if you include gestures) in a continuous flow, but he’s not completely solid here. We still need to wait for him to fully connect. This will fill in those little (interactional) holes.

For the first time, Jacob is using his imagination. This is a hallmark of FDL IV—simple pretend play. Yay! What’s more: he can also imagine the way things ought to be and when they aren’t, he gets upset as ‘The sad saga of Mack and the lost wheels’ proved. Poor guy was really disappointed. Jacob’s emotional vocabulary (like being ‘disappointed and sad’) is expanding. Double ‘yay’!

**FDL V—Shared Meanings and Thematic Play: 50-75% Solid.** This is Jacob’s cutting edge. Not only is his emotional vocabulary expanding, but his language vocabulary is expanding too. We have to make sure Jacob understands what we are saying. Here’s where the speech and language therapist can help you out. Here is also where ABA therapy makes more sense.

So much of FDL V is about receptive and expressive language. Jacob is still struggling with open-ended ‘wh-questions’. So I want you to ask him: ‘Jacob, what are you doing?’ If he doesn’t answer, you can model for him by saying: ‘Oh, you’re playing.’ I want you to lay down the track of language, so to speak. Model for him and repeat yourself. Close all symbolic circles. Don’t let him ignore your overtures.

Talk a lot and especially read stories. I think you can really read them now and not just describe the pictures. Jacob will understand the story on the page, and if you summarize a lot, he’ll start to understand the story in the book too.

Finally, I want you to do a lot of fun, thematic play. Swords, chase, monster, pretend feeding of puppets, cars crashing, etc. Song games are going to be more meaningful, like ‘The Wheels on the Bus’ (I shouldn’t mention wheels!). Sing all the time! Oh yes, and don’t forget to be silly and joke a lot.
FLD VI—Emotional Thinking: 25% Solid. Congratulations. Jacob is reaching his hands up, so to speak, to FDL VI on the developmental ladder. He’s just beginning to be an emotional thinker and connect cause and effect. He’s not there yet, but I always like to preview coming attractions (See Appendix D for FDL VI summaries).

FDL VI is more than just being able to answer ‘why’ or ‘when’ questions. As Greenspan says, it’s about ‘bridging ideas together’, connecting ideas. So, for example, when you make logical connections: ‘Jacob, we can’t go outside. It’s raining. You’ll get wet.’ or ‘I’m hungry. Let’s eat’, you are connecting ideas together. You’ll know he’s there when he can answer the question: ‘What do you do when you’re hungry Jacob?’, which he can’t do yet.

We will help him connect ideas by drawing out the consequences of his actions: ‘When you take your brother’s toy without asking it hurts his feelings. He’s sad’.

You can help him by being aware of social ideas. I introduced the idea of ‘When you meet someone, you say hello’ and ‘When you leave someone, you say good bye’ while we were playing with Mack, Racer, and Black Sedan. After a while, he’ll make the connections and be able to do greetings and good-byes because he understands ‘manners’. This is a FDL VI achievement. He’s not there yet, but if we keep showing him how to make the connections, he’ll get it. Get it?

The royal road to FDL VI is through pretend play with two themes, i.e., the play has a story, not just a simple racing around the floor but racing to win, or going to Mack’s house and having something to eat with his friend Lightning. Jacob’s not there yet, but he’s going there.

Also, connecting time to events will help him move up. I want you to talk about ‘the eggs he had for breakfast’ and ‘the store we’re going to so we can buy groceries’. I want you to point out sunrise, moonrise, and sunset and show him pictures about waking up, eating, and going to sleep. You’ll know he’s well into FDL VI when he can answer the question: ‘What did you do today at school?’ He’s not there yet.

Don’t push the river. Stay mostly at FDL V, as open-ended ‘wh-questions’ are the highest level for him. One theme play should be fun. Read fun books, talk throughout the day, argue, and enjoy resolving conflict. Help him understand as much as he can by using repetition, pictures, and saying things in different ways.

That’s it. Jacob is doing great. And so are you. You are amazing parents. Keep up the great work. It’s paying off.
Chapter 15
Visit 8
Rich Pretend Play

Pretend Play
Pretend play is one of the hallmarks of childhood. Yet, very few interventions for children with autism truly promote it. For children like Jacob Grant, pretend play is the bridge that helps them cross over from simple interests to complex functioning, social sophistication, and true peer play.

When a child with autism can pretend...• That because the baby is hungry, her mommy or daddy feeds her;• Or that a car wants to win the race and beat the other cars;• Or that the teddy bear wants to play with his friend the lion so he’s not lonely;we are helping him or her imagine what others are thinking and feeling. This is empathy, the most important social capacity of all—being able to consider the other person! Pretend play leads to creating stories and making jokes, knowing whether someone is serious or ‘just pretending’. The ability to use our imaginations is what makes us fully human. When children with autism become truly creative and begin rich pretend play, it is a joyous event.

Background to this Visit
During the last visit, I was excited to see that mister-five-year-old Jacob had progressed to the point where he could understand the simple ‘what’, ‘who’, and ‘where’ questions; he could answer ‘yes’ & ‘no’; he pointed to action pictures (“Where’s the doggy who’s sleeping, Jacob?”) in a children’s book; he followed one-step commands; and he had a slap stick sense of fun. Jacob ‘got’ simple one-thematic pretend play (See Chapters 13 and 14).

But there were still clear limits to his development. Emotionally, he was still driven by simple needs and desires. He primarily used others selfishly to get what he wanted. Though affection, empathy, and understanding for those closest to him were emerging, Jacob was still very self-centered, impulsive instead of thoughtful, demanding, and often dominating—everything had to happen on his terms, all of which caused a number of behavioral problems (See Section III Introduction: Jacob Grant—Pain in the Butt!).

Understandably, Jim and Julie want Jacob to move to the next level—Functional Developmental Level VI—where he could:
• Become aware not only of his own but also of other people’s feelings (i.e., become a true emotional thinker)
• Understand causation (i.e., ‘Why’ questions and connect two ideas logically together)
• Understand time (i.e., ‘When’ questions; recall the past, anticipate the future)
• Play well with his peers at school
• Be better behaved at home

There was a feeling of foreboding in the Grant family. Kindergarten was right around the corner! (See Chapter 16: The Seven Habits of Highly Effective Kindergarteners).
But since the last visit, four months ago, Jim and Julie Grant had had a hard time ‘taking Jacob to the next level’. Amber, their PLAY Consultant, reported, for example, that they were struggling with pretend play by playing too high. I thought to myself “The way to ‘take Jacob to the next level’ is to join him at the ‘just right level’ and he'll move up naturally.” But for many parents joining the higher level child at the just right level is complicated work. In this visit we do a close analysis of Jacob’s profile, support mom’s PLAY at the just right level, and work on moving Jacob up into higher realms of FDL V.

**A Pretend PLAY Session**

With this background in mind, I go out to get Jacob from the waiting room. He greets me with a high five and flashes some eye contact, but when I ask him how he's doing (an open ended ‘wh-question’ having to do with recalling the past and understanding casual social conversation), he ignores me. I note this gap in his social skills but keep talking to him naturally at a fairly high level.

*Dr. Rick:* “So, Jacob, you ready to play?”

*Jacob* (nodding): “Yes. Play Mack-the-truck.”

*Dr. Rick:* “O yeah, I still have my ‘Mack-the-truck’. And Lightning McQueen too.”

*Mom* (following us toward the play room): “He's been talking about that truck since the last time. His memory's amazing.”

*Dr. Rick:* “That was a five-word sentence!”

*Mom:* “He's becoming a real talker. Comments on everything and tells everybody what to do.”

*Dr. Rick:* “Come on in, Julie. That's really great. Where are Jim and Charlie?”


*Dr. Rick:* “If you don’t mind, I'll record our visit for dad. Without Charlie, we'll have a chance to focus on Mr. Jacob.”

Jacob takes my hand (!) and pulls me off of my chair and onto the playroom floor, immediately going to Mack the big red semi-trailer truck, which is in the big box of toys. Mack’s sides open up to reveal a luxurious car suite (with TV, plush bed, fridge, etc.) for none other than Lightning McQueen, the racecar. But Jacob cannot find Lightning McQueen. I wait for him to figure out that he needs my help, and it doesn’t take but a few seconds when he looks at me (opening a circle) and then asks (opening a second circle) . . .

*Jacob:* “Where Lightning Queen?” Then in a more urgent, demanding voice, “Where Lightning Queen?”

*Dr. Rick:* “Hmm. Where is Lightning McQueen? Hmm. (I stretch out the interaction a little looking around the room then say. . .) Look in that drawer in that table over there, Jacob, the yellow drawer. I think it's in there. (To mom) The boy can be demanding!”

*Mom:* “Tell me about it.”

Jacob, without hesitation, follows this two-step command, goes to the yellow drawer in the table and, to his delight, finds Lightning McQueen, the hero of the animated movie ‘Cars’. A big proud smile lights up his face.

*Dr. Rick* (to Mom): “Did you see how he problem-solved that? I didn’t prompt him to ask me for Lightning. And no problem with spontaneous two-step commands, knows his colors, and he’s pretty pleased with himself. This boy is definitely putting ideas together.”
Struggling with PLAY. As we begin Jacob’s routine quarterly review, my plan is the usual: get history, talk about his language gains, social interactions, OT and SLP therapies, and behavioral issues, etc. But it turns out that Julie is feeling a little insecure about doing rich pretend play. So I change my plans and ‘follow her lead’.

Mom (with an embarrassed look): “I think I’m not creative enough to play with Jacob the way Amber (the PLAY Consultant) does. She makes it look so simple, but I can’t come up with enough play ideas or I play too high.”

Dr. Rick: “Sounds like you’re putting a lot of pressure on yourself.”

Mom: “I feel like I’m either pushing him too much or I just don’t know what to do.”

Dr. Rick: “How about rough housing. That’s always a great place to start.”

Mom: “Oh, I’ve joined ‘the dark side’, Dr. Rick. The sword fighting is daily. I chase after the boys screaming like a banshee. I eat ‘em up with puppets. I give horsey back rides until my back is sore. Maybe I’m just getting a little greedy.”

Dr. Rick: “You want to know how to expand the play upward.”

Mom: “Right. I want to get into real pretend play. I think he’s ready.”

Dr. Rick: “How are he and Charlie doing that way? Charlie’s what, almost three? He and Jacob are buddies I bet.”

Mom (somewhat sadly): “Charlie’s pretend is amazing, better than Jake’s.”

Dr. Rick: “That’s hard to see isn’t it? I’m sorry.”

Mom: “That’s OK. Jacob’s had a great year, and I should be happy with that.”

Dr. Rick: “It’s OK to be both sad and happy. That’s one of the things I really admire about you Julie. You let it all in.”

There is a pause of acknowledgement both of how far Jacob had come but also that, in some developmental areas, Jacob’s little brother Charlie was passing him by.

Mom: “Charlie’s starting to make friends, and it’s hard to watch Jacob struggle socially.”

Dr. Rick: “But that’s exactly where a younger sibling can be a big help. He can show you how to have fun, model pretend play, and he can be a play partner for Jacob.”

Mom: “These days, it’s more fighting than fun and friendship.”

Dr. Rick: “That’s all good too (Mom gives a look like ‘easy for you to say’). Maybe we’ll get to sibling rivalry and play dates later (See Chapter 16: The Seven Habits of Highly Effective Kindergarteners and Chapter 24: Siblings With Rivalry!). But, come on, let’s play a little...”

Review of PLAY Strategies

Mom (hesitating): “When I’m in the middle of the play, I feel lost a lot, so I ask a lot of questions and Amber—you know how sweet and kind she is—is hinting that I shouldn’t be asking so many questions.”

Dr. Rick (joking): “PLAY shouldn’t be such hard work! As the kids get older and more complex it’s easy to forget the old PLAY strategies. So let’s take this step by step.

“The five main methods are:

- **Being with Jacob** to (1) Read his cues and truly (2) following Jacob’s idea, intention, and lead;
- **Going for Circles** (3) to increase back and forth interactions;
- **Playing at the right level** (4) so it’s fun but also challenging (i.e., in Jacob’s Zone of Proximal Development); and
• *Wooing Jacob upward by expanding* on his idea (5).

Parents have the most trouble with this last step, but I’ll teach you some cool tricks to make it easier.”

**Step 1: Being with/Joining.** So I remind Julie of the first principle of the PLAY Project—to have ‘fun with people’ and keep fun and playfulness in the front of her mind. What I do is literally ask myself:

- *What would be fun for Jacob?* and the answer comes to me, usually something physical and silly. It’s almost always good to start with sensory-motor play.
- The next thing is to feel free to do nothing.
- Put on your Zen head (just be with Jacob) and observe him.
- Pay attention to his attention and
- Pay attention to his intention in order to connect in the moment.
- In other words, *tune in to Jacob.*

**Mom:** “I’m pretty good at doing nothing (laughs) and joining, but *how do I build on Jacob’s play?* I worry that it’s not going to happen naturally. Maybe that’s what makes me want to take over.”

**Dr. Rick:** “Exactly. You have to have faith in Jacob’s imagination and be willing to take the risk that things won’t go the way you want them to.”

**Mom** (joking): “You know how I like to have control.”

**Dr. Rick** (joking back): “Who doesn’t? So let’s control in a way that isn’t too controlling. *And just remember: If you’re lost, do nothing, wait, and read Jacob’s intention.* Then ‘woo’ him upward by expanding on what he intends, his idea. The biggest mistake parents make is playing too high by introducing their own ideas. This is not about how creative you are. You can always tell when parents are playing too high because the child usually tunes out and the flow of play is interrupted.”

**Mom:** “Yes. That’s exactly what happens. Jacob just kind of drifts off or doesn’t answer. His head goes down.”

**Dr. Rick:** “It’s good that you notice. Always ask yourself: ‘Whose idea is this?’ Jacob has lots of ideas now. Most of his ideas are at FDL V, but I’ll bet he can get to Level VI. Let’s just join him and I’ll coach you as we go—if you need it.”

**Mom:** “I’ll take all the coaching I can get, but one thing I’m good at is joining and getting circles.”

Jacob is getting more cars from the yellow drawer and putting them in groups.

**Mom:** “I think he’s creating a scene from the ‘Cars’ movie where all the cars are in a parking lot. He does that a lot. I’m not sure if he’s lining up or pretending.”

**Dr. Rick:** “He uses the movie as a script?”

**Mom:** “Right. His play kind of gets stuck doing what the movie does, but he talks for the cars. That’s when I don’t know what to do.”

**Dr. Rick:** “Maybe that’s his Comfort Zone, doing the same scene or same game over and over, but it could be real pretend. My best advice is that if he goes down into his Comfort Zone, you go down too. *(Make sure you watch the movie!)* If and when he goes up into pretend play, you go up.

**Mom:** “How do I know which is which?”

**Dr. Rick:** “When his head is down and he’s absorbed visually; when he’s not looking at you, not referencing you, mostly ignoring you, I think you can safely assume he’s in his Comfort Zone.”

**Mom:** “Then what do I do?”
Dr. Rick: “First, notice that he’s gone down. Then, I’d use the ‘Rabbit Hole Techniques’ (See list below) you learned a long time ago. They are not just for lower functioning kids because all kids on the spectrum will ‘disappear down the rabbit hole’ some of the time.”

Mom: “I used to use those all the time. I just have to remember to use them. There are how many?”

**The Six Rabbit Hole Techniques**

- Being with; see exactly where he’s at
- Narrate with feeling the child’s behavior and/or intention
- Help him do it better
- Parallel play what he is doing; imitate him
- Use theme and variation
- Change the sensory mode

Dr. Rick: “Six. And the first one is to just be with him and the second one is to ‘narrate’—just simply mirror back to him in words—what he is doing in the form of statements. So let’s sit on the floor and tell Jacob what he’s doing. I’ll coach as we go. I’ll try not to interrupt the flow.”

Jacob is driving his cars to form a group and lining them up in rows.

Mom: “What are all the cars doing Jacob?”

Dr. Rick (coaching quietly): “That’s a question; make a statement and be a mirror to what you see. Questions pull the children out of the flow of play. That’s why questions are not good.”

Mom: “Oops, sorry. I have a real problem with that.”

Dr. Rick: “Very common. Describe what you see and what is happening—with feeling!”

Mom: “Just look at all those cars! (Mom takes her car) Here comes another one.”

Dr. Rick: “That is a statement. Yes!! (We slap five). Now, add a little drama by acting like an announcer ‘He-e-e-e’s going into the parking lot!’ and don’t forget some onomatopoeia.”

Mom: “Onomato-what?”

Dr. Rick: “Onomatopoeia. It’s a term you learned in English class. It means that the sound of the word sounds like what it means. Like ‘vroom’ is a word that sounds like a car going fast, or ‘putt-putt-puttt-putt’ sounds like a car going slow. Think of it as narrating sound effects.”

Mom (drives her car over to the other cars on the ‘parking lot’ making a low motor sound): “R-r-r-r-r. Here I come. . . into the parking lot. I want to come in.”

Dr. Rick: “Perfect, mom. Now wait. You’ve created a problem for Jacob. Will he let your car in?”

Jacob (gives her a knowing look and with a very nice tone and rhythm says . . .): “Come in, car.”

Dr. Rick: “That was his response to your idea. You’ve gained entrance!”

**Step 2: Going for Circles.**

Dr. Rick: “OK, now let’s think circles.”

Mom: “After almost two years in the PLAY Project, that’s my specialty.”

Dr. Rick: “I know I’m putting you through the paces, but I want to be systematic. The details matter in this kind of play. It seems complicated but when you’re doing it right, it’s fun and natural.”

Julie drives her car zigzagging in a crazy way like a chicken with its head cut off saying “Rum-rum”, then she waits (the secret to getting circles). Jacob laughs and thinks she’s funny. She and Jacob share some eye contact and a smile (opening some micro-circles).
Mom: “Where do I go, Jacob? (Waits, brings the car up to Jacob’s face and gets a humorous look from Jacob) Rum-rum. Where do I go? (Waits and gets more eye contact. Then upping her affect and acting very frustrated, she says in a louder voice) Hey Mr. Parking Lot Attendant, where do I go?”

Jacob (laughs at her frustration and points): “Here. Go here.”

Mom: “I’m looking forward to the race, are you?”

Dr. Rick (coaching, whispering): “Good job being the car. But that last comment about looking forward was too high. Notice how he ignored you. Keep the pretend conversation more at Level V.”

Mom (in a deep car voice): “O thank you, Mr. Parking Lot Attendant. Here I come. (She makes a quick puttering sound). Bwt-bwt-bwt-bwt.”

Dr. Rick: “Much better. This is great back and forth. If you count the gestures and the words...”

Mom: “…We must have opened up 10 circles.”

Dr. Rick: “Show off.”

Mom: “Amber has got me counting circles and now it’s second nature.”

Step 3: Playing at the right level.

Dr. Rick: “I could see you slowing down to give Jacob time to look at you and process what you were saying. Nice work Julie! What level were you playing at?”

Mom: “Five?”

Dr. Rick: “Right. You are perfectly following his idea, his lead, and his intention. FDL V is about one theme—'the cars go in'. Different cars could go in, but it would still be the same theme.”

Mom: “Cars go in. So that comment about looking forward to the race was at Level VI.”

Dr. Rick: “It was about ‘time’—the future—and you introduced your own idea instead of building on his. Did you see that?”

Mom: “That’s what I’ve been doing wrong. I’m going up to Level VI too fast.”

Dr. Rick: “Nice analysis Julie! There are a number of ways that you can change the content of the play without changing the level.”

Mom: “Change the content? Oh, like I could drive in a bus or a truck instead of a car.”

Dr. Rick: “Exactly. That would be different content but similar play, also known as a variation on the theme. Or you could start your own parking lot, which would be parallel play. Both are Rabbit Hole Techniques, by the way. That would keep it all at the same level.”

Mom: “But I always want to go higher and that’s where I go wrong I think.”

Step 4: Wooing/Gently Expanding on Jacob’s Play to Higher Level V.

Dr. Rick: “Actually you did go higher. By pretending to be another car that talks you used a technique called Everything Come Alive, and you’ve already expanded on Jacob’s play. Good work.”

Mom: “I didn’t even realize it.”

Dr. Rick: “He totally loved that and when he’s enjoying himself with you, you know you’re playing at the right level. Now, let’s expand a little more and see what Jacob thinks. Let’s create another little problem for Jacob to solve.”

Mom: “Hmmm. Like what?”

Dr. Rick: “Well, what would be:

- Fun,
- Not break the flow of the play; and
- Still be within Jacob’s idea of a parking lot.

I call it playing at a slightly higher level like a 5(V).1 or 5(V).2 idea, not a Level VI idea (yet!).”

Mom: “I get it, slightly higher. But now I’m confused. When do you just follow and when do you expand?”
Dr. Rick: “It is tricky. Normally you follow but remember method five is to gently expand. So let’s push him a little just to see how far up he can go. If you play too high, that’s not good. But I want to show you how to do that, provide the just right challenge without going too high. OK? There are probably 10 Variations on the Theme that would work.”

Theme and Variation
(from Less to More Complex)
Cars in a Parking Lot
- Count the cars in the lot (Simple FDL V-5.0)
- Name the colors of the cars (Simple FDL V-5.0)
- Cars go in slow or fast (FDL V-5.1)
- Car can’t fit in the line (FDL V-5.3)
- Police car tells car to slow down (FDL V-5.6)
- Car crashes into another car, gets hurt, needs a car doctor (FDL V-5.9 verging on FDL VI)
- Car doctor comes and fixes car (FDL VI - there is a story line with cause and effect)

Mom: “How about I act like my car wants to fit in between two cars who are his friends?”
Dr. Rick: “OK. Ask your pals to make room. Make it fun and let’s see if Jacob likes it.”
Mom (totally into it, pretending to be the car, making the ‘bwt-bwt-bwt’ sound, drives over to fit in between two cars in the parking lot and grunts as if she’s pushing in but can’t fit): “Hey youse guys. I can’t get in here! I want to go right here with my friends! Please move over.”
Jacob: “No! Go here (pointing to the end of the row).”
Mom (lifts her car to Jacob’s face and says): “Hey mister, I can’t get in. Boo hoo I want to go here with my friends.”
Dr. Rick: “Nice touch with the crying. That requires some emotional thinking on Jacob’s part. Now wait. Wait.”
Mom holds her car up, waiting. A count of three passes. Then... Jacob makes a space between the two cars.

Mom (in the deep voice): “O thank you! I can fit in now. Hi friends. I like being with my friends!”
Dr. Rick: “That was awesome! (To Jacob) OK, Jacob, you keep playing. Mommy and I have to talk.”
Mom (sitting in her seat): “That was fun.”
Dr. Rick: “I loved that ‘bwt-bwt-bwt’ sound and the ‘boo hoo’. You are great. You helped Jacob move from Comfort Zone to engagement to two-way communication and with some problem solving you went all the way up to pretend play in a matter of a couple of minutes.”
Mom: “You mean, I went from Functional Developmental Level I-II to Level V.”
Dr. Rick: “Show off!”
Mom: “Hey, I know my levels.”
Dr. Rick: “I think you may have even gotten up to 5.8. The car couldn’t fit in so he was sad. That’s two simple ideas. And Jacob, seeing that the car was sad, made space and that was two ideas! He didn’t quite get the friends idea, but we were close to FDL VI.”
“Jacob’s idea was ‘putting cars in the parking lot’ and so you were building on his idea with your ideas. That’s called ‘wooing him upward’. If Jacob didn’t join you, then you would have had to wait and see what his next idea would be. But he liked what you were doing and I thought your play was great.”

Mom: “Thanks. This has been really helpful. It’s like aiming your play at just the right level. It’s amazing how precise you can be.”

Dr. Rick: “There’s a method to our madness.”

Quick Summary
So even in this short interaction, what mom and Jacob accomplished together was significant:

- First, she joined Jacob in his Comfort Zone (of lining up cars and scripting on ‘Cars’ parking lot movie scene) by sitting there and being with him.
- By narrating, she got him engaged (FDL II) when he looked at her and allowed her to join him.
- Then, she promoted initiation/two-way communication (FDL III) when they exchanged glances, and he talked to her car.
- They moved into FDL IV when he laughed at her car running around like a chicken (simple slap stick pretend = IV). Plus, there were a lot of circles flowing between them gesturally (continuous flow = IV).
- And he moved up to FDL V when he included her cars to park in his parking lot one after the other (one theme—parking the cars—is FDL V).
- Finally, by taking on the car role and giving Jacob the Mr. Parking Lot Attendant role, they were truly pretending, moving up FDL V (to 5.1, 5.2, 5.3 play with the little variations) all the way up to FDL VI by putting two or more ideas together, i.e., ‘I’m a car, I want to park. I’m sad if I can’t get my own space. Move over, you guys, there’s no room. I can’t. Boo hoo. Mr. Attendant would you help me?’ etc.
- She made the drama both silly and realistic, but I don’t think Jacob completely got the story line. He understood that the car couldn’t fit and that the car was sad, but I don’t think he understood that the car wanted to be with his pals. So he was just at the edge of FDL VI.
- Still, and most importantly, it was fun for both mother and son!

Going Even Higher: FDL VI
Jacob was now taking mom’s idea and driving his car around wildly like mom did and squeezing it between the cars.

Dr. Rick: “See, he liked your idea so much that he’s imitating it—the highest form of flattery. You wooed him up! (We slap five) After all, a real test of Jacob’s ability to play at the higher levels, especially with his peers, is to play someone else’s game, right? I’m going to test him out in a few minutes.”

Mom: “Kids are always following other kids’ ideas for play.”

Dr. Rick: “Right. So it’s OK to build and expand, which is very different from taking over.”

Mom: “I see that. Still, it felt easier when Jacob was just feeding a puppet or playing doctor one instrument at a time. This more complicated play is hard.”

Dr. Rick: “But you did it! Now we’re going to try to go even a little higher.”

Mom: “But not so much that we lose him.”
Jacob gets up from his play with the cars and stands right in between mom and me.

Dr. Rick: “Yes?”
Jacob: “Solomon. Play.”
Mom: “That’s Dr. Solomon, Jake.”
Dr. Rick: “I think it’s cute he calls me ‘Solomon’. Plus, he’s initiating and problem solving. Besides, expecting him to have manners—calling me by my proper title—is high Level VI. He’s not there yet. (Turning to Jacob) Jacob, can you wait one minute? We’ll play in a minute. (To mom) I want to make sure we’re clear about the differences between FDL V and VI.”

FDL V vs FDL VI PLAY

- FDL V: One Thematic PLAY
  - May have different activities, but it’s basically the same game over and over
  - E.g., Doctor kit: look in ears, listen to chest, take blood pressure but not ‘play doctor’

- FDL VI: Two Thematic PLAY
  - Has the quality of a story:
    - “Come in. What’s wrong?”
    - “I have a tummy ache”
    - Listens to the stomach with a stethoscope. “You need medicine!”

Then, I explained that rich pretend play (FDL VI) involves some degree of emotional thinking that follows themes similar to Level V (feeding, being a doctor, etc.), but these themes are more complicated in that they have **two or more ideas that are logically and realistically connected to each other in the form of role playing or a story**. In Level V play the child plays doctor by using one instrument (stethoscope, otoscope, shots, etc.) after another. In Level VI play the ‘patient’ knocks on the door and says ‘Doctor, I’m sick. I need help’. And the doctor gives a shot and says ‘All better’. There’s a story line.

FDL VI: Emotional Thinking

- Talking in sentences
- Asks and answers ‘Why’ questions
- Able to recall the immediate past
- Two thematic play; builds bridges between ideas
  - Play is more logical and realistic
  - Identifies own and others’ feelings
  - Recognizes relationship between feeling, behavior and consequences
- Peer play emerging
- Has simple conversations
- Misbehavior as developmental accomplishment’
Mom looks a little confused—and I don’t blame her—this is complicated work!—so I get a little doll character and hold it on the edge of my writing table.

**Dr. Rick:** “Let me act this out. Here is Level V.”

**Doll** (I act like I am the doll): “Watch out! I’m going to jump. Ayyyyyyyy!”

And I have the doll jump. Jacob, by the ways, thinks this is very funny.

**Dr. Rick:** “And this is the same scene but at Level VI.”

I repeat the scene with the doll going to the edge of my table; only this time I have the doll look over the edge and then turn to mom and Jacob.

**Doll:** “I’m scared. It’s too far to jump.”

**Dr. Rick** (to the doll): “Jump doll. It’s fun.”

**Doll:** “No, no. It’s too far!”

**Jacob:** “Jump doll.”

**Doll** (In a very reluctant and scared voice): “OK. I’ll jump. But I don’t want to get hurt. Ayyyyyyyy!”

**Jacob:** “Cars, come on, cars. Go in.”

**Dr. Rick** (to mom): “He’s been very patient. So what’s his idea?”

**Mom:** “Driving the cars into the lot again.”

**Dr. Rick:** “What level is that?”

**Mom:** “Five?”

**Dr. Rick:** “Right, one theme, one idea repeated in different ways—this car goes in, that car goes in. So he’s back down to FDL V again. We wooed him into low level FDL VI with our car that cried and wanted to fit in and he liked that. What variation on his theme can we do that might take him higher?”

**Mom:** “This is so interesting. I’m not used to ‘thinking about play’ like this.”

**Dr. Rick:** “It’s like marching up from 5.0 to 5.5 to 5.9 to 6.0. If you know how to find the just right challenge, he’ll move up and he’ll like it. Eventually, he will want to play there because it’s more fun.”

**Mom:** “So we can stay at his level and see where he goes or we can try another variation at an even higher level.”

**Dr. Rick:** “Exactly. But let’s go to 5.9 or even FDL VI and see what happens. Let’s create a story with a theme.”

**Mom:** “I don’t know... Make the cars crash?”

**Dr. Rick:** “That could be fun, and it could lead to the theme of fixing and helping. Let’s try it and see what happens.”
Jacob meanwhile is contentedly getting more cars from the drawer and has created a pretty big parking lot.

Mom (re-joining Jacob): “Brrrm-brrm. I’m back.”
Jacob: “Go in car.”
Mom: “Hi, Mr. Parking Lot Attendant. (She waits for his attention. He looks at her, opening an ‘eye contact’ circle) Where should I go?”
Jacob: (Points to the end of the line.)

And she crashes into one of the cars and makes a loud crashing sound.

Dr. Rick: “Perfect.”
Mom: “Oh no, I crashed! Oh no. Are you OK, blue car?”
Dr. Rick (narrating to help Jacob process the new scene): “Oh no, red car you crashed into the blue car!”
Jacob: “No crashing. No crashing!”

Mom looks at me.

Dr. Rick: “We could back off and honor his feelings or we can push him a little. Let's keep going. Be hurt.”
Mom: (picks up the blue car): “Ow-ow. I need some help! I got a boo boo! I need help!!”
Dr. Rick: “That’s just perfect. He can totally understand a ‘boo boo’. Now wait…”

Mom and I wait for what seems like a long time. Jacob is thinking. We are teetering between Jacob going back to his original plan or rising to the challenge that this dramatic turn in the pretend play presents. It’s a moment of decision. If he goes back, then we go back. But if we’ve hooked him with the ‘just right challenge’, something new will emerge. It is a developmental moment. . .

Dr. Rick: “Tell him again what the problem is.”
Mom: “Mr. Parking Lot Attendant, I got a boo boo!”
Jacob: “He hurt.”
Dr. Rick (modeling for Jacob): “Mommy, he's hurt! (Then, to mom, coaching in a low voice) Give him the problem one more time.”
Mom: “I crashed. I got a boo boo (she whimpers pathetically). I need help! What are we going to do?”
Dr. Rick (aside to mom): “Now, let’s wait. That was an open-ended ‘wh-question’. That kind of question is good because it keeps the flow of play going. And it requires some problem solving. (To Jacob) Oh no! What are we going to do?”
Jacob: “Go to docker.”
Dr. Rick: “What did he say?”
Mom: “Go to the doctor?”

I get up and quickly open the doctor’s kit and pull out a ‘shot’, a plastic hypodermic syringe. I make the sound of an ambulance and show up at the scene.

Dr. Rick: “Jacob, should I be the doctor or do you want to be the doctor?”
Mom: “I didn’t know you could do that?!”
Dr. Rick: “Do what? Step outside the play and talk to Jacob about what to do? Why not? Kids do that all the time.”
Mom: “That’s a whole new idea.”
Jacob: (takes the shot from me)
Dr. Rick: (I mirror his gesture with words): “OK. You be the doctor.”
Jacob: (gives the poor blue car a shot.) “All better.”
Dr. Rick: “All better. (To mom) See! You have to have faith. Car doctor was his idea! Now summarize the story.”
Mom (jumping right in, pretending to be the blue car by wiggling it as it talks to Dr. Jacob): “Thank you Dr. Jacob. (She has the blue car give Jacob a kiss. Then in her ‘car voice’ says) I was in a crash. I got hurt. You gave me a shot, and I feel all better now. That shot worked! And now that I’m better, I can go back to the parking lot.”
Jacob: “Go back to parking lot.”
Dr. Rick: (to mom and Jacob): “He can go back because he’s all better. (To mom) That’s cause and effect. That’s a ‘why’ question.
Mom: “Yes sir, I’ll go back in line. I’m all better now.”

Jacob returned to lining up the cars.

Mom: “But now he’s back.”
Dr. Rick: “Children will go up to their highest level and then back down to their most comfortable level. But over time, they will go up.”
Mom: “Why?”
Dr. Rick: “Because it’s more fun!”

The Power of Rich Pretend Play
Mom: “That was amazing. He totally got it.”
Dr. Rick: “Julie, you were brilliant.”
Mom (proudly): “Jacob is brilliant. He helped me create a whole story. He came up with the doctor idea.”
Dr. Rick: “You gave him a logical problem to solve, and he solved it. That’s cause and effect thinking—Level VI!”
Mom: “He needed some help.”
Dr. Rick: “Well, this is called ‘wooing’. You ‘wooed’ him up by using a bunch of techniques including:

- modeling upward
- providing the just right challenge
- to solve a problem
- we used some repetition,
- some timely waiting and
- some drama
- you summarized the story

“But you couldn’t have done it unless he was ready. And if he’s really ready, he’ll play it out on his own later with no help from you. This is the real test: Do nothing and see what happens.”
Then I explain to Julie just how powerful rich pretend play is. So much was happening. This type of play is the best way to get the most developmental progress in the shortest time. Jacob is working on ‘why’ questions—the car needed a shot because he was hurt; and ‘when’ questions—first, he had to get the shot, and then he could get back in line. That’s about time sequences. He learned about feelings—the car was hurt, about helping when the doctor came.

Dr. Rick: “Did you notice how fast I moved to get that doctor’s kit.”
Mom: “I was wondering about that. I didn’t know you could add your own idea like that.”
Dr. Rick: “Really I was just supporting his intention in a logical and more realistic way. When the child has ideas, you have to be quick to support their intentions. This is called structure or scaffolding.”
Mom: “I also noticed that you did a lot of mirroring, summarizing what was going on.”
Dr. Rick: “When I don’t know what to do, I mirror or reflect the child’s language, feelings or activities. It’s my favorite method for staying in the flow of the play.”

**Conclusion: The Yuck Frog**

Dr. Rick: “OK. So, we’ve followed Jacob’s idea. We built upward slowly to mid-Level V by asking to fit between cars, and we went all the way up to Level VI by having the cars crash and getting the car doctor. Let’s create one more challenge. I mentioned it earlier—the ability to follow someone else’s idea.”
Mom: “Well, if he’s going to play with other kids, he’s going to have to do that.”
Dr. Rick: “Right. But first, it has to be done with adults. Kids aren’t going to read Jacob’s cues like we do.”
Mom: “That’s why he ends up on the sidelines. He can’t keep up.”
Dr. Rick: “Right, but we can work in that direction step by step. And pretty soon we'll talk about play dates.”
Mom: “I can’t wait for him to have little friends.”
Dr. Rick: “That’s coming but not yet. Everything in due time. Right now, it’s great that he has Charlie to play with.”
Mom: “You mean argue with.”
Dr. Rick: “That’s what I mean. OK, now let’s challenge Jacob to play our game. I’m going to be ‘The Yuck Frog’. (To Jacob) Hey Jacob would you get me that green frog? (To Mom) Does he know what a frog is?”
Mom: “We have a book on reptiles and amphibians that he loves.”

Jacob goes to the big box of toys and finds the green frog puppet with the big mouth and the googly eyes and brings it over to me. I put it on my hand, squeeze it, and it makes a ‘ribit’ sound which immediately attracts Jacob’s attention.

**Frog** (in a loud, obnoxious, demanding voice to Jacob): “I’m hungry! Hey, little boy, I’m hungry. Give me something to EAT!”
**Dr. Rick** (to the frog): “Oh frog. If you’re hungry, there’s food over there (pointing to the basket of very realistic plastic pretend food).”
**Frog:** “I’m hungry! FEED ME!”
**Jacob** (immediately goes over to the basket of pretend food and grabs, of all things, an onion ring) “Here frog. Eat.”
**Dr. Rick** (to mom): “That didn’t take long!”
The Yuck Frog sniffs the food three times. Pauses. Gives Jacob a quick look, rears back with a wide-open mouth (saying “a-h-h-h-h-h”), and attacks the onion ring in Jacob's hand with a munching “num-num-num-num” sound. This startles Jacob a little, but he loves it.

Frog: (rears back again with a deep-throated growling Yu-u-u-u-ck sound, then suddenly spits out the onion ring and shouts): “YUCK!! Me no like onion ring!”

The onion ring goes flying across the room and smashes into the blinds making a loud, ringing, metallic sound. There is a shocked pause, and then Jacob starts laughing so hard that he gets the hiccups. Of course, we’re laughing at him laughing.

For the next five minutes, he gets more and more food, and we play Yuck Frog with themes and variations.

• Some foods the frog likes, others he spits out against the blinds
• The frog locks his mouth and Jacob has to pry it open
• The frog attacks Jacob for giving him ‘bad’ food, and
• Kisses Jacob for giving him donuts (Frog: “I LOVE donuts!”)

. . . all of which get a continuous flow of circles, play at FDL V and VI, and lots of laughs all around.

When it’s time to stop, Jacob gets angry in a very cute way.

Jacob: “Play more Yuck Frog Solomon.”
Mom: “Please.”
Jacob: “Please. More Yuck Frog.”
Dr. Rick: “I know Jacob. You want to play more Yuck Frog because that was so much fun. . . . Next time Jacob. Next time, later (he starts to get sad and cry, so I distract him). But it’s time for a sucker. Would you like a sucker?”
Jacob: “Sucker? Yes.”
Mom: “He’s a sucker for suckers.”
Dr. Rick: “Did you see what happened just now. I explained that we had to stop Yuck Frog because it was time to go and we could play later. So, I was using ‘why’ and ‘when’ concepts with him. Remember, Level VI is about connecting ideas logically. He doesn’t have to literally answer and ask why and when questions. He just has to get the ideas of cause and effect and time. And he handled the transition much better than the last time when he cried a lot when we stopped.”
Mom: “You seem to have that effect on him.”
Dr. Rick: “But I want you to see that it’s not just about pretend play.”
Mom: “You mean incorporating cause and effect ideas throughout the day.”
Dr. Rick: “Right. Use every day circumstances to put ideas together. Like sharing with Charlie.”
Mom: “That’s a huge problem these days.”

Dr. Rick: “We have to talk about my six rules for sharing (See Chapter 21: Siblings With Rivalry). My point is that we are now at the point in Jacob’s progress where the PLAY Project isn’t just about getting on the floor and playing. It’s about ‘life itself’.”
Mom: “I understand. But before I leave, I just have to tell you that I’m very concerned about next year and what we’re going to do about school.”
Dr. Rick: “OK. Let’s add that to our discussion—school and play dates. Let’s get together and talk about that soon.”
Mom: “We have to make a decision.”
Dr. Rick: “I have a check list called the *The Seven Habits of Highly Effective Kindergarteners*, and we can go through that.”

Mom: “That’s a cute title. I’m looking forward to that. And, Dr. Rick, thanks so much. This was very helpful today. I feel much more confident about pretending at the higher levels.”

Dr. Rick: “You were great, and Jacob is humming. It makes my heart very happy to see him doing so well. (To Jacob). Bye buddy. Give me five.”

Jacob: “Bye Solomon (he slaps me a high five and heads off to get his sucker).”

**Summary**
- Jacob is capable of one thematic pretend play, a major achievement at FDL V
- Julie is feeling insecure in her ability to play at the right pretend level, so I follow her lead and we have a play session instead of the usual visit
- We follow Jacob’s lead and have a fun play session starting at Level V
- Then, we expand on his play (Method 5) by degrees to play at higher levels of imagination, introducing two themes until we are playing at Level VI (at least briefly)!
- Rich pretend play teaches children so much! Sense of humor, understanding the feelings of others, concepts of cause and effect and time, problem solving—it is the way young children learn the best

**Coming Up Next**
- Julie is worried about the coming school year and how Jacob will do playing with the other children. We discuss the critical skills for success in kindergarten called “*The Seven Habits of Highly Effective Kindergarteners*” and touch on play dates to help Jacob with his social skills.
Chapter 16
Visit 9
The Seven Habits of Highly Effective Kindergardeners

Introduction: Life Itself
Jacob and Charlie have been to my office so many times now that I don’t even have to invite them into the playroom. They shed their winter clothes (it’s a snowy day in February) dash for the room (without asking—to their parent’s chagrin) and start playing with their favorite toys—Mac the Truck, the Jack in the Box and Thomas the Tank Engine trains.

As soon as we settle into our chairs, the boys want to sword fight with my soft pipe insulator ‘swords’. I love their initiative, but I tell them that we have to talk first. Charlie, now 3 ½ years old, goes “Aw” and Jacob, 5+ years old, goes “Aw”, but they understand that it’s not time to play just yet. It amazes me that Jacob, diagnosed originally with moderately severe autism, not only understands but also ‘reads’ and imitates his brother’s responses. I think to myself: ‘We’ve got to talk about social skills and play dates.’ But the Grants have a more urgent agenda today.

Dr. Rick: “I’m always so pleased by his progress. His social ability is really improving.”
Dad: “He’s really catching on. Still not where he should be but definitely doing better.”
Dr. Rick: “They’re like the dynamic duo.”
Mom: “They play Toy Story. I ask Jacob what Buzz Lightyear is doing and he’ll say, ‘Getting the bad guy, Zerg’. He makes Charlie play Zerg of course.”
Dr. Rick: “I know he’s got those open-ended ‘wh-questions’ down. How’s he doing with the ‘why’ and ‘when’ questions?”
Mom: “We’re still working with the language therapist on those and the little filler words, but he’s getting there.”
Dad: “He’s connecting two ideas together like a champ. I tell him we can’t go to Target…”
Mom: “…his favorite big box store…”
Dad: “…because first we have to go to grandma’s, then Target and he totally understands.”
Mom: “If he’s having a good day.”
Dad: “Most of his days are good these days. The information you gave us about The Good, The Bad, and The Ugly really helped (See Section 3 Chapter 17).”
Mom: “It’s true. He’s slowly but surely beginning to get it that ‘when you have a fit you never get’.”
Dad: “We caught him lying the other day. He had eaten some chocolate…”
Mom: “…which was all over his face.”
Dad: “And when we asked him if he had eaten the chocolate, he looked at us so sincerely when he said ‘No’ we just had to laugh. His face was so smeared up!”
Dr. Rick: “You know me; I’m a big fan of the ‘dark side’. Even misbehavior, especially when it’s manipulative and sneaky, is a sign of problem solving.”
Dad (not convinced): “If you say so. I’m not happy about the lying.”
Dr. Rick: “No, but it is a sign of emotional thinking. Let me test something, and then we’ll get down to business. Hey Jacob (he looks over quickly). What did you have for lunch? (He looks up from playing and I repeat loudly and firmly) Jacob, what did you eat for lunch?”
Jacob (mumbling): “Mac and cheese.”
Dr. Rick: “Thanks bud, sorry to interrupt.”
Mom: “Mac and cheese is right.”
Dr. Rick: “He couldn’t have done that six months ago. That shows the ability to recall the immediate past—a major milestone of abstract thinking. So the ‘why’ and ‘when’ questions are definitely getting there. He’s putting ideas together. He’s thinking emotionally. Fantastic! That bodes well for school. How’s his pretend play?”

Mom: “Much better. And since our last visit, I feel more comfortable with the higher level pretend. Not so much pressure like I use to. It’s more fun.”

Dr. Rick (needling mom a little): “Play should be fun.”

Mom (ignoring me): “When I ask him, ‘What do you want to play?’ he’ll tell me. He’s also telling me how to play. You do this mom and you that mom. He’s a bit of a control freak.”

Dr. Rick: “If you don’t like him controlling you, tell him. ‘Jacob, don’t tell mommy what to do all the time. I don’t like it. You’re too bossy.’ Share your feelings. Share your mind. The more complexity he can handle, the better. Be like another kid. Other kids aren’t going to put up with that. And I’d also make him pay a price for ignoring or not helping out. Use his misbehavior to teach him the rules as well as reasoning about why there are rules and the real consequences if you do or don’t follow the rules.” (See Section 3)

Mom: “I’m getting more and more worried about his social skills with his peers. He’s so self-centered! He’s good with Charlie.”

Dr. Rick: “You can’t lose your brother, but you can lose your friends. Jacob needs to ‘consider’ others, and he’s going to need play dates (See Section 3), which will help him learn the hidden social rules that he’s not getting (See Resources: The Hidden Curriculum).

Kindergarten: The Big Decision

As I was launching into my talk about play dates, I could see that the Grant’s were looking a little anxious and pre-occupied. I read their cues.

Dr. Rick: “So . . . what’s up? I’m sensing that you’ve got something on your minds.”

Mom: “Well, Dr. Rick, helping Jacob with play dates is very important, but we have a big decision to make for Jakey. This fall, he’s going to school, kindergarten.”

Dad: “About a year ago, you suggested we wait. That turned out really good.”

Mom: “Jacob wasn’t ready last year. But I thought this year he’d be ready but….”

Suddenly mom looks sad, and her face gets cloudy as if she were holding back tears.

Dad: “He went to a kindergarten roundup and they tested him. . .”

Mom (starting to tear up): “. . . and he did terrible! He wouldn’t cooperate with the testing. And he knew all that stuff, his numbers, colors, shapes, and letters.”

Dad: “And we just heard that his IEP is going to be in March.”

Dr. Rick: “He’ll be six in October.”

Dad: “Right. So we don’t really have a choice. He’s got to go to school.”

Dr. Rick: “Technically, if he isn’t six by the time school starts in September you could wait another year.”

Dad: “But he’s already taller than the other kids.”

Mom: “If we wait another year, he’ll be almost seven.”

Dr. Rick: “I hear you, but tallness and age are less important than true readiness.”

Dad: “I know, I know, but you said he’d be ready for kindergarten.”

Mom: “But that test. . . it didn’t really test Jacob. He was having a really bad day. There was so much noise and so many kids. He just fell apart.”

Dr. Rick: “That’s the problem with tests. They are only as good as the day they are given on. I really think Jacob is ready for kindergarten.”
Mom: “I’m so glad you think so.”
Dr. Rick: “He may need some support like an aide or resource room help...”
Dad: “An aide? Like someone who sits by him all day to help him? I don’t want that.”
Dr. Rick: “Me neither but let’s go about this systematically and figure out a plan for his upcoming IEP.”

The Seven Habits of Highly Effective Kindergarteners
So begins the discussion of school readiness—again. Earlier in Kindergarten: Ready or Not Here We Come (See Chapter 12), I urged the Grants to give Jacob time to mature. Even though Jacob seems ready academically, being effective in kindergarten involves a lot more than knowing one’s colors, shapes, and letters.

Kindergarten is the new first grade. There’s a lot less playing. The demands have really gone up for functional abilities, compliance with rules, and social skills as well as academics. Kindergarten is a full day in most states. To be independently effective in kindergarten, a child like Jacob needs to develop The Seven Habits of Highly Effective Kindergarteners.

Dr. Rick: “Here’s the list of The Seven Habits of Highly Effective Kindergarteners, which summarizes the functional skills children need in order to succeed in school.”
Mom: “Would you record this?”

The Seven Habits of Highly Effective Kindergarteners
1. Go along with the gang
2. Auditory process from a distance
3. Get the main idea
4. Perform sequences of actions
5. Use active memory
6. Process information quickly
7. Know when to ask for help

Dr. Rick (recording): “Most elementary schools and kindergarten teachers assume that children come to school with these habits already developed. But it’s crucial for you to not make that assumption. These seven habits must be part of Jacob’s educational plan, his IEP (Individualized Education Plan) (See Resources & Websites).

“Since this is your big issue today—how to help Jacob be successful in kindergarten—let’s go over this list and talk it through. Even though Jacob is developing these habits, there are lots of things the school can do through the IEP process to help him solidify his abilities.”

Dad: “And we’ll figure out if Jacob can get along without any help?”
Dr. Rick: “That’s one of the most common decisions I help parents make in my practice. We’re going to shoot for the least restrictive educational environment—regular classroom, no extra help—but if he needs the support, we should err on the side of more intervention rather than less.”
Dad: “Why is that?”
Dr. Rick: “It’s a lot easier to take away services from your IEP than it is to add them later.”
Dad: “Got it.”

Doctor Jacob (and Charlie).
Right on cue, Jacob having discovered the doctor’s kit and remembering the last time I played sick, intrudes on our conversation and interrupts us.

**Jacob:** “Docker Rick. Play doctor?”

**Dad:** “Jacob, say ‘Excuse me’.”

Jacob ignores dad, but instead of dealing with this social faux pas of being intrusive, I immediately join the pretend play. After all, he looks so cute with his doctor’s glasses on and a plastic stethoscope around his neck, how could I not join him! He comes at me with an evil smile on his face, wielding the toy syringe in his little hand.

**Dr. Rick:** “Doctor, I’m s-o-o-o-o sick, but I don’t want a shot. It will hurt.”

**Jacob:** “It won’t hurt. You feel better.”

I’m cringing away from him, screwing up my face in anticipation of the painful shot, which he laughs at while coming at me. Then, he jams me.

**Dr. Rick** (in mock agony): “Owwwwwww! Ow-ow-ow!”

Of course, Charlie and Jacob now take several turns at making me yell.

**Jacob:** “All better.”

**Dr. Rick** (suddenly smiling and healthy): “You know what, Doctor Jacob and Doctor Charlie? You guys really helped me! I was sick. You gave me shots and I’m all better!!”

**Jacob:** “Yeah.”

**Charlie:** “All better.”

**Dr. Rick:** “Thank you so much.”

**Jacob:** “You get a toy. I got a toy at the store.”

**Dr. Rick** (to Julie and Jim): “What’s he saying?”

**Mom:** “Maybe he’s giving you a prize for being such a good patient, but I think he’s just changing the subject. He does that.”

**Dad:** “His conversation just shifts.”

**Mom:** “Very quickly. I worry about his attention span. Sometimes, his mind goes all over the place. How’s he going to do in school if he can’t stay focused?”

**Dr. Rick:** “That’s one of the seven habits and we have to keep our eye out for problems with attention (See Chapter 23: Medications?). (To Jacob) OK bud, I’m all better now. Now go play with your brother. (Turning back to the Grants) That was fun even though he did interrupt us. We could have dealt with that, but he was too cute.”

**Dad:** “He knows it too.”

**Dr. Rick:** “Also, notice that by connecting the shot with hurting and with getting better, we’re building bridges between ideas. Rich pretend play is one of the best ways to promote abstract thinking. That’s crucial to school readiness. Boy, is he making progress!”

**Dad:** “We love doing pretend.”

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*Is Jacob Ready for a Full Day?*

**Dr. Rick:** “Let’s go through these seven habits and how to incorporate them into Jacob’s IEP. I’ll warn you that schools see their number one job as helping all children achieve academic readiness, and not necessarily on these more functional seven habits.”
Dad: “I remember the last IEP. They wanted Jacob to go to kindergarten for a full day, and we decided together that he would do another year in preschool, only half days. We were surrounded and outnumbered, but we stuck to our guns and kept Jacob in pre-school based on your advice and they caved. It was definitely the right decision.”

Mom: “This year has been an amazing year for Jacob.”

Dad: “If we need to get these seven habits into his IEP, we will.”

Dr. Rick: “You’re a bulldog dad, but most schools will work with you (especially when you know your rights under the law).”

Dad smiles. Mom looks concerned.

Dr. Rick (to mom): “I know Jacob didn’t do great at the kindergarten evaluation, but he had a bad day. In my heart, I know he has the ability to make it. But let me ask you this: Do you think Jacob is ready for a full day of school?”

Mom: “Can’t kids go to a half day anymore?”

Dr. Rick: “Nope. Schools all over the country are moving to a full day. But remember, within the limits of the law, you’re the boss. I’ve had a number of families do a partial full day where they take their child out of school to go to various therapies.”

Dad: “You mean we keep Jacob’s speech and language and occupational therapy...”

Mom: “...to help with his handwriting. And he’s getting music therapy too.”

Dr. Rick (writing in his chart): “You didn’t tell me that. I love music therapy. So, my point is, you could take him out of school to go to the various therapies at least in kindergarten.”

Mom: “I would never have thought of that. You sure the school will let us do that?”

Dr. Rick: “What do I always tell you?”

Dad: “We’re the boss of our child.”

Habit #1: Going Along with the Gang

Dr. Rick: “So let’s talk about the first habit—Going Along with the Gang. When I’ve observed kindergarten classes, it’s obvious that there is a hidden curriculum, an unwritten expectation (often with no IEP goals!) of social compliance—that children will do what they are supposed to do in the classroom setting. It’s like the children have a group mind. They are consciously and unconsciously aware of the movements and intentions of their peers. When the group moves to circle time or lines up to go outside, all go. They give up their agenda and comply. Children with ASD are often the exception. They might be oblivious to what the group is doing or worse, go off and do their own thing.”

Mom: “I just talked with the preschool teacher about that, and she said Jacob’s doing better that way. At the beginning of preschool, Jacob left circle time a lot and wandered off, to the trains mostly, but he’s doing much better now.”

Dad: “But we don’t want him just to do better, do we? I want Jacob to really fit in.”

Dr. Rick: “So how do we get there? The answer lies in the question. Luckily, he has the pre-requisites. Thanks to all of your hard work over the last two and half years, he has moved up the functional developmental ladder and he can:

- Understand most of what you are saying to him (FDL V)
- He’s making logical connections and bridging ideas together (FDL VI) like the idea: ‘I have to do what my friends are doing.’
- He can interact in a fairly long give and take fashion.”
• And he delays gratification, i.e., gives up his agenda to go along with the gang and the school rules.

“Here’s a quick summary of what Jacob has to do to go along with the gang:

Habit #1: Go Along With the Gang
• IEP Goal: Jacob will go along with his peers without prompting
• Key to success: Requires FDL V to VI!
  • Understand meaning
  • Make logical connections/bridge ideas
    ▪ “I should do what my friends do.”
• Delay gratification, i.e., give up his agenda
• Teacher or paraprofessional should talk to Jacob throughout the day about going along

Mom: “He’s waiting better but he still needs work on that one.”
Dr. Rick: “Believe me, school will definitely help with that.”
Dad: “How so? And who’s going to help him?”

Go Along with the Gang: Methods
Dr. Rick: “Hopefully, his teacher or teacher’s helper. Someone needs to give Jacob the following message on a regular basis: Jacob, look around. Look at all your friends. We want you to do what your friends are doing. But our ultimate IEP goal is for Jacob to go along with his peers completely independently without prompting him to do so. Let’s talk about the ‘tricks of the trade’, some of the methods I recommend for helping Jacob Go Along with the Gang.”

Schedules, Pictures, & Rules. To achieve this goal, all teachers use activity schedules that list and sometimes picture the activities by the hour and even within the hour—every change should be listed.

Go Along with the Gang: Methods
• Use picture schedules; get a class picture. Know student names.
• Make the ‘hidden curriculum’ visible: List the social rules for ‘going along with the gang’
  • When my friends line up to go outside, I line up too
• All social rules will be discussed with Jacob
• Use social stories and fables
• If needed, use rewards and charts to motivate
• IEP Goal: Jacob will have longer and more complex interactions with peers over time

Dr. Rick: “At home, you should get a picture of Jacob’s class (if there is one) and put it on the bulletin board in his room. I’d ask him who his friends are and have him name them.

“Also, in the beginning, we should make a list of rules, for example:
• Jacob will follow the daily schedule.”
When the class goes to circle time, Jacob goes to circle time.
When your friends line up, Jacob lines up, etc.

“As I said, all rules should be discussed with Jacob. Trust me, the school will make compliance a high priority. What they might not do is sympathize with Jacob about wanting to do his own thing (‘I know, Jacob, you would like to go and play on the computer. . .but right now it’s time to work on your project’) Good teachers do this well.”

Dad: “Let’s just hope he gets a good one.”
Dr. Rick: “As I said before, you can’t pick Jacob’s teacher, but that’s what good principals do—they put students where they will learn the best, and the teacher is the most important factor for a child’s learning.

“There should be a clear expectation that Jacob will go along with the group. I call this the ‘iron fist in the velvet glove’ approach. You can be gentle and nurturing (the velvet glove) but clear and firm with high expectations (the iron fist). That’s part of my ‘philosophy of can’. Literally ask yourself: ‘Can Jacob do it?’ If the answer is ‘Yes, he can’, then he should.”

Mom: “There’s no doubt he can go along with routines.”
Dad: “At least most of the time. The question is, does he want to.”
Dr. Rick: “I’ll get to issue of motivation, but if he truly cannot go along with the gang consistently, then he would definitely need an aide either part time or full time. Then the teacher and aide would start with what he can do and gradually expand the amount of time in the group. We don’t want Jacob to be stressed to the point of upset. That would be counterproductive. Personally, I think he can follow along and won’t need that much help.”
Dad: “I’m against an aide.”
Dr. Rick: “I hear you dad. But compliance and going along with the gang are the key factors determining if Jacob needs help, and if he needs the help, we should give it to him.”

Social Stories & Fables.

Dr. Rick: “If we need to, we could make up a Social Story™ (See Resources: Carol Gray) about a boy who doesn’t go along with the gang. Here’s a sample social story for Jacob. We could put this into a book with simple pictures (from the internet) or not:

- Jacob, sometimes you like to be by yourself (show a boy reading a book or playing alone with trains). You like to read books or play trains by yourself and that is fun.
- But when you are in school, you have to do what your friends are doing. When they go to circle time, you go to circle time (draw a picture). When they go to table time, you go to table time (draw a picture). When they stand in line to the playground, you stand in line to go to the playground too (picture). You can just follow the schedule (picture of schedule)!
- Everyone goes along with their friends all day long in school! (Sing this in a fun and silly way to: ‘This is the way we brush our teeth so early in the morning’). (I sing into the recorder. . .)”

“Another way to get the point across is to use fables. I have a cute fable about Willy the Walking Koala Bear who always walked away. (See the fable at the end of this chapter).”
Incentives vs. Reasons.

**Dr. Rick:** “If necessary, the teacher can institute a system of rewards with a chart that motivates Jacob to go along with the group and also documents his behavior.

“I want to emphasize, though, that there is a difference between an incentive and a reason. Incentives motivate in the short run. Reasons motivate in the long run (I’m reserving bribes for the harder habits later!). The reason to be part of the group is not to get stickers but to have fun, make friends, and interact. However, incentives will get the process going.

“The Going Along Chart (See below) should list all the group activities:

<Insert 1.6 JPEG 7HABITS here>

“Every time Jacob goes along, he gets a star. When he gets five smiley face stickers, he gets a prize. We can up the demands so that he gets a star only if he does it on his own without prompting, etc. Because eventually, we want to wean him off of a reward system.”

**Mom:** “We could give him computer time for getting five smiley face stickers.”

**Dr. Rick:** “That would be a good incentive. You’d coordinate with the school every day for a while, and when they give you his reward chart, he’d get more computer time at home. But I don’t want to use a reward system unless Jacob really needs it.”

**Increased Interactions.**

**Dr. Rick:** “Finally, the most important outcome of going along with the gang is that Jacob will interact more with his peers. This should be a key IEP goal and stated explicitly: Jacob will increase the number and complexity of interactions with his peers. The teacher/aide should be promoting interactions between Jacob and his peers frequently throughout the day.”

**Dad:** “We take going for circles of interaction for granted as part of the PLAY Project.”

**Dr. Rick:** “But a lot of time, the school assumes that peer-to-peer interaction is easy.”

**Mom:** “And for Jacob, it’s not easy yet. He interacts a lot with Charlie, of course.”

**Dr. Rick:** “Once Jacob is going along with the gang consistently then the other habits of highly effective kindergarteners will be easier to achieve.”

**Habit #2: Auditory Process at a Distance**

**Dr. Rick:** “In fact, going along with the gang is closely related to this next habit—Auditory Processing at a Distance. Notice that I did not call this section ‘Good Listening’ because good listening is the end product of being able to hear first and process sounds. While typical children can hear, listen, and make sense of the words spoken across space, children with ASD often can’t.”

**Dad:** “Why is that?”

**Dr. Rick:** “Remember way back we talked about the web of neurons that catches the complexity of the world? It’s a complex process to make sense of what is heard. The airwaves (sounds) have to go into the brain area that de-codes them and turns them into sense. Compared to the visual system, the auditory system typically is weak for children with ASD. When you listen, your brain has to send out messages to short and long term memory areas, to visual areas, and to thinking (frontal lobe) areas of the brain. It is tough work for the brain to make sense of sound.”

**Habit #2: Auditory Process at a Distance**
IEP Goal: Jacob will be able to hear, make sense of and do what the teacher says—without having to be prompted.

Not just ‘good listening’
- Ability to process sounds
- Attend, hear, listen, think, react—circuit

Sensory integration issues
- Words compete with ambient noise
- Distance interferes with hearing and meaning

**Hearing vs Listening.**

**Dr. Rick:** “So first of all, there is the issue of sound itself—the act of hearing first and then translating sound into meaning next—listening. This is the definition of auditory processing. The spoken word literally disappears into thin air unless you are really paying attention. So first, Jacob will have to be paying attention.”

**Mom:** “So hearing comes first and listening come next. This is so interesting.”

**Dr. Rick:** “Listening is also related to the complexity of the task. Long complicated sentences are going to harder for Jacob. Things should be broken down into short clearer statements.

“Also, if there are other noises in the room like talking, shuffling feet, moving chairs, heat/air conditioning noises, etc., then the spoken word must compete with class noise.

“And finally, the farther away one gets from the source (i.e., the teacher’s voice), the more likely it is to get diluted by these other sounds. Have you noticed that Jacob understands what you are saying a lot better the closer you are to him?”

**Mom:** “Definitely. So, maybe he’s not just ignoring me on purpose.”

**Dr. Rick:** “He might be ignoring you on purpose! (We all laugh) but he might not be hearing you and that’s why he’s not listening. He might not be processing what you are saying.

“Remember, our IEP goal is: **Jacob will be able to hear what the teacher is saying from across the room, make sense of it, and do what the teacher says—without having to prompt him.**”

**Dad:** “So, how can we promote better listening and auditory processing skills?”

**Dr. Rick:** “The answer lies in the question, dad! First, let’s make sure Jacob is sitting closer to the source, i.e., near the teacher whenever auditory processing is important.

**Auditory Process at a Distance: Methods**

- Make sure you have the child’s full attention
- Move the child closer to the teacher
- Use visual supports: calendars, pictures and importantly, gestures (from teacher/aide)
- Repeat the message
- Have the child repeat the message back
- Use high affect, drama, silliness, singing, games, suspense & surprise to motivate
- Praise success!
“We can also use visual supports. I’ve already mentioned calendars and schedules and gestural supports like the teacher getting Jacob’s attention by pointing to her mouth and Jacob’s ears as if to say, ‘Listen up, Jacob’. Good teachers do these things all the time, but it’s good for you to know what it’s going to take for Jacob to be good at auditory processing at a distance.

“Third, instructions should be repeated in such a way as to help Jacob understand. Make sure you have his full attention, that you are connected. Put the understanding into his brain. I know this sounds a bit strange but it means talking with the intent to put the meaning into Jacob’s mind. Use high affect. Use different phrases. Make it make sense to Jacob. Good teachers, of course, do this too.”

Mom: “We can use all these ideas at home too.”

Dr. Rick: “A fourth technique is to ask Jacob or even the whole class to repeat what has just been said and reward the effort with high affect, praise, and jokes (‘OK class, who can say what I say? If you can, I’ll do a dance for you!’).

“Other techniques to get the point across include singing with rhythm and rhyme! Yes, singing is a way of making sounds salient and memorable. If you can’t sing, then speak with high affect, rhythm and rhyme.

“It should go without saying (get the pun?) that attentive listening should be praised intermittently (‘Good listening, Jacob!’).

“Most of these ideas are common practices by good teachers, but they are rarely made explicit in the IEP; and for kids on the spectrum, like Jacob, they need to be made explicit.

“At home, you can practice ‘listening skills’ by playing games, with both boys, based on a Jeopardy format. Put on your announcer’s deep voice: ‘Are you ready panel contestants? And now. . . Can You Say What I Say for 100?’—Then do a simple sentence like ‘I love mommy and daddy’. Then. . . Can You Say What I Say for 200?’ Then do a longer, harder sentence like ‘I love mommy and daddy and Charlie and Grandma and Grandpa’. Give prizes, money, trips: ‘Today’s contestant will win an all expenses paid trip to Chuckeeeee Cheeses.’

“This second habit leads to the third and fourth habits. Ultimately, Jacob should be able to get the main idea and then be able to follow a sequence of instructions like: ‘Find the bunny, color her brown. Then, find the dog and color him black. After that cut them out and paste them on the construction paper. Write your name at the bottom.’

Mom: “That would be a challenge for Jacob.”

Dr. Rick: “That’s why we need to work on it as an IEP goal.”

Habit #3: Get the Main Idea
Closely related to auditory processing skills is the idea of Getting the Main Idea, our third habit. After Jacob listens, he must translate sound into sense. In other words, he must not only be able to parrot what has been said but also understand it and summarize it.

Of course, this doesn’t just apply to listening. Getting the main idea means grasping the meaning of whatever is going on in the classroom and is closely connected to:
• Sequencing
• Active memory
• Processing speed

which are the next three habits.

Habit #3: Get the Main Idea

• Ability to see the ‘Forest for the trees’
• Can child answer open-ended ‘wh’, why, when and how questions
  • ‘What’s next?’ ‘What did the teacher just tell you?’ ‘What’s the story about?’ ‘How should we do that?’ ‘Why did Sally say that?’
• State the main idea throughout the day when:
  • Teacher is reading or giving instructions
  • A friend is talking
• Use different strategies (visuals, stories, dramatizing, etc.) to help the child ‘get it’

I hope you’re getting the main idea of the main idea. It’s seeing the ‘forest for the trees’. This ability is closely related to Greenspan’s Functional Developmental Level VI: Emotional Thinking/Bridging Ideas and represents a very important set of IEP goals (See Appendix H) that are luckily a focus of academics in the schools. The key language milestones for Level VI include:

• Understanding ‘why’, ‘when’ and ‘how’ questions
• The ability to read with comprehension, and
• The ability to recall events from the school day without much prompting”

Mom: “I still have to prompt Jacob.”
Dr. Rick: “But I asked him what he had for lunch, and he told me.”
Dad: “After you repeated the question three times.”
Dr. Rick: “It might help to recall what just happened. For example, you might say ‘Boy that was a good lunch. Did you like that lunch, Jacob? Let’s see, what did you have?’ You can go around the table. ‘Daddy what did you like?’ ‘Charlie what did you like?’”
Dad: “We’ll practice that.”
Dr. Rick: “A kindergartener needs to get the main idea when:
  • The teacher is reading a book in circle time
  • The teacher is giving instructions to the class
  • The class is moving on to a new task
  • The child is joining a classmate in a new activity
  • A friend is talking

“In other words, Jacob should be able to, at least briefly, answer open-ended what-type questions like:

• What are you doing?
• What was that book about?
• What game are you guys playing?”
• What did you do at recess?
• What do you want to do next, Jacob?
• What does your friend want?

“Ideally, Jacob should be able to answer ‘why’ and ‘when’ questions like:
• Jacob, why did you do that?
• Why did Thomas (referring to a book about Thomas the Tank Engine) go over the mountain?
• When is it going to be your turn?
• What’s Sally going to think if you do that?”

Mom: “I think he could do all of those except maybe the last question.”
Dad: “He has a hard time with understanding Charlie’s feelings.”
Dr. Rick: “That’s where his social skills work is and the school can help. Answering complex ‘wh-type questions’ should be one of Jacob’s IEP language goals. But that’s not my main idea here. I’m talking about generalizing, the ability to answer and truly understand open ended ‘what-questions’ in real time in real situations in the ongoing classroom.

“And don’t get me wrong. Teachers reading this will say: ‘But we do this all the time.’ And I agree. But it is not emphasized as a social process and made explicit in the IEP goals because it is part of the hidden curriculum, and it needs to be an IEP goal not just in language therapy but all throughout the day.

The Main Idea: IEP Goals
Throughout the day:
• Child will answer open ended ‘wh questions’
• Child will ask and answer ‘why’ questions
• Child will connect two ideas in a logical fashion
• Child will recall the immediate past
• Child will briefly summarize the plot of a story
• Child will use pronouns appropriately
• Child will demonstrate thematic pretend play with a peer (e.g., doctor, tea party, cooking food)
• Child will state the intentions of others

Reading
Dad: “So, we’ll make these Jakey’s IEP goals, but how do we help him get the main ideas?”
Dr. Rick: “The answer lies in the question. One thing for sure is read a lot. Make sure Jacob and Charlie tell you what each page is about. Reading is the high road to getting the main idea.”
Mom: “I read to the boys all the time, but Jacob especially just wants me to read it the same way, straight through without stopping.”
Dr. Rick: “You should discuss it as you go.”
Mom: “I’ve tried. He doesn’t like it. He says, ‘Just read, mom!’”
Dr. Rick: “Well, trick him and state the main idea on the page as well as of the book and ask little questions and be dramatic. It should be a discussion.”
Mom: “I’ll try that.”
Dr. Rick: “Let me summarize the methods of the main idea habit, and then we'll talk them through.”

“First, we must state the main ideas frequently throughout the day.

- ‘Oh, I see, the Big Bad Wolf wants to eat the Three Little Pigs. That’s why he wants to blow their house down. The three little pigs have to be smart to beat the Big Bad Wolf.’
- Or: ‘This book is about bees and how they live together and make honey…’
- ‘Jacob, Johnny wants you to help him build this tower. What are we going to do?’
- ‘What’s everybody doing now, Jacob? Look around. Yes! They’re getting ready to go outside for recess.’ (Here, I’d pause and let Jacob draw the conclusion. I’d only prompt him with a ‘what should we do next, Jacob?’ if he doesn’t figure it out)

“A second more sophisticated approach is to NOT summarize the main idea and let Jacob figure it out himself, even if he gets a little lost in the process. Ask each of the ‘what’, ‘why’, and ‘when’ questions above and WAIT. WAIT. WAIT! If he figures out the answers, then I’d praise him heavily and summarize. ‘Way to go, Jacob, you figured out what to do (or say)! Yay, good job!’

“A third key method is the ‘show, not tell. Dramatize the story or idea. For instance, have Jacob and two other students stand on one side of the door and be the three little pigs. Have another student be the wolf and pound on the door and say, ‘Little pigs, little pigs, let me in.’ etc. Other modalities besides words include using:

- Pictures
- Songs
- Cartoons
- Peer modeling
- Social stories
- Fables (See Fable at the end of the chapter)
- Videotape (iPad)

Dad: “Videotape?”
Dr. Rick: “Or iPad.”
Dad: “Jakey loves taking movies with the iPad.”
Dr. Rick: “Take a movie of the main ideas for Jacob. You could record mom reading a book, watch it again and go over the main ideas. Teachers could record other students playing a game and go over the main ideas of the game. Making movies allows for mastery through repetition. Why not use our most sophisticated technology to help Jacob understand the main idea?”

Dad: “That’s a great idea, but do you think the school would actually do that?”
Dr. Rick: “Innovative schools use all sorts of creative approaches to teaching students.”
Mom: “I think something like that would be good for all the students.”
Dr. Rick: “One key to making any method effective is high affect. This means that the adults have been fun, energetic, dramatic, and touchy-feely to get the main idea across. They shouldn’t be afraid to be silly, expressive, a little over the top. You have to ask the question: ‘What’s the best way to get ‘the main idea’ into Jacob’s mind?’”
Mom: “I think Jacob might shy away from someone coming on too strong.”
Dr. Rick: “True, but if done with sensitivity, caring, and at the right developmental level, I think Jacob would be OK with it. An IEP goal like: ‘School personnel will act silly and be dramatic to help Jacob get the main ideas’ might be asking too much.” (We all laugh)

The Boys. Intermittently, through all the talking, I am keeping an eye on Charlie and Jacob who are playing great together. First, of course, they played with all my newest toys—my new Buzz Lightyear (from Toy Story) who speaks Spanish; has big plastic wings that pop out when you push a button; and a space helmet that opens and closes. I have a big dragon that shoots gold coins from his mouth. And Jacob’s favorite is my new Mack the Truck with all the wheels (Remember the fit he had when he discovered the wheels were missing?!) Then, they played pretend with the dozens of matchbox cars, zooming around the room.

As they lose interest and start to get a little bored and intrusive, I pull out my Beyblades, little spinning metal discs that battle by bumping into each other. They absolutely love the Beyblades and stop only to pester and beg their parents to buy them a set, which Jim Grant promises to do if they would just let us talk. That keeps them busy through the next two habits. I have my ways...

Habit #4: Perform Sequences of Actions

Dr. Rick: “OK. Let’s talk about sequences. This is a tough one. In order to perform sequences of actions WITHOUT being prompted, the child with ASD needs to not only go along with the gang, not only auditory process at a distance, not only understand the main ideas—but also remember and implement a series of connected actions.”

Habit #4: Sequences
• Goal: Remember and implement a series of connected actions without being prompted
• Requires the first three habits
• Observe child’s motor planning. OT can help.
• Use M&M’s: Meaning and Motivation
• Techniques:
  • Calendars (for month/week)
  • Schedules (for day/hours)
  • Lists (for minutes), and
  • Sequences (for seconds)

“Here’s a typical teaching instruction: ‘OK children, circle time is over. Now go over to your tables, sit down, and in front of your seat is a folder. Take out the papers from the folder and wait for me to show you what to do next.’

Mom: “Wow.”

Dr. Rick: “Wow is right. This can be hard for many of the typical children. The child with ASD can easily get stuck on sensory stimuli (like visually ‘stimming’ on a Thomas the Tank Engine) or disappear into their Comfort Zone. It is truly difficult for them to follow a multiple step instruction and then perform a series of connected actions.”

Mom: “I have a hard time with that.”

Dad: “Yes, you do, dear.”
Dr. Rick: “Watch out dad! The right answer is ‘You do great, dear’. We all have our limits as to how many things we can do in a row at a given time.”

Creating IEP Goals.

Dr. Rick: “Just as with all the Seven Habits, we’re going to have to develop a set of IEP goals and methods to help Jacob process sequences.”

Mom: “That sounds challenging. How do you do that?”

Dad (beating me to the punch): “The answer lies in the question.”

Dr. Rick: “Smart aleck! If you don’t ask, it won’t happen. I’ll give you a handout for each habit and you can give the handouts to the school.”

Dad: “Does the school have to incorporate our ideas into the IEP?”

Dr. Rick: “Well, we tell the school what we would like, and they will add them to their goals.

• Send them an official letter (all important communications must be in writing) and tell them that ‘We would like the school to incorporate goals related to the Seven Habits into Jacob’s plan. See the enclosed list.’

• Give them the Seven Habits and the methods for each of the habits that I have provided and send them along with your letter to the school before the IEP meeting. They can help you put them in the right form. They’re good at that.

Occupational Therapy.

Dr. Rick: “When it comes to the sequencing habit, the first thing we have to do is actually observe how Jacob sequences and motor plans.”

Dad: “I hate to say it, but he’s not that coordinated. At least not at sports.”

Mom: “His handwriting is a real problem too.”

Dr. Rick: “We’re probably going to need the help of an occupational therapist (OT). They are the experts at this.” (See Resources & Websites: Handwriting Without Tears)

Mom: “He’s got an OT now in preschool, and the private OT you recommended is great with Jacob.”

Dr. Rick: “Then we should ask the new school’s OT to observe and find out:

• Where Jacob gets stuck in the sequence: in the beginning, middle, and/or end?
• If you gave him a set of pictures that depict actions, could he order them correctly? (Boy gets up. Boy walks to desk. Boy sits down. Boy takes out paper. Boy waits for teacher.) Mix them up and see if he can order them.
• How are Jacob’s gross motor events, like getting up from sitting and moving across the room?
• And what about fine motor events like writing or even taking a crayon from its package?
• Where does Jacob lose the thread of the sequence?
• Does noise or visually stimulating objects distract him from the task?
• How far can he get without help?

“Let’s assume Jacob has problems with all of the above. The focus for the school OT will be on sequencing, motor planning, and fine motor skills, as well as sensory integration issues related to distracting noises and or sights. And he may need a break to keep him regulated so he can stay focused in order to make sure that he can sequence a series of connected events.”

Give Me & Mine: Motivation and Meaning.
Dad: “Even though he has some problems with sequencing, I think Jacob could do most, if not all, of this IF he really wanted to…”
Mom: “…It’s just that, you know, he has his own agenda.”
Dad: “What if he doesn’t want to go along, listen, or sequence?”
Dr. Rick: “The answer lies in the question! Gotcha Jim!”

“This is really a critical issue. We assume (as part of the hidden social curriculum), that children want to learn, but kids on the spectrum have their own agendas and may not find the Seven Habits to be much fun. So let’s talk about motivation because the ability to sequence (Habit #4) and use working memory (Habit #5) to get things done in a timely fashion (Habit #6) need the most motivation—they’re the hardest task for kids with ASD to do.

“Most typical children naturally want to please their parents and teachers. While it might be boring or too challenging some of the time, most of the time children find school to be relatively easy and fun.

“When children are NOT motivated, we often blame the child. We might see lack of motivation as the cause for school failure. But I see it the other way around; I see school failure as the cause for lack of motivation. The vast majority of children—including those with ASD—want to do well and to please; the reason they don’t is because school tasks are often too hard so they give up.”

Dad: “That makes total sense.”
Dr. Rick: “And school is going to be a big challenge for Jacob. You guys have been following his lead for years now, and this is going to be a big switch. Now, he’s going to have to comply with school rules—a big change.”
Mom: “He doesn’t comply with house rules. I think he’s smarter than we are.” (See Section 3: Daily Hassles: Using Misbehavior to Promote Jacob’s Emotional Thinking)
Dr. Rick: “That’s a good thing. His behavior is becoming more challenging. He’s testing more. By going through the Seven Habits, we’re coming up with a school plan for Jacob.”

The Best Type of Teacher!
Dr. Rick: “The bottom line is that if we make school a fun experience, if he has a teacher he likes, and we give him (and his teacher) support, he’ll do well.”
Dad: “But you said we can’t pick his teacher?”
Dr. Rick: “It’s not one of your rights by law. You can try, but most principals won’t go there. If they let parents pick teachers, it would be chaos. Having said that, the principal will often try to pick the best teacher for the child.”
Mom: “You said before that the teacher is the single most important factor.”
Dr. Rick: “She or he is. And the best teacher is one who is structured and nurturing. If they are rigid, that’s no good. If they are too loose, that’s not good. But even the best teacher can’t help Jacob if he needs more support than she or he can supply.”
Mom (turning to her husband): “So if we don’t give him the necessary support, Jim, he could have trouble in school.”
Dad: “I want to see how he does on his own.”
Dr. Rick: “Dad, I know you want Jacob to make it on his own, and we don’t want Jacob to have help if he doesn’t need it, but as your advisor on this, I want to give you fair warning that if Jacob doesn’t get the support he needs and starts school off on a bad foot, he could have serious problems with motivation for a long time. I think it’s a fundamental mistake to assume that Jacob will want to do well in
School unless it makes sense to him AND is not too difficult. School, learning, and making friends have to be fun and meaningful to Jacob. Dad, we have to give Jacob the necessary supports and that means giving him M&M’s.”

**Dad:** “He doesn’t even like M&M’s.”

**Dr. Rick:** “Motivation and Meaning—M&M’s.”

**Mom:** “I thought you were talking about the candy.”

**Dr. Rick:** “That’s the joke.”

**Dad (smiling):** “Not funny.”

**Dr. Rick:** “Actually what I’d do, in the beginning at least, is not just support him, I’d *bribe* him if I had to! Kindergarten is going to be challenging. Forewarned is forearmed. We might have to really motivate Jacob with some short-term incentives.”

**Dad:** “But shouldn’t he just do the work because it’s school and he has to.”

**Dr. Rick:** “You would hope, but there’s nothing wrong with incentives. You get paid to work. Hopefully, your work is meaningful in and of itself, but getting paid is a definite incentive. Let’s face it, not everything in school is fun. Jacob will have to delay gratification. Incentives can motivate him when the learning process bogs down, gets boring, or if it’s too hard. So what would be some meaningful incentives?”

**Mom:** “Oh I don’t know, maybe, some stickers.”

**Dr. Rick:** “Stickers are good, but what can he get for his stickers?”

**Dad:** “Computer time?”

**Dr. Rick:** “OK, that could work, but what would Jacob really love.”

**Mom:** “Going to Target. He loves to go to Target and Lowes.”

**Dr. Rick:** “Bingo!”

Jacob hears the word and looks up from his play with a big smile.

**Jacob:** “Target? I want to go to Target.”

**Dr. Rick:** “If you do good in school, you’ll go to Target. Not now.”

Poor Jacob understood too well, and his face dropped into disappointment and then returned to play with Charlie.

**Dr. Rick:** “So this could be our secret weapon. The school, for example, could make a *Target* chart and Jacob could get smiley face stickers for sequencing a series of actions (Habit #4). If our meaningful discussions and our bribe, I mean our incentive, for motivation helps him be successful, that’s great; then, we can wean the incentives down over time. This is an important behavioral principle.”

**Dad:** “But we can’t give a prize for every little thing.”

**Dr. Rick:** “You know what I say to that? (I stick out my tongue and give dad the ‘raspberries’) Not for ‘every little thing’, Jim, just the important things. And just in the beginning. Our ultimate goal is for Jacob to completely internalize the motivation so he loves school and loves learning because it’s not too hard and it’s fun.”

**Mom:** “But what if Jacob still has trouble even if he’s motivated.”

**Dad:** “Julie, I think we have to be optimistic.”

**Dr. Rick:** “Mom, you’re talking about an aide again.”

**Dad:** “I’m against it.”

**Dr. Rick:** “Jim, it’s a lot easier to wean an aide than it is to get one in the first place. If Jacob has some trouble going along with the gang, if his mind still wanders a lot when people are talking to
him from a distance, if he has some trouble getting the main idea and he struggles with sequences some—he might need a part time aide. I want to be optimistic too, but it's sounding like Jacob is going to need at least a part time aide.”

“A good aide could:
- Repeat the teacher’s instructions to help with auditory processing.
- Have Jacob practice the steps by previewing what happens next. For instance, show Jacob a picture of the steps in order.
- Read his cues to see if he is distracted and/or tuned out and prompt him to pay attention and ignore distractions.
- Support the fine motor difficulties by breaking down the task into simple doable steps and don’t let him get too frustrated. When he’s having problems, step in.
- Praise persistence, problem solving, and success.
- And finally, remind Jacob of his incentives. ‘When you do all this stuff, Jacob, you get to go to Target. Who’s going to do all this?’

Mom: “[Jim, he might need one.”
Dad: (silent)
Dr. Rick: “Just consider it.”
Dad: “I’ll consider it.”
Dr. Rick: “So, here’s a quick summary of what we’ve been talking about (see below).”
Dad (taking the handout): “I’ll admit it sounds like too much for the teacher. I’m just not happy about the idea of an aide.”

**Sequences: Methods**
- Repeat instructions (may need a helper)
- Practice the steps ‘on paper’, then do them
  - Picture the sequence
  - Use numbers or colors to create steps
  - Model using puppets or favorite characters
- Teach him to avoid distractions. Use call and response: Should we listen to cars outside? No!
- Break down difficult fine motor tasks into steps
  - Don’t let him get too frustrated. Help him!
- Praise persistence, give incentives

Dr. Rick: “I hear you, dad. You’d like Jacob to be completely independent in the classroom, and maybe he will be. Believe me, if you tell the school you want the aide weaned off by the middle of the year, they’ll be happy to do that. They want Jacob to be independent too. How does that sound? Start with a part time aide and wean off over a few months. If we can.”
Dad: “And if we can’t.”
Dr. Rick: “Then it means we did the right thing.”
Mom: “Jim, I think Dr. Solomon is right. Jacob is going to need some help.”
Dad: “I know Jacob. He’s going to start depending on the aide.”
Dr. Rick: “That is a real danger, but we have to be clear that the ultimate IEP goal for all of the Seven Habits is complete independence.”
**Habit #5: Use Active Memory**

By now, the boys are getting restless and starting to get into the closet in the corner and play with toys that make noise like my bell and my Mr. Roger's push button toy, where he says, 'I like you just the way you are' and sings, 'It's a beautiful day in the neighborhood'. Played over and over and over again.

**Dr. Rick** (loudly): “I think we need a sucker. Who wants a sucker?”

**Charlie**: “I do!”

**Jacob**: “I do!”

I send them out to Amy for a sucker and that buys us some quiet time.

**Dr. Rick**: “So, how is Jacob’s active memory, the next of the Seven Habits?”

**Mom**: “He has an amazing memory.”

**Dad**: “He can literally quote from books or movies he’s seen over and over.”

**Mom**: “He remembers the way to Chuck E. Cheese’s (a pizza and arcade chain).”

**Dr. Rick**: “And he can still remember a game he played at my office from a year ago, but active memory (also known as working memory) is different from this kind of rote, static memory. Active memory is the ability to bring what you know from the past into the present in order to DO something new. It requires a sense of purpose, of getting something done within a certain timeframe. And it requires a ‘sense of self’ acting in the world.

**Habit #5: Active Memory**

- Use past information and apply it to a new task
  - As opposed to rote memory or long term memory
- Active memory
  - Remember information to complete a task
  - Needed for multi-step activities, math, and following complex instructions
- IEP Goals
  - Preview and then review the task
  - Summarize the task as it’s being completed
  - Increase vocabulary, definitions, and general knowledge.

“Active Memory and Processing Speed, the next habit, are the ultimate achievements among the Seven Habits of Highly Effective Kindergarteners. Think of it as ‘fine tuning’ the radio, or, better yet, the ‘finishing work’ of carpenters. It’s not good enough for Jacob to just go along with the gang, listen to the teacher, make sense of the task and establish a plan to do something (sequence); now, Jacob must put it all together using active memory.”

The Grants look a little confused.

**Dr. Rick**: “OK, let me give you an example. When kindergarteners are expected to do a classroom craft, it goes something like this:

‘OK children,’ says the teacher, ‘it’s autumn outside. Who knows what autumn is?’

- Is Jacob auditory processing? Is he raising his hand like his peers? Is he getting the main idea?
"That's right. It's when leaves fall from the trees, and it starts to get colder outside. Right now, we're going to make a present for your mommies and daddies."

- Does Jacob know what 'a present' is?
  
- We're going to make a tree with colorful leaves that are falling to the ground.

- Does he get: 'falling' to the ground? What about 'colorful'? Working memory has to do with vocabulary and definitions.

- On your tables are different colored construction paper, scissors, and paste. Here, up on the board, is an example.

- Does Jacob remember how to use both the scissors and paste together AND, at the same time, recall what a leaf falling might look like AND will he know to look up at the example on the board?

Dad: “When you break it down that way, it’s amazing we function at all.”

Dr. Rick: “For most kids, it’s automatic.”

Mom: “Now I’m feeling overwhelmed with all these habits. I can’t imagine how Jacob is going to feel. Now you’ve got me worried.”

Dr. Rick: “Forewarned is forearmed, mom. If he can’t cope he’ll probably protect himself emotionally and go into his Comfort Zone, or he’s going to become anxious and possibly misbehave. Personally, I think he’ll hold it together emotionally at school. What I’m afraid is that in a busy classroom, no one will notice that Jacob is overwhelmed.

“But let’s assume for the moment that he will be able to use all the Seven Habits. The question about Active Memory here is: How can we help Jacob use information he knows from the past and use it to something new? Dad?”

Dad: “The answer lies in the question.”

Dr. Rick: “By George, I think he’s got it.”

“Definitions, General Knowledge, and Time. Common active memory skills include using past knowledge like definitions/vocabulary, general knowledge, and time for a new task. Another way of thinking about active memory is that it involves putting the main idea together with sequencing in order to achieve a specific task. Most kindergarteners, for example, know what ‘autumn’, ‘presents’, and even ‘example’ mean. Jacob may not. He may need help with new vocabulary and definitions. Most children will have a sense of how long it should take to do a task. Does Jacob get lost in the visual stimulation of the task, or can he learn to ‘stay on task’ and have a sense of time.”

Mom: “It’s like a whole other realm I hadn’t even thought of.”

Dr. Rick: “I’m sorry to overwhelm you, but I just don’t want Jacob to feel overwhelmed and then tune out. It’s this kind of little demands throughout the school day that can add up to be very stressful and cause anxiety.”

Dad: “Unless he tunes out.”

Mom: “But then he’s not learning.”

Dr. Rick: “So let me give you some examples of IEP goals that will help Jacob develop active memory skills:

- Jacob will increase his vocabulary related to what the teacher says

- Jacob will expand his general knowledge of common daily, weekly, monthly, seasonal, and yearly events
• Jacob will **review** what he needs in order to complete a task **before** beginning, and then the process will be **summarized** afterwards
• Jacob will answer open ended ‘what’ questions, ‘why’, ‘when’, and ‘how’ questions throughout the day
• Jacob will complete a craft without help or prompting in a timely fashion (See also **Process Information Quickly** below)

**Dad:** “This is still pretty abstract for me. Can you give us an example?”

**Dr. Rick:** “OK. Let’s do a little thought experiment and apply these IEP goals to Jacob as he sits at his desk doing a craft.”

“Let’s pretend that the teacher’s helper (not an ‘aide’, dad) **waits without prompting** and Jacob goes to his chair, sits at his desk, and even takes out the materials from his folder all on his own (by going along with the gang, auditory processing at a distance, and sequencing). **Good waiting, Mrs. Helper. Good sequencing, Jacob!”**

As I act out the scene dramatically getting up from my chair to be **The Helper** and sitting in my chair to be **Jacob**, the boys sit quietly, lick their suckers, and listen as I put on my little drama.

**Dr. Rick:** “Now, let’s pretend that Jacob is sitting in his seat and not doing much. He seems a little lost. The helper reads his cues and goes up to him. She says ‘Hi’. She waits for him to acknowledge her. A few seconds pass and he looks at her:

**Helper (always in a deep dramatic voice)**: ‘So what are you up to Jacob?’ (This is an open-ended question to see if he gets the main idea). She gives him time to auditory process.

**Jacob:** ‘Making leaves.’

**Helper:** ‘Right, you’re making leaves. Green summer leaves or red and yellow and brown autumn leaves?’ (Note: She throws him a softball multiple-choice question instead of the more difficult open-ended ‘wh-question’: ‘What kind of leaves?’ I’ll forgive her.)

**Jacob:** ‘Autumn leaves.’

Jacob and Charlie like it when my voice changes from **The Helper (deep voice)** to **Jacob (high voice)**. Of course, I ham it up by being loud and dramatic.

**Helper:** ‘Right you are, Jacob. High five (I give Jacob a high five). But Jacob, What is ‘autumn’?’

**Jacob** (silence). “Hmmm.”

**Helper:** (waits, then repeats in a demanding funny voice). ‘What is autumn?’

**Jacob:** ‘When the leaves fall down.’

**Helper:** ‘Right Jacob! In summer, it’s hot; in autumn, the leaves fall down; in winter, it’s very . . .’

And here Jacob actually answers . . .

**Jacob:** ‘. . .cold.’

**Helper** (I give a big high five): ‘. . .and in spring, the flowers grow. Four different seasons.’ (To Jim and Julie: “So here the helper reviews the concepts.”)

**Helper:** ‘So now what are you going to do Jacob?’ (an open ended ‘wh-question’).

**Jacob:** ‘Make a picture for mommy and daddy.’

**Helper:** ‘Right, you’re going to make an autumn picture for your mommy and daddy. You know how to do that?’

**Jacob:** (I exaggerate my head with big nods. The boys love it.)
Helper: ‘And Jacob, how are you going to make a picture for your mommy and daddy?’
Helper: ‘Beautiful! You got it Jacob. If you have any questions, check in with your partner Susie over here. Have fun.’

Dad: “That was very helpful. Funny that this helper was using all the play techniques like reading Jacob’s cues, following Jacob’s lead, and getting circles.”
Dr. Rick: “Funny about that!”
Mom: “Jacob could do all that and it would be fun for him.”
Dr. Rick: “With a little help from his friends. What I don’t want is for Jacob to sit there lost or not understanding the meaning of what he’s doing.”

**Habit #6: Process Information Quickly**

Dr. Rick: “Onward. We’re almost done. Let’s talk about Habit #6: Processing Information Quickly. This is primarily a matter of focused attention but there is a lot that goes into paying attention. If you watch any kindergarten classroom closely, you will notice that the children are moving smoothly and quickly through their day. They are usually (though certainly not always!) paying attention and completing tasks (with some help) in a timely fashion. The hidden (unspoken but expected) curriculum here is sequencing, using working memory, and processing information quickly—our last three habits.

“Children with ASD have problems with these. They become fragmented and wander off to do their own thing. This keeps them from connecting sequences of actions. They have trouble using what they know from the past in order to apply it to a task (active memory), and as a result, they lose focus and don’t get things done in an efficient manner.”

Dad: “And all this is part of Jacob’s autism?”
Dr. Rick: “Remember a long time ago when I first diagnosed Jacob, I talked about the brain of the child with ASD as being like a loose web of nerve cells that can’t capture the complexity of the world?”
Mom: “I remember that. It really helped me understand that autism was a brain problem.”
Dr. Rick: “Processing information quickly is a big challenge to Jacob’s brain. In kindergarten, the children are expected to pay attention, stay on task and get things done well and quickly without (too much) help. Here’s an overview of Habit 6: Processing Information Quickly.”

**Habit #6: Process Quickly**
- Goal: Tasks are done well and quickly
- Key Factor: Pay attention & stay on task
- Rule out LD, ADHD, Fine Motor Concerns
- Methods:
  - Keep environment predictable, structured
  - Help with transitions
  - Pick up cues of distress early & process feelings
  - Be clear about task/work rules & reasons
  - Reward paying attention
  - Create high interest, affect, & relevance
Learning Disabilities and ADHD Must Be Ruled Out.

Dr. Rick: “Our first consideration is: Does Jacob have a learning disability of some sort. Difficulties with processing information quickly are going to show up in writing, phonics/reading, and multiple step crafts, namely, in the most complex work that kindergarteners do. I’m assuming that Jacob does not have specific learning disabilities (LD) or attention deficit hyperactivity disorder (ADHD) (See Glossary and Note*) but I’ll be keeping my eye on him for these as school continues.”

*Note: I didn’t share these considerations with Jacob’s parents at the time because I didn’t want to worry them any more than I already had, but a specific learning disability (LD) (See Glossary) means that a child has trouble learning in a specific academic area despite an overall average intelligence. My clinical opinion was that Jacob didn’t have LD or ADHD, but these considerations were on my mind. For instance, many children with autism have terrible problems with handwriting because they have fine motor (small muscle) coordination problems. This would be an example of a specific learning disability.

A child can have a learning disability in any area of academics including most commonly in reading and/or math. When establishing the need for an IEP as part of the initial multi-disciplinary team evaluation, schools often test the child in all areas of learning to rule out specific learning disabilities. We can’t expect a child to process information quickly if they have a learning disability.

On the other hand, ADHD or Attention Deficit Hyperactivity Disorder means the child has fundamental difficulties with attention, distractibility, impulse control, and over-activity. The diagnosis is clinical, meaning that the teacher and the parents need to fill out forms and/or share their observations with a trained professional usually a doctor or psychologist. As of this writing, there is no objective test for ADHD. To complicate matters even more, the medical literature suggests that children with ASD, who have been professionally diagnosed with ADHD, do not respond to medications nearly as well as typical children. In fact, the response rate to stimulant (i.e. Ritalin-like medications) is less than 50%.

Dad: “But how do you know he doesn’t?”

Dr. Rick: “Honestly, I don’t know for sure. It’s too early to tell yet until he gets more into academics. One test will be Jacob’s ability to complete tasks in a timely manner. This will be a huge achievement (and challenge) for Jacob. But I think he can do it. I’ve got a bunch of tricks up my sleeve to help Jacob stay on task and get schoolwork done.”

Dad: “You mean we have to focus on focusing.”

Mom: “Oh no! Now you’ve got Jim punning.” (I slap five with dad)

Processing Information Quickly: Methods.

Dr. Rick: Probably the most important factor in helping Jacob focus and process things quickly is to keep the school environment predictable. I’ve already mentioned the importance of a teacher who is nurturing but structured. If there’s a lack of order and predictability Jacob will get upset, lose control, and it could ruin his whole school experience. To keep the environment predictable good teachers will:

- Help Jacob get through transitions
- Pick up on Jacob’s distress signals/cues early
- Be clear about the work rules and reasons for a given task and
- Reward attention to task

Let’s take each of these school ‘methods’ in order.
Dr. Rick: “The first task is to help Jacob transition from what he was doing to the new task. This is not easy for children with ASD.”

Mom: “We’ve been using your 20 Transition Tricks, and that has really helped us.” (See Chapter 18: Dr. Rick’s 20 Transition Tricks)

Dr. Rick: “The school needs to use them too. Problems with transitions can look like attention deficit disorder but it’s not. Kids with ASD have real trouble with transitions and shifting their attention from one act, let alone task, to another can be challenging.”

Dad: “But Jacob focuses for hours on his Legos or cars. His attention span is amazing.”

Dr. Rick: “He can focus when it’s easy and interesting and he doesn’t have to change or transition. His problems start when the task gets more complicated, right?”

Mom: “Or he gets absorbed in thinking about his own thing. Then, it can be really hard to get him to focus on what we want him to.”

Dad: “He ignores or, lately, he argues or just refuses. He’s getting downright stubborn.”

Dr. Rick: “These are all factors in transitioning and attention. What’s going to happen when he can’t do his own thing for the whole day? Calendars can’t compare to Buzz and Woody.”

Mom: “It could be a nightmare.”

Dr. Rick: “Or he’ll hold it together at school...”

Dad: “...and take it out on us at home. That’s already happening some days when he comes home from pre-school.”

Dr. Rick: “Let’s face it. Transitions, especially to non-preferred activities, are going to be hard for Jacob. If the school does not help him transition well, it will interfere with attention and compliance.”

Dad: “We should make these part of Jacob’s IEP goals too, right?”

Dr. Rick: “You’re getting savvy dad! Let’s take an example. Let’s say the teacher has just finished reading a story in circle time. She notices that Jacob was restless, internally distracted, and not listening very well (even though he sat without getting up or disturbing the other children).

“Now, the children are supposed to change from circle time to going to their desks and making a calendar by cutting out the names of the days of the week from a ditto sheet and pasting them, Monday through Sunday, on top of a blank calendar and then numbering the days of the month from 1 to 31 inside the calendar. This task is from one of the classes I observed.”

Mom: “Learning about calendars and the days of the week is important.”

Dr. Rick: “But before the teacher gets to the task, I feel that she (or the aide) should tune in to Jacob’s cues (‘How you doing buddy. It was hard to sit in circle time’) and acknowledge that it’s time to change. Connect with him knowing that transitions are hard. Good teachers do this.

“Next, she states the work rule about what to do next and explains the reasons for the task: ‘OK. Now it’s time to do your calendar, Jacob. Please sit down and paste the days across the top of the calendar, then put numbers on the calendar. All children have to know about the seasons, calendars, and days. The helper Mrs. Jones will help you.’”

Dad: “Jacob’s good at counting. I know he could do a task like that.”

Dr. Rick: “If Jacob is not getting started, the teacher might need to use a carrot and stick approach. She might say something like: ‘And I’ll make you a deal, Jacob. If you do a good job and you get it done in five minutes (holds five fingers up), I’ve got Buzz and Woody stickers (that were provided by Jim and Julie Grant, of course). So, do a good job and do it quickly, and you’ll get two Toy Story stickers! Ready, set, go!”
Dad: “I really think that would work for getting Jacob to do things around the house too. He likes races. He’s becoming competitive.”

Dr. Rick: “I wonder where he got that from, dad?”

Reading Signs of Distress Early (Or Not!)

Dr. Rick: “Usually, schools do a good job of keeping the environment predictable. But sometimes they don’t recognize that changes in the schedule or special events can be very upsetting for children with ASD and they miss reading the signs of distress early enough.

“Here’s an example from one of my recent school visits. It was sub-zero and bitter cold outside. Instead of going out for recess, the class had to stay inside. The class got more noisy and chaotic. The child I was observing who had high functioning autism was clearly upset by this. I could easily tell by his cues. He started to pace; he frowned; his head went down. He was showing signs of distress. He really wanted to go out.”

Mom: “When Jacob expects something to happen and it doesn’t, he still has hard time.”

Dr. Rick: “The staff person missed the early cues. By the time the obvious signs manifested themselves—bolting for the door, hitting, pinching, and screaming when the staff tried to stop him—it was too late.

“Unpredictable environments are noisy and/or chaotic, involve sudden and/or unexpected transitions, expect the child to get work done that is too hard, or if there are challenging situations (like other children misbehaving).

“Observant staff will notice the early signs of distress like facial and body tension, shutdown and withdrawal or excessive activity. Sometimes the children will start talking loud, or be silly or just won’t do what they’re supposed to like leaving their seat without permission.

“If school personnel (or parents!) don’t recognize the signs and act early, the children won’t stay calm and regulated. That’s when behavior problems happen.”

Processing Jacob’s Feelings.

Mom: “I could see something like this happening with Jacob. What should they do?”

Dad: “The answer lies in the question.”

Dr. Rick: “I knew you were going to say that. So what’s the answer?”

Dad: “As you taught us, they should mirror his feelings: ‘Jacob, you really want to go outside.’”

Dr. Rick: “Dad, you’re a genius! And good teacher and aides do this; but remember, schools are primarily focused on academics not feelings.”

Mom: “I don’t want Jakey suppressing his feelings all day long in order to get along at school.”

Dr. Rick: “I’ve seen too many of my kids hold it in and explode later. It would be great if the school could help Jacob resolve upsets on the spot.”

Dad: “You think the school won’t do that? Can you can put that in his IEP?”

Dr. Rick: “That would be radical, dad, because IEP goals are for the child, not the school personnel, but here’s what it could look like:

• School staff will help Jacob control his behavior by acknowledging and ‘mirroring’ Jacob’s strong feelings by telling (not asking) him what he wants and/or how he feels.”
“I call this ‘processing’ a child’s feeling. The point is that all these things—helping with transitions, making clear rules, rewarding him, and reading his cues and acknowledging—will not only prepare Jacob for getting tasks done well and quickly—the 6th Habit—but should make school fun for him.”

Mom: “It’s amazing what it takes to . . .”

Dr. Rick: “. . . Process quickly? True, but when a child like Jacob is supported he’ll pay attention and get the job done. So, all this leads to the last element of processing quickly—paying attention.

Pay Attention to Attention.

Dr. Rick: “So how can we improve attention itself? All together now . . .”

All: “The answer lies in the question!”

Dr. Rick: “Very good children! There is good scientific evidence that when we pay attention to attention, we can increase attention span. Obviously, the most important factor in attention is interest. The more we can make the topic relevant to Jacob, the more he will pay attention.”

Mom: “When I’m reading him a book about Thomas the Tank Engine or Toy Story, he’s riveted.”

Dr. Rick: “I like to build the school curriculum around the child’s interests as much as possible. This is called being child centered.”

Dad: “But how much can a teacher in a busy classroom with 25 kids do that?”

Mom: “Jacob’s teacher this year is fantastic. She’s high energy and makes learning fun.”

Dad: “But, Dr. Solomon, don’t kids in school have to tolerate boredom and just do it? I remember school as boring most of the time, but I did my work because it was expected.”

Dr. Rick: “I call it ‘delayed gratification’. Put off fun to get work done. It’s one of the big things you learn in school. But that’s where reasoning and motivation come in.”

Time it! Pay attention to attention.

Dr. Rick: Last two things. Let’s say Jacob is only half way through the calendar task of cutting out the days of the week, pasting them on top of the calendar, and then numbering the November calendar from 1 to 30. Let’s say he’s ‘scripting’, repeating quotes verbatim from Toy Story or Thomas. The other children are almost done. Here, I’d have the teacher or aide set a timer, focus on attention itself, and play ‘beat the clock’. I’d also try some reverse psychology. In fact, I’m going to try some right now. I’ll demonstrate my techniques of structure, motivation, high affect, working quickly, paying attention, and reverse psychology by getting them to clean up this mess.”

Dad: “I gotta see this.”

Mom: “They hate to clean up.”

Jacob and Charlie have made a total mess of my playroom, toys everywhere.

Dr. Rick: “ Jacob and Charlie. Hey guys. (They look) You want to sword fight and beat the evil Dr. Solomon?!”

Charlie and Jacob (start chanting): “Sword fight, sword fight!”

Dr. Rick (chanting): “Sword fight, sword fight. All right, let’s clean up first, and then we’ll sword fight AND you can have an extra sucker!! AND don’t you put the tracks in the basket. I’m going to put the train tracks in the basket first. Don’t you put them in. I’m going to put more in than you. Really fast! (I quickly throw in a track) That’s one. Ha ha, I got one and you didn’t get any.”

Well that did it, Charlie and Jacob start throwing the tracks in like madmen while I yelled, “Don’t! Stop! I want to put them in. Darn it, you’re beating me. Stop!” They love beating me. We move on to the doctor’s kit, then the food, then the big box of toys, and then the Legos. I feign mock anger with each defeat and the room is cleaned up in no time.
Mom: “Unbelievable.”
Dad: “Impressive.”
Dr. Rick: “Sword fight, sword fight, sword fight!!”

I get out three long soft pipe insulator tubes—which make loud but harmless slapping sounds when they hit—and we have a rousing round of sword fighting where the evil Dr. S attacks the superheroes but is defeated, slumping against the door and sliding down to the floor begging for mercy.


They race out to get more suckers from Amy.

Mom: “And tell Amy thank you.”
Dr. Rick (still breathing hard from the battle): “No problems with attention when all the planets are aligned. And success breeds success. OK. Let’s tackle this last habit quickly.”

Final Agreement on Jacob’s IEP Plans
Mom: “But we have to decide how much support Jacob needs in kindergarten next year and whether he goes full or half day.”
Dr. Rick: “By talking through the Seven Habits, isn’t it pretty clear? I’d recommend a part time aide. And he still needs time for his therapies. So make sure you let the school know that he may be leaving for various therapies.”
Dad: “Will the school help with social skills?”
Dr. Rick: “More and more schools are adding social skills as part of speech and language or social work. I’d put a social skills group into his IEP. If they don’t offer it, you’ll have to do it yourself with play dates. We don’t have time to talk about that now but we will.” (See Chapter 24: Sibling With Rivalry)

Dad: “With all due respect, Dr. Solomon, I’m against an aide. I’m OK with taking him out for therapies, but I’m against an aide.”
Dr. Rick: “You’re the boss, and you could be right. I’m just warning you that it’s a lot easier to take support away than it is to get more support if you need it.”
Mom: “We’ll talk about it at home, Dr. Solomon. What about the rest of his IEP goals?”
Dr. Rick: “The handouts I’ve been giving you outline the most important goals based on the Seven Habits but I’ve got a nice list of other IEP goals as well (See Appendix H). The school will have academic goals. I’ll help you draft a final document of IEP Goals by having this visit typed up and edited for you.”
Dad: “That would be great!”
Mom: “Thank you so much. I’m feeling better. This has been so helpful.”
Dr. Rick: “Forewarned is forearmed. You are such wonderful parents, and Jacob is an amazing guy who’s doing so well. I don’t want him to plateau. Can we just touch on this last habit, and then we’ll finish up.”

Habit #7: Knowing When to Ask for Help
Dr. Rick: “Really, everything we’ve been talking about is a form of problem solving. The last habit—knowing when to ask for help—is simply letting Jacob know that when he can’t solve the problems on his own, he can ask for help. Give him permission to ask for help.”
Dad: “He’s already got that one down. He says ‘Help’ all the time.”
Mom: “It took a long time for him to even know he needed help.”

Dr. Rick: “This lack of self-awareness is one of the hallmarks of autism. That children with ASD are often unaware of others’ feelings is common knowledge, but much less appreciated and more important is that they often don’t register their own feelings of frustration. Helping Jacob become more aware and conscious of his own feelings will not only help him solve problems but may help him understand the feelings of others.

“While Jacob might be able to ask for help at home, it’s going to be much harder in school. And if he sits there and doesn’t ask for help, he’s going to get stressed out.”

Mom: “I was starting to feel better, but now I’m feeling stressed again. I didn’t realize how hard school is for kids like Jacob.”

Dr. Rick: “That’s one of things I love about you Julie. You are self aware and honest about your feelings. Jacob will get it. It just takes work.

“And remember, forewarned is forearmed. That’s why we have to get him and the school (and you two!) prepared. The school should make sure that they ‘give Jacob permission to ask for help’. Throughout the school day, his teacher and/or helper should say: ‘Jacob, if you can’t do something and you’re getting frustrated, you can always ask for help.’

Habit #7: Asking for Help

- Lack of self-awareness leads to school problems
- And leads to two major problems:
  - Not knowing when to ask for help
  - Stress!
- Methods:
  - Give permission to ask for help
  - Wait for child to problem-solve
  - Praise, practice, problem-solve, prize
  - Read cues early & reflect the child’s feeling

Dad: “Another IEP Goal like: ‘Jacob will recognize when he needs help by asking for help.’”

Dr. Rick: “Bingo, dad. It’s not enough to say it once. It will need to be repeated at each failure to ask for help when he needs it. This habit takes time and repetition to develop. Here’s another opportunity to read Jacob’s cues and reflect back his feelings: ‘Jacob, it looks like you are having a tough time getting that glue on the little pieces of paper’. Jacob would probably nod and be relieved that they noticed. Then the helper should say: ‘When you’re having a hard time and getting frustrated, what can you do to help yourself?’ Give him the problem.”

Mom: “I think I’m too quick to step in and help Jacob.”
Dad: “Not me.”

Dr. Rick: “The answer lies somewhere in the middle. It’s very important to pause and give Jacob a chance to problem-solve on his own. Wait. Give him a chance to raise his hand. But not too long, though usually longer than you think. It takes time to process for these kids. You can repeat the question maybe after a 10 count.”
Praise.
Dr. Rick: “If Jacob raises his hand or comes up with the answer, give him lots of praise. If he still hasn't answered, then tell him: ‘You can always ask for help.’ Now ask him again: ‘So when you're having a hard time and getting frustrated, what can you do to help yourself?’ Jacob: ‘Ask for help.’ Slap five and yoo-hoo!”

Practice.
Dr. Rick: “Next, you must immediately practice the skill. “OK, Jacob, let’s practice this again. Let’s pretend you’re having trouble. I’ll go over to the other side of the room and you raise your hand to ask me for help. Would you do that?

“Here, again, it is very important to pause and give Jacob a chance to problem-solve on his own. If he says: ‘Raise my hand?’, high five and yoo-hoo! ‘That’s right, Jacob, good going. You raise your hand, and I’ll come right over and give you some help.’ Then you practice.”

Mom: “That’s a great idea—practice the process of problem solving.”
Dr. Rick: “I call this ‘meta-cognitive’ thinking or thinking about thinking. Then, of course, you keep an eye on Jacob to see if this new way of thinking leads to a change in behavior and truly becomes a habit.”

Prize.
Dr. Rick: “If not, the last thing I recommend is upping the ante. When Jacob asks for help, he gets a prize—something that will really motivate him—like points toward a trip to Target.”
Mom: “He’d raise his hand a lot for that.”
Dr. Rick: “Of course, we don’t want Jacob asking for help when he doesn’t need it. But one step at a time. Let’s get him asking first and then shape his behavior to be more appropriate. Of course, Jacob needs to get the message: ‘We want you to try first on your own, but I’m always here if you really need help’.”

“The second cost of not knowing when to ask for help is that it leads to stress for a child like Jacob. When stress mounts—related to all the habits we’ve talked about—meltdowns, tantrums, misbehavior, resistance, poor transitions, and other forms of displaced anger could disrupt Jacob’s functioning in school, which could disrupt the whole class.”

Mom: “That would be bad. He’s doing so well at home now; I’d hate to see him get worse because of school.”
Dr. Rick: “I’ve seen it too many times. Everything we talked about earlier—reading cues, reflecting feeling, helping Jacob stay regulated—applies here too. When Jacob is calm he’ll be able to problem solve and ask for help when he needs it.”
Dad: “What if the school says they don’t have time to deal with Jacob’s stress.”
Dr. Rick: “This is a central part of Jacob’s education. The time it takes to work through feelings and stressful situations will save time from meltdowns and misbehavior in the future.”

The boys are done with their second suckers and are starting to take my toys out again.

Dr. Rick: “Whoa, whoa. It’s time to stop you guys. Get your coats on. You have to go and it’s cold outside. Did you have fun at my office today?”
Charlie and Jacob nod and slap me five.

**Dr. Rick:** “Hope all this was helpful. I know it was a lot to take in, but you’ve got your handy dandy handouts, and I’ll send you the transcript when it’s done.”

**Dad** (getting up and shaking my hand): “Very helpful.”

**Mom** (shaking my hand): “I always feel a bit overwhelmed when I leave your office. There’s so much to deal with.”

**Dr. Rick:** “It is a lot. But better to know and be overwhelmed than not know and be surprised when Jacob is struggling.”

**Dad:** “We’ll deal with it.”

**Follow up phone call**

Two days after our visit, Julie Grant calls to say that after the visit, she and Jim had a ‘bad argument’ about Jacob’s upcoming IEP. She wanted Jacob to have a full time aide and Jim wanted Jacob to have no help at all. They arrived at a compromise, and she wanted to know if I agreed. The compromise was that Jacob would start with a shared or part time paraprofessional and depending on how he did the school could either increase or decrease the para’s time.

I told her I loved that solution, but I warned her that schools in Michigan just went through some budget crunching and there might be push back to start Jacob in kindergarten without a ‘para’ (paraprofessional). I quickly added: “The school should never tell you that they can’t afford a certain educational plan because of money considerations, but it happens all the time. You have to be tough and strong and fight for the part time para if you need to”. She didn’t think that being tough and strong was going to be a problem for Jim. I said I thought she was pretty tough too seeing as she got Jim to compromise. We had a good laugh together.

**Summary**

- Jacob continues to make progress functionally, developmentally, and academically. But Julie Grant is upset. Jacob did poorly in his kindergarten evaluation. Is he really ready?

- For children with ASD, kindergarten presents daunting challenges that can be met by helping them develop the ‘Seven Habits of Highly Effective Kindergarteners’.

  - They must:
    - Learn to ‘go along with the gang’ (Habit #1);
    - Listen and process what they hear (Habit #2);
    - Accurately grasp the main idea of books, conversations, and situations (Habit #3);
    - Then they have to organize themselves by sequencing multiple steps (Habit #4);
    - Remembering to remember important facts, concepts and strategies (Habit #5); and
    - Focus their attention in order to get things done well in a timely fashion (Habit #6);
    - Finally, they must know when they are having trouble and ask for help not just for academics but also for upsets (Habit #7).

- I help the Grants think through their IEP Goals, especially how much help Jacob might need in kindergarten. Jim Grant is against having an ‘aide’ for Jacob even though it’s clear that he needs one.

- Jacob is becoming more and more of a behavior problem at home and the Grants are worried that this will spill over to school.
Resources & Links

Websites

Books
- 7 Easy Steps to Take Charge of Your Child's Education (2013), Beverly Geltner PhD.
- Know Your Child's Educational Rights! Learn about the law
- The Hidden Curriculum (2004), Brenda Smith Myles
- Carol Gray's Social Stories
- Handwriting Without Tears (1997), Jan Z. Olsen

Coming Up Next
In Section 3: Daily Hassles: Using Misbehavior to Promote Jacob's Emotional Thinking, a series of office visits addresses common behavioral problems like tantrums and aggression, problems with morning routines, sibling rivalry, eating, toileting, etc.
Storytelling and fables help get a message across like nothing else. I'll give an example below but here's my underlying technique:

1. Pick a lesson/main idea to be learned.
2. Find an animal with the same first letter as the lesson.
3. Show the problem using the animal character.
4. Bring in the wise old animal that teaches the lesson.
5. Have the animal resist the lesson.
6. The animal suffers consequences and changes his mind.
7. Happy ending with a social story conclusion.

Let's say Jacob doesn't get the ‘main idea’ of ‘going along with the gang’. I've given you an example of a social story; now let me create a fable on the same subject for Jacob (who, by the way, loves Koala bears).

Once upon a time there was a Koala Bear named Willy. They called him Willy the Walking Koala Bear. You know why? Because he walked all around the school. (Show Jacob what wandering is as you say. . . ) When the other children were sitting in circle time, Willy walked away. When the children were standing in line, what was Willy the Walking Koala Bear doing? That's right. He walked away. When the other children were playing together outside what was Willy doing? He walked away and did not play with the other children.

Poor Willy. He couldn't stop walking away and you know what happened? He didn't learn his lessons, and he didn't make friends. Poor Willy the Walking Koala Bear! He was sad.

One day, when he was walking back home from school feeling kind of sad and lonely, a wise old Koala Bear jumped down from the tree and said, ‘What's wrong, Willy, you look sad’. ‘I want to learn my lessons, and I want to play with the other children, but I like to walk around’. ‘Well, I've got good news for you Willy the Walking Koala Bear.’ And Willy looked at the old wise Koala to see what he was going to say. ‘You can do both! Sometimes you can walk, and sometimes you can sit or stand’. ‘I don't think I can sit or stand’. Willy worried. ‘I know it seems hard, but you can do it. And. . . ’ said the Wise One raising his eyebrows, ‘when you sit or stand with all your friends, you will get two prizes! First, you will learn and make friends. Second, you can get a new Thomas the Tank Engine train!’ Willy liked that idea. ‘O boy, when I sit in circle time I will learn, make friends AND get a prize’. Willy the Wandering Walking Koala Bear loved prizes.

So Willy the Walking Koala Bear decided he was going to sit in circle time and stand in line with his friends so he could learn his lessons and make friends at school. At first, it was hard because he wanted to walk away but you know what? He did it! He stayed put! He sat in circle time; he sat at his desk to do crafts; he stood in line to go to the library. At first, just for a little time and then for more and more time. And he got a Thomas the Tank Engine prize! The Wise Old Koala bear was right! He felt good about sitting and not walking away. And that's how Willy the Walking Koala bear learned to stop walking. The End!
Section 3
Daily Hassles
Using Misbehavior to Promote Jacob’s Emotional Thinking
Section 3: Introduction
Jacob Grant—Pain in the Butt!

Over the last two and half years, Jacob Grant has followed ‘the path’ of functional development. At diagnosis he had no words, now he talks constantly and won’t stop! He was self-isolating, in a world of his own. Now he pesters his parents all the time! His feeling life has evolved too. He used to want to line up trains and watch a door open and close. Now he wants to play with people; he loves to play pretend. In fact, he wants what he wants when he wants it and if he doesn’t get it now—watch out! He used to ignore his brother. Now he wants Charlie to play but only if Charlie plays the way Jacob wants to play—or else. Nice as Charlie is (or was), he is starting to push back. The sibling rivalry issues have gotten much worse over time. Jacob used to be easy to take places; now tantrums in public are holding the family hostage. In fact, almost all transitions trigger anxiety and frequently lead to upsets.

In short, Jacob has made so much progress developmentally that he has become, as Jim Grant said recently, “a real pain in the butt” behaviorally. As Julie said to me over the phone: “Everyone is walking on egg shells. We’re afraid to go anywhere in public. And poor Charlie is always looking over his shoulder.”

Life Itself
The Grants have outgrown the simpler methods of the PLAY Project per se. It is no longer good enough to simply get down on the floor and play. While rich pretend play continues to be very important, life itself has become Jacob’s playground. He has become a true emotional thinker and he thinks he can do whatever he wants without regard for other’s feelings or the natural consequences of his actions. He’s even begun to lie (when he knows he’s done something wrong), cheat (because he hates to lose), and steal (take Charlie’s toys and hide in the closet in order to play with them)! While I welcome these misbehaviors as a sign of emotional sophistication (As you should know by now, I am a big fan of the ‘dark side’), the Grants are not so happy about it. As Julie said: “Dr. Rick you don’t have to live with him. We do.”

In this third section I go back just a little in time—about six months—when Jacob is beginning to misbehave on purpose. He gives him mom ‘that look’, the one that says “I hear you but I’m not going to do what you say!” This oppositional behavior pushes his parents’ buttons, triggering strong feelings. Julie and Jim, as you’ll see, react quite differently because of their different personalities and family backgrounds.

As with most families who have a child with autism, the Grant family is stressed. Jim and Julie have had to work hard to keep their marriage strong. Grief returns in different guises and overwhelms Julie with sadness. Jim gets angry. Charlie, now old enough to understand, feels threatened and confused by Jacob’s aggression, and seeks attention (often in negative ways) from his parents who are often too busy with Jacob’s different therapies to give Charlie the time and attention he often needs. During our visits I always explore with every member of the family how they are feeling and what they can do next to make it better.

Throughout it all I keep exhorting and urging the Grants to use Jacob’s ‘pain in the butt’ behavior to help Jacob’s symbolic and emotional thinking. I urge them to expand conversations with Jacob especially when he is angry, upset, and/or highly motivated to get something he wants (and can’t have!).
Expanding means asking Jacob not only what he wants, but what else he wants and why he wants its. Expanding means ‘telling Jacob how he feels’ by mirroring back his feelings. I encourage them to connect ideas for Jacob by looking for the unseen motives behind desires, impulses, and misbehaviors. By working intensively, consciously, and compassionately with misbehavior, with life itself, Jacob (and all children with ASD) will gain the vitally important emotional and social skills like:

- Controlling strong emotions
- Complying with demands
- Considering others’ perspectives and
- Being more flexible

In these visits I introduce Jim and Julie to my tried and true parenting protocols including how to deal with ‘The Good, The Bad & The Ugly’ behaviors, implementing ‘Dr. Rick’s 20 Transition Tricks’, using sibling rivalry to help with social skills, and having a plan to deal with common daily hassles and public meltdowns. Welcome to Section 3: Daily Hassles—Using Misbehavior to Help Jacob’s Emotional Thinking.
Chapter 17
Visit 10
The Good, The Bad & The Ugly

The Chief Complaint: Misbehavior

From birth to age three Jacob was content to ‘do his own thing’ and just ‘go with the flow’. It was as if he was so much in his own world that nothing could bother him. But by age 3 to 3½, as he became more engaged and functional, behavior problems began with the emergence of occasional yelling, protesting and small fits of temper (See Chapter 10, Visit 5: Moving On Up?). His behaviors worsened until, at around 4½, he was frequently upset and becoming regularly aggressive (especially toward his brother Charlie) with pushing, pinching and even biting (See Chapter 11, Visit 6: The Turning Point). By age five his behavior has escalated to frequent daily episodes of tantrums and aggression—throwing objects, hitting, kicking, and some self-injurious behaviors like head banging. He was going after Charlie for no apparent reason. I call this the ‘lightning rod’ phenomenon—no matter what made Jacob mad, he went after Charlie to discharge his upset. The phone call notes from Julie Grant went from ‘Mom is worried’, to ‘Mom is upset’ to ‘Please call asap, mom is frantic. Jacob is out of control’.

It was time to talk about ‘The Good, The Bad, & The Ugly’ my approach to handling bad behavior.

I walked into the waiting room where Jacob (age five) was sitting on the floor with his brother Charlie (age three), crashing trucks together with loud crashing noises, then laughing. They were pretending together! I said, “Hi Jacob” testing to see if he would respond. I waited. He looked right at me. I waited. And he said “Hi”. I said: “Give me five.” He slapped me five! Charlie too. “You guys ready to play?” As he and his brother got up and headed for the playroom, I thought to myself “Wow, Jacob has come so far!”

Now, at age five, after two years of a comprehensive program that included intensive, play-based intervention (See Section 2: The PLAY Project Approach) plus special education preschool (four half days/week) as well as speech/language and occupational therapies (an hour per week each), he was back for another follow up visit. The potential within Jacob was great and his program brought out that potential. Now, he was with us, easily engaged, able to carry on a natural, back and forth interactions and his receptive language was good. School had helped him begin to socialize with peers and learn pre-academic skills and routines. His SLP and OT therapies helped with his language and with his coordination, and fine/gross motor development, respectively. I was thrilled with his progress.

Jacob’s parents confirmed that he was making ‘amazing progress’. He was talking in short two to five word sentences, answering ‘wh’ type questions like ‘What are you doing?’ ‘What do you want to eat?’ ‘Where do you want to go?’ but still struggling with ‘why’ questions (though he was beginning to understand simple cause and effect, e.g., ‘Bandaid for boo boo!’). He was still significantly behind his peers developmentally (maybe a year or more) but his parents had already decided to wait another year before putting him in kindergarten (See Chapter 12: Kindergarten: Ready or Not Here We Come). That wasn’t the issue.

Despite all of Jacob’s gains, Jacob’s parents didn’t look happy.
Mom: “Jacob has become a major behavior problem. He almost got kicked out of preschool for pinching a little girl yesterday and the sibling rivalry is terrible. He goes after Charlie all the time.”

Dr. Rick: “How old is Charlie now?”

Mom: “Almost three. They are getting to be buddies but when Charlie wants to play with one of Jacob’s favorite toys... well, Dr. Rick, it’s gotten bad. Plus, he just doesn’t listen until we’re screaming at him. Then he gets mad at us and screams back. He hits, pulls my hair, tries to kick me. It’s gotten BAD!”

Dad nodded in total agreement.

Dr. Rick: “Well, if it’s any consolation, this is a sign of Jacob’s developmental progress.”

Dad: “Great! You can take him home, fix him up, and then return him to us like the good boy he used to be. When we discipline Charlie, he responds and shapes up.”

Mom: “But when we use the same approach with Jacob he seems to get worse.”

Dr. Rick: “That’s right. Children with autism are often tougher to discipline than typical children. You’ve got to be much more systematic in your approach. I have an approach I’ve developed over the years that will hopefully help us help Jacob get himself under control. Let me spend this visit outlining that approach and then over the next few visits we can deal with specific behaviors. But, first I’d like to talk about what goes on for the two of you when Jacob misbehaves.”

**When Children Push Your Buttons**

When misbehavior is the chief complaint, I start by exploring how the parents experience conflict. Because most children with autism are going to create conflict! When young children start to purposefully misbehave and challenge their parents’ authority, parents react emotionally—their buttons get pushed—and they often react out of old feelings that can go way back to the way they were parented; to the way their families of origin handled conflict. Or they react emotionally based on their temperaments. Hotheaded parents get angry. Timid parents withdraw. Everyone wishes the bad behavior would just go away. These reactions are common and completely normal. But they are not necessarily helpful.

Because children with autism think and feel differently, they challenge parents in new ways and elicit new reactions. The parenting methods that worked with Jacob’s younger brother Charlie haven’t worked with Jacob. Remember: It is the theme song of children with autism to ‘keep the world the same’. This means they want life to be predictable and life is a lot more predictable when you get what you want when you want it. And if you don’t get it—watch out!

So I help parents get ready psychologically by exploring how their child with autism pushes their parenting buttons i.e., makes them react emotionally. Then we talk about how to handle misbehavior.

As part of my medical history taking, I collect a three-generation genogram—a family tree (See below)—that looks not only at genetic, neurologic, psychiatric, and developmental disorders, but also personality traits like impulsivity, perfectionism, obsessiveness, shyness, and/or aggression that are also inherited. These family trees can be very revealing about family dynamics too. Here’s where many of ‘the buttons’ get created. An area of great interest to me is how the parents’ parents resolved conflict.

In Jacob’s family genogram you can see some very revealing information:
Jacob’s mom confessed that her dad, who was a heavy drinker, got angry when he was drinking. Her mother was depressed and eventually divorced her husband later in life. Julie and her sister often withdrew and hid when their dad went on one of his ‘rampages’. Her brother who got the worst of it became very angry himself. None of the siblings are very close.

For her, then, anger felt dangerous. Mom wanted Jacob’s anger to just ‘go away’. She felt anxious and helpless and tended to ‘let things go’. She was also very tenderhearted and felt sorry for Jacob. Finally she had a kind, somewhat passive, personality. Her parenting style emboldened Jacob who seemed to know somehow that his anger got him what he wanted from his mom. She backed off when he got angry and didn’t really know what to do. In short, he was learning how to push her buttons.

Dr. Rick: “What I say to parents is: If you are getting angry or yelling then you’re doing something wrong.”

Dad: “We’re doing something wrong?”

Dr. Rick: “You’ll know you have hidden or removed your buttons when you can discipline Jacob and feel fairly neutral. Parents generally fall into 4-5 basic feelings when their child pushes their buttons: overly angry, guilty, sad, helpless, or anxious—about it. You ought to be able to appreciate how smart Jacob is in knowing how to push your buttons. Get a little perspective. Have a sense of humor about it.”

Mom: “Easier said than done.”

Dr. Rick: “True. So, let me ask you a question mom. How does it make you feel when Jacob misbehaves on purpose?”

Mom: “I give him a warning and then I start counting to three and . . .”

Dr. Rick: “Sorry to interrupt, mom, but I’m not asking what you do. I’m asking how you feel when he gives you a hard time.”

Mom (looking confused): “I feel . . . upset, nervous. I don’t want to get into a big fight . . .”

Dr. Rick: “You feel like backing off?”

Mom: “Kind of. Sometimes. Yes, I keep hoping he’ll listen so I don’t have to yell. But then I have to yell and then I end up screaming sometimes. It’s so confusing.”

Dr. Rick: “Do you see how your buttons show up as feelings? In your case you feel nervous, confused, and a bit afraid.”

Mom: “And you mentioned helpless. I don’t know what to do sometimes.”

Jim Grant, on the other hand, recalled rarely misbehaving as a child. All his parents had to do was ‘give that look’ and the children in the family ‘toed the line’. His dad was strict; his parents were Catholic and religious; and they instilled the ‘fear of God in us’. His sister was moody and was recently evaluated for possible bipolar disorder.

If Jim Grant misbehaved as a child he felt guilty. He was a ‘good boy’ and he expected Jacob to ‘be a good boy’ too without having to say much. When Jacob actively disobeyed him, it felt like disrespect and really made dad angry. He tended to lash out in a loud booming voice, which upset everybody in the house (including dad!). He yelled a lot but he didn’t really know what to do. Interestingly, Jacob developed a loud booming voice when he got mad and yelled back! He found dad’s buttons.
For mom especially, there was one other ‘button’ that showed up frequently—the ‘sadness button’.

Mom: “It breaks my heart to see him cry.”

Dr. Rick: “I know, he’s suffered so much already. These kids have it so hard!”

It was mom’s turn to cry. I handed her a tissue. Mom was feeling the grief that hangs like a constant cloud over families; a profound sadness about how hard life is for their child with autism.

Later we would have a discussion about challenging Jacob and not babying or underestimating him, about giving him a ‘message of competence’. Later we would talk about how grief and tender heartedness can interfere with discipline. But now was not the time. The process of grieving must be honored one cry at a time.

So Jacob’s parents—who are loving, kind, concerned, and dedicated—have their buttons and Jacob has learned how to push them. I have found that parents, once they know about and can see their ‘buttons’ being pushed, once they know that the old ways of resolving conflict don’t work so well with children on the spectrum—they are usually ready to try something different.

Note: If parents’ buttons are continually being pushed I will often recommend counseling to help them go deeper into their reactions so they can get to that ‘neutral’ feeling.

Dr. Rick: “So, this is not about love. I know you both love Jacob and Charlie unconditionally. But this is not about guilt, anger or fear either. This is about bad behavior in a child with autism and how to deal with it.”

Dad: “You’re saying that children with autism are harder to discipline, right?”

Dr. Rick: “Right. In two ways. First, they are often, but not always, naturally stubborn because they want to ‘keep the world the same’. Second, their emotional life is immature. Their brains process feelings differently, often slowly. They are easily overwhelmed by their impulses. So the approach I want to teach you has two benefits. First, it will help Jacob behave. But, more importantly, it will help Jacob to become a more mature thinker and feeler.”

Mom and dad looked at each other, then looked at me as if to say, “OK then, let’s get going!”

Dr. Rick: “What we need is a plan—a set of parenting protocols. You cannot fly by the seat of your pants. You need to know what to do ahead of time when Jacob misbehaves so he won’t push your buttons. Your job is to help him get himself under control and learn from the conflicts. And the first step is to define clearly for Jacob and yourselves what bad behavior is. In other words we need to talk about The Good, The Bad, & The Ugly.”

The Good, The Bad, & The Ugly
Jacob was having at least one to two major meltdowns—crying, hitting, kicking, throwing things—every day; with minor meltdowns—yelling, threatening, swearing (‘You poopy!’)—5-10 times per day! Not to mention whining, pouting, and crying.

Dr. Rick: “He is really struggling! So what triggers all these tantrums.”

Dad: “You name it. He wants what he wants when he wants it; and when he doesn’t get it he throws a fit so fast it makes your head spin. I mean 0-60 in one second.”

Dr. Rick: “So broken expectations trigger him.”
Mom: “And whenever Charlie gets into Jacob’s space.”
Dad: “And when he has to stop doing something he likes.”
Dr. Rick: “Transitions are a trigger.”
Mom: “Especially when he has to get ready for school or go to bed.”
Dr. Rick: “No wonder you’re freaking out! We’re going to help this boy get under control. By the time you leave today we may not get to all the specifics but we are going to have a plan.”
Dad: “Amen.”

The very first step in helping Jacob behave is to define his behaviors as either good, bad, or ugly (see the chart below):

<Insert 1.8 JPEG GBU here>

**Good** behaviors—listening, cooperating, helping, etc.—are easy to define. **Ugly** behaviors—whining, making faces, arguing, minor pushing, etc.—are defined as neither good nor bad. **Bad** behaviors are defined as **behaviors that break rules**.

- We want to increase **good behaviors** by giving those behaviors lots of attention.
- We want to reduce **ugly behaviors** by mostly ignoring them or **changing** (transforming) them into good behaviors.
- And we want to **discipline** **bad behaviors**. The word ‘discipline’ comes from the Latin ‘to instruct or teach’. The main task here is to teach Jacob how to get what he wants in a way that is acceptable. We don’t want to punish him or fight with him and hurt his feelings on purpose (though our discipline will certainly make him unhappy at times!).

Dr. Rick: “By definition then, **bad behavior breaks rules**. So what are the rules of your house?”

Jacob’s parents looked at me with blank faces.

**Visit Overview**
My plan for this visit was to give an overview of *The Good, The Bad, & The Ugly* approach to misbehavior. I also wanted to make sure that we discussed the three most common mistakes parents make (besides letting their buttons get pushed!) in handling problem behaviors of children on the spectrum, namely:

1. Paying attention to ‘ugly’ behavior that should be ignored;
2. Not being clear about the rules that define bad behavior; and
3. Not paying enough attention to their children’s feelings.

**Do NOT Give Attention to ‘Ugly’ Behaviors.**

**Perhaps the most common mistake parents make is giving attention to ‘ugly’ behaviors.** One of the fundamental rules of behavioral psychology is: *The more attention you pay to any behavior, the more it will increase*. After listening carefully to Jacob’s parent’s complaints I made a tentative list of what I saw as Jacob’s ugly behaviors. Would any parent look at this list and want these behaviors to increase?

*Jacob’s ‘Ugly’ Behaviors*

- Whining
• Crying
• Pouting
• Tantrums
• Threatening (‘Hit mommy.’)
• Potty mouth/‘swearing’ (‘Poopy daddy.’)
• Minor teasing (being mean is ‘bad’ behavior)
• Minor sibling arguing
• Minor sibling roughhousing
• Running around wildly
• Being silly (making fart noises, wiggling butt)

No? Then don’t give them too much of your attention!

And yet Jacob’s mom and dad admitted that they paid a lot of attention to these behaviors. Just in the short time they were in the office I heard them say:
- Jacob, please stop whining.
- Don’t tease your brother!
- Jacob, don’t run around! You’ll get hurt.
- Mommy doesn’t like it when you say ‘You’re a poopy.’
- You’re going to hurt each other wrestling like that. Stop it, now!
- We cannot go yet, stop asking please.
- Young man, do NOT threaten me!

Dr. Rick: “Here’s a list I made of Jacob’s behaviors that we could consider ‘ugly’ (See the list above). **Ugly behaviors are behaviors that don’t break rules but are not good behaviors.** They are the kind of behaviors nobody likes yet in most families (who don’t know the secret of ignoring) they are the most common of the three types of behaviors. Would you like to get rid of any of these?”

Mom: “I would love it. These behaviors are so constant they’re driving me crazy.”

Dr. Rick: “I’m warning you. If you withdraw attention from ugly behavior I’m worried you won’t know what to do with all your free time!”

Dad: “We’ll take the risk.” (We all laugh.)

Dr. Rick: “Reducing ugly behaviors is not easy. They’re designed to get your attention and push your buttons. But remember, this is not about you. It’s not about love. It’s not about Jacob being a ‘bad boy’. It’s about Jacob’s behavior. Ugly behaviors are, well, ugly but, by definition, they do not break any rules because they are not truly harmful or destructive or disobedient. If you ignore them, they lose energy and they will go away. I promise.”

Mom: “I think I could ignore whining and crying and even tantrums but what about threatening and disrespectful language?”

Dr. Rick: “You’ve heard the phrase ‘pick your battles? Well, pick your battles.”

Mom: “I can tell you that threatening my mother or calling my dad ‘poopy’ would never have been tolerated by my parents! This would have been called ‘disrespectful’.”

Dr. Rick: “That’s a hard one for many parents. It pushes their buttons. But, in fact, this is not really about respect. The boys respect you. They just get angry at you and then they say things which they think will make you angry.”

Dad: “Well, it works. I think it’s mean and it makes me very angry.”
Dr. Rick: “We'll put disrespectful behavior on our list of ‘bad behaviors’ that break the rules. (I add it to the list.) And we'll talk about what to do about that later.”

Dad (smiling): “Good.”

Dr. Rick: “The important point here is to make sure the boys don’t get a lot of your attention or energy for ugly behavior. Here’s how I recommend handling ugly behavior:

- **Acknowledge** what Jacob wants, e.g., ‘You want to go to K-Mart right now.’
- **Explain** why he can’t have what he wants, e.g., ‘But it’s too late, Jacob. We can’t go.’
- Tell him: ‘I don’t like your (whining, yelling, crying, tantrumming) behavior. It will not help you get what you want.’
- **Offer them a better way** to get what they want (See below: Transforming Ugly Behavior).
- **Say these words:** ‘If you keep (whining, yelling, crying, tantrumming) I am going to ignore you.’ Then **walk away** to another room, and finally
- **Make sure they never get what they want** for this type of behavior.
- **Note:** You do not have to go through all these steps if you’ve gone through them already. Just say: ‘I’m done talking to you about this.’ Then walk away. Talking too much is a form of attention!

**Crossing the Line: Pestering.**

Mom: “But what if Jacob’s pestering is constant and he comes after me and whines at me wherever I go?”

Dr. Rick: “That’s a great question and, in my home, that kind of pestering would be called ‘bad’ behavior. It’s intrusive and aggressive. So let’s call that kind of aggressive pestering ‘bad’ behavior. (I add it to the list of rules for the Grants.) Call it ‘The No Pestering Rule’ and say: ‘Jacob you may not pester me. I will count to three and it better stop.’ If he pesters one more time, that’s it. He put his toe over the line. You decide the consequence beforehand and the consequence should fit the crime and be fair.”

Mom: “What do you recommend?”

Dr. Rick: “If he can’t be nice around me I’d send him to his room until he is ready to stop the behavior. I just want you to have a plan for every bad behavior.”

Dad: “Not five minutes? One minute for each year?”

Dr. Rick: “You could do five minutes. That’s popular right now in parenting circles but I just want his behavior to change.”

Dad: “I’m starting to see how this works. ‘Ugly’ behavior you can ignore. Jacob might get mad but it won’t really hurt anything. ‘Bad’ behavior we have to turn into a rule and do something about.”

Dr. Rick: “Exactly right, dad! But we’re not doing this to hurt his feelings or ‘punish’ him. We just want the pestering to stop.”

Mom: “What if he won’t go to his room?”

Dr. Rick: “You’ll win that battle. Can we put that discussion off until later in the visit?”

**Transforming Ugly Behavior: Good negative behavior**

What’s also interesting about ‘ugly’ behavior is that, while it can cross over into ‘bad’ behavior, it can also be changed into ‘good’ behavior. While I knew we would be discussing Jacob’s many challenging behavior at the next few visits, talking about pestering would be a good place to start.

Behind all of these ugly and bad behaviors are upsets, frustration, and/or angers. We want our children to be able to express these feelings in a mature way. I call this ‘good negative’ behavior. It means expressing your negative feelings in a good, acceptable way, which is what we do (hopefully) as mature adults.
We don't want to repress Jacob's feelings but we don't want him screaming (ugly) and stomping (ugly) and slamming doors (ugly) either. Our goal then is to teach our children to 'use their words' to express upset and anger in a better way: 'If you are mad at mommy, just say: “Mommy I'm mad at you. I want to go to K-Mart now and you said No!”' It is ‘good’ behavior for your children to be able to express negative feelings toward you in a way that is direct and not disrespectful (i.e., good negative behavior). Give Jacob permission to be mad at you in an acceptable way. It’s OK for him to be angry with you, isn’t it?"

**Mom:** “Yes.”

**Dad:** “I guess.”

**Dr. Rick:** “So dad, let me guess. You couldn’t be angry with your folks.”

**Dad:** “Good guess. But I don’t want my kids to feel the way I did.”

In this way, most of the ugly behaviors can be transformed to more mature, good behaviors. Of course, it doesn’t mean Jacob will always get what he wants for ‘using his words’, but he will get what he wants more often. And he should never, ever, ever, ever, ever, ever, ever get what he wants for ugly behavior.

Finally, when you, as parents, have faith that ‘ugly’ behaviors will go away you will transmit strength to your child. The child gets the message of competence: ‘We expect you to act in a mature way.’ There is a sense of humor and perspective that your children will sense. They will know that ugly behavior doesn’t push your buttons and if ‘ugly’ behavior turns ‘bad’ you will deal with it by enforcing the rules. But you must be very clear about the rules.

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**Being Clear About the Rules**

The second most common mistake parents make is not being clear about the rules. It’s not that Jacob’s parents didn’t have rules; they just couldn’t list them off the top of their heads. You can’t be clear about the rules if you can’t list them!

Most families have about 10-15 rules whether they know it or not. (See *Family Rules: The Top 5* below; we’ll discuss the other rules later.) I highly recommend that families write down their rules, with reasons and consequences and place them on the refrigerator for all to see. I call this the Rules, Reasons and Consequences Chart. This is especially helpful for children with ASD.

In listening to Jim and Julie I hear at least five rules emerging from the discussion:

**Family Rules: The Top Five**

1) No hitting or aggression.
2) No throwing things on purpose. No being destructive.
3) No ignoring. We listen to each other.
4) No disrespect.
5) No pestering.

Note: I will talk about how to enforce these rules after we have a discussion about ‘Rules, Reasons, and Consequences’.

**Rules Have Reasons. . .**
All rules must have reasons and everybody follows the same rules (including mommy and daddy) for the same reasons. Remember, our ultimate goal is to help the children become more mature in their thinking and feeling. They should not follow rules simply because we ‘said so’.

Reasoning and talking, rather than yelling, threatening and/or spanking, are better at improving children’s behavior in the long run. But too much talking and not enough action can lead to misbehavior and ‘spoiled’ children. We want to steer a middle ground between being too hard or too soft. I call it the ‘iron fist in the velvet glove’ approach. We want to be attentive, sensitive, understanding, and nurturing. Our ultimate goal is for our children to internalize the rules, reasons, and consequences so we do not have to tell them what to do all the time. This may take dozens of repeated opportunities and lots of practice. Some children, like Jacob, have to learn the hard way by suffering repeated negative (iron fist) consequences. So it goes.

Here’s how I explain the reasons for the top three rules to the children. I tend to deepen my voice an octave, make it louder by 10 decibels, and make sure my face is stern so that gesturally the message is clear:

- There is ‘No Hitting’ because it hurts people. My mantra is: “When you hit you never get!” There are better ways to be angry than hitting.
- There is ‘No Throwing’. It breaks things and can hurt people. There are better ways to be angry than throwing.
- You are not listening to me. ‘We listen to each other’ so we can talk. You don’t have to do what I say but you may not ignore me. I listen to you. I want you to listen to me.

Of course, when children are in the fury of a meltdown there is no point in reasoning at all. Even when children are not tantrumming and can hear you, simply explaining the reasons is usually not enough to help children internalize the rules. They need to suffer, I mean experience, the iron fisted consequences of their behaviors. This approach is tried and true. While it may take a while to work (i.e., a few weeks to a few months) it will work but parents must be consistent. Rules may have reasons but that is rarely enough; they also need consequences.

**. . .And Consequences**

Consequences are of two types: positive and negative.

- Positive:
  - If you follow the rules life gets better (this is the whole point!). People are happier; they get along; you get what you want more often; you may get prizes, etc.

- Negative:
  - If you don’t follow the rules it causes the people in your family to be unhappy. You don’t get what you want, you will lose privileges that you like (loss of computer time, your freedom, etc.) and you won’t get the rewards and prizes that you would have gotten if you had behaved. If you can’t be nice to others you will have to spend time away from them.

There are dozens of specific consequences that include a wide range of positive rewards, prizes, and benefits on the one hand, to time outs/time away, natural negative consequences and loss of privileges on the other hand depending on the nature of the specific rules that are followed or broken (See Resources & Websites: ‘1,2,3 Magic’).
We will discuss these in the coming visits as we address Jacob’s specific behavioral problems in the rest of Section Three.

The most severe consequence—the one we save for the worst behaviors like hitting and throwing—is the use of force.

The Use of Force
As I explained the Good, Bad, & Ugly approach Jim Grant jumped in:

Dad: “This is all very good but are you going to tell us what to do when Jacob won’t listen, and starts throwing things at us and then won’t go to his room?”

Dr. Rick: “The quick answer is you help him get himself under control immediately. What is your alternative? Let him ignore you, hit you, destroy the house? He has broken the rules. He does not have a choice. Let me give you a few quick examples.”

- From the Mini Time Out to Longer Time Outs. Let’s take not listening (Rule 3: We listen to each other) as an example. Let’s say it was time to clean up. You have given Jacob fair notice; you have asked him to clean up twice and he ignores you. You go over to him, get down at face level and say (not yell) in a calm neutral but firm clear voice: “Excuse me Jacob, you are not listening. Please stand up, stop what you are doing, and have a seat here (a mini time out). Thank you. When you get up from the chair I want you to clean up or you will go to your room (or time out chair) for five minutes.” If he is does not clean up immediately then he gets a five minute time out. (Afterward he will still have to clean up.)

Dad: “What if he still doesn’t clean up?”

Dr. Rick: “You repeat the procedure and double the time in time out. You do that for three times (total of half an hour). Then you warn Jacob. If I have to clean up your mess then I will put the toys away. Your toys will be gone for the rest of the day. No more toys. All gone!”

Mom: “That’s pretty harsh.”

Dad: “Sounds fair to me. He should clean up after himself.”

Dr. Rick: “You can try different consequences. That’s how I would do it. Just remember. The consequences should be enough to make him think twice the next time. ‘Do I want to lose half an hour of my life and lose my toys for a day?’ The consequences should fit the crime and be effective.

- For aggression and throwing you will stop him immediately by force, i.e., hold him, if necessary.
  We’ll talk about how to do this next.

- For resisting going to his room you may have to physically take him to his room and you might double the time he spends there for resisting.

The point here is to have a plan, a parenting protocol, so you don’t have to think about it too much. The child should be completely aware of the plan. There should be no sudden surprises or arbitrary punishments, i.e., “That’s it you’re grounded for a month!” We’ll go over exactly how to do this later but when it comes to discipline your main job as parents is to enforce the rules. You must win all battles related to the rules. Generally it takes about one to two weeks of consistent battle winning for the child to realize that he is not going to get what he wants by misbehaving. It can take months, however, before mature behavior is completely internalized.”

Mom: “I don’t think I could stop him when he gets violent.”

Dr. Rick: “I truly hope that the two of you do not have to physically restrain Jacob. Physical consequences are a last resort. We’re going to do everything we can to be loving, kind, gentle, and fair (use the velvet glove!). We are going to reason with Jacob. But if he doesn’t follow the rules after
you've reasoned with him, you must strictly enforce the rules and may have to physically guide him to a chair or physically take him to his room or even hold him. I even say to the children: ‘I don’t want to do this but you have made a bad choice so now we have to help you get under control’.”

Dad: “I guess it’s better to do this now when he’s five than later when he’s fifteen.”

Dr. Rick: “Absolutely. Mom, you are physically much stronger than he is, for now. . .but I really want you to understand that we are not doing this to punish Jacob. We are doing this so he will learn to control his impulses, get his behavior under control, and become a more mature thinker and feeler.”

Mom: “I don’t think I could do that.”

Dr. Rick: “You're worried about getting physical with Jacob.”

Mom: “My husband is much better at this.”

Dr. Rick: “But when dad's not home what is your alternative? Let him hit you or Charlie? What if he is out of control breaking things? You really must know how to get him under control.”

Mom: (looking doubtful).

Dr. Rick: “Mom, let me just tell you that when you establish the rules, Jacob hopefully will only test you for a short time and then you won’t have to resort to physical control. I'll show you how to control him in a way that is safe.”

Mom: (still looking doubtful).

Dr. Rick: “Let's not worry about this now. Let's get back to some do's and don'ts for making sure the ‘Rules, Reasons, and Consequences’ approach works with the least amount of arguing and battling.”

Mom: (temporarily relieved) “Sounds good to me.”

Rules: The Do’s and Don’ts
The most potent force for reducing misbehavior is to create a loving, nurturing family environment with a positive love-charge.

Rules: Do’s and Don’ts
• Nurture, nurture, nurture
• The ‘mirror’ technique*:
  • Feeling reflections
  • Behavior reflections
  • Language reflections
• The ‘never, ever, ever, ever, ever, ever rule’
• Rule by the rules, not emotions
• Toe over the line rule
• Message of competence
• GOYA

*Mirroring: Do not ask questions. Make statements: “You are mad because your brother took your toy!!!”

Nurture, nurture, nurture. Everyone in the family should feel loved, supported, and cared for. That’s why Nurture, nurture, nurture is first on the list. When parents pay attention to good behavior by giving lots of time, doing things together as a family, appreciating cooperation, complimenting kindness, and acknowledging accomplishments then the children will want to please their parents. Too often we take good behavior for granted. Give your full, undivided, loving attention to each of your children
and do what they want. Attention is a basic need. We all love it, crave it, and need it. (See Section 2: The PLAY Project Approach)

Yet, these days the demands on parents are greater than ever which can make it hard to ‘nurture, nurture, nurture’. Two working parent families, single parent families, families who are distant from grandparents, and lack of the traditional social supports from neighbors, churches and community agencies have, I’m afraid, become the norm. Families are more isolated and vulnerable than ever before.

**Dad**: “I have been working a lot lately.”
**Mom**: “But honey you are such a good dad.”
**Dr. Rick**: “You are a wonderful family but it’s easy to slip into routines. Just don’t let nurturing take a back seat! Make time for each other too. Mom, let the laundry go. Dad, take mom out for a romantic dinner at least once a month. Forget the email, turn off the TV, and don’t answer the phone. Place the highest value on people not things, on play and having fun times together. Time slips away and, before you know it, the children are older.”

“For typical children, the lack of nurturing shows up in resentment, neediness, and often misbehavior. For children with autism, the lack of nurturing shows up in isolation, repetitiveness, poor development, poor impulse control and . . . misbehavior.”

**Dad**: “Julie’s amazing but the stress is tough and there is a lot of yelling going on.”
**Mom**: “We have some big differences what to do when it comes to discipline.”
**Dr. Rick**: “But still it sounds like you guys are doing OK together?”
**Dad**: “We did go to the minister at our church a couple times and that helped but we still haven’t figured out this behavior thing.”
**Dr. Rick**: “One of the most important weapons to help you deal with ‘this behavior thing’ and maybe the best way to ‘nurture, nurture, nurture’, is to recognize Jacob’s feelings.”

Reflecting (Mirror back) Feelings! In my discussion with Jacob’s parents, though, I could see that there was one source of nurturing that was missing. Now we come to the third most common mistake parents make in handling problem behaviors of children on the spectrum.

**Jacob’s parents were not consistently acknowledging Jacob’s feelings.**

For example, Jacob’s parents reported that almost every time Jacob was told to turn the TV off because it was time for dinner, he would get mad and throw a 15-minute fit (See Chapter 18, Visit 11: Dr. Rick’s 20 Transition Tricks).

**Dr. Rick**: “So tell me exactly what happens.”
**Mom**: “I say: ‘Jacob, it’s time for dinner. Turn off the TV.’ Then Jacob screams ‘No-o-o-o-o-o!’ and I know we’re in for it,”
**Dr. Rick**: “Then what do you do?”
**Mom**: “I start counting. I tell him: ‘Jacob I’m going to count to three. If you don’t turn off the TV, I will.’ Then I count to three and turn the TV off (because he never does) and then he attacks me. He actually hits me and he’s getting big.”
**Dr. Rick**: “OK. So you skip how he’s feeling and move right on to discipline.”
**Mom**: “What do you mean, ‘skipping his feelings?’”
Dr. Rick: “I mean you don’t talk about how he feels. He’s upset that he has to stop. He feels upset and you don’t say anything about that.”

Mom: “I never even thought about it.”

Dr. Rick: “You should ‘mirror his feelings’. So when Jacob says ‘No-o-o-o!’ you could say:

- ‘You’re mad! You don’t want to stop.’ OR
- ‘Jacob, you don’t want to stop TV right now. You love that show.’ OR
- ‘No-o-o-o mommy! Watch TV. No dinner-r-r-r!’

Dad: “We could say that but how is that going to change anything?”

Dr. Rick: “Mirroring feelings does three things:

- First, it helps him recognize his feelings, which is the first thing mature thinkers and feelers do. They are aware of their feelings.
- Second, it lets him know that you know how he feels. And it feels good to be understood.
- And, most importantly when it comes to behavior, simply mirroring back to a child what he is feeling can stop a tantrum in its tracks.”

Dad: “I’ll believe that when I see it. When Jacob hits my wife all I want to do is give him a good spanking, not ‘mirror his feelings’.”

Dr. Rick: “You sound skeptical. And when Jacob hits mom you think that’s just not right and he deserves something more than just talking.”

Dad: “You got that right.”

Dr. Rick: “I was just mirroring your feelings.”

Dad: “H-m-m. Very tricky.”

Dr. Rick: “I wasn’t trying to be tricky. For me it’s second nature. It’s probably the technique I use the most with children. I mirror or reflect back to the children their feelings, their behaviors, and their language. I learned this from a wise education professor back in my fellowship days. It gives the children important feedback about what they are feeling, doing, and saying. I’m always listening for how people feel because it works to help them feel understood. It will really help Jacob to calm down before he throws a fit. In fact I’ll show you right now.”

Settling an Argument. Just as we were talking about this, I noticed out of the corner of my eye that Jacob and his brother were starting to argue over one of the toys in my office. Jacob took Charlie’s toy—a Thomas the Tank Engine—without asking. Charlie was yelling and starting to climb on top of Jacob to get it back.

Dr. Rick (quickly removing Charlie from climbing on Jacob): “Whoa, whoa, Charlie, we’ll get your train back. We’ll get your toy back.”

Jacob pulled the train to his chest as if to say, ‘The heck he will get this toy back.’

Dr. Rick (reflecting Jacob’s feeling): “You want that train so bad!”

Jacob: “My train.”

Dr. Rick: “You think that’s your train.”

Jacob: “My train.”

Dr. Rick: “You really want that train.”

Jacob: (smiles)

Charlie: (getting mad)

Dr. Rick: “Oh, Charlie, you want that train too! You were playing with it and Jacob took it away! Oh no. Jacob took your train!”
At this point both boys are calm but Charlie is still angry and Jacob is hopeful that he can have the train (I’ve been reflecting their feelings throughout).

**Dr. Rick:** “Jacob, I know you want that train and you can have it when Charlie is done playing. We have a rule: ‘No taking toys without asking.’ Charlie had it first.”

**Dad:** “Give the toy back to Charlie, now.”

**Jacob:** (clinging tighter to the toy)

**Dr. Rick:** “OK. Dad, jump in here. Mirror Jacob’s feeling. Use a statement, don’t ask a question.”

**Dad:** “He should just give it back.”

**Dr. Rick:** “I agree but I want to work this through by **mirroring feelings** so Jacob truly understands how to behave. *Tell* him, *don’t ask* him, *how he feels.*”

**Dad:** “He doesn’t want to give it back.”

**Dr. Rick:** “That’s the feeling. Make it a statement.”

**Dad:** “Jacob. You don’t want to give the toy back.”

**Dr. Rick:** “Perfect, dad. We have reflected back to him his feelings. Now, let’s tell him the rule, the reason, and the consequences.”

**Dad:** “You can’t take Charlie’s toy. You have to ask. Charlie had it first. If you don’t give it back. . .(dad looks at me).

**Dr. Rick:** “. . .we’ll take it back and if you hit or throw you’ll have to sit in the time out chair. Jacob, please give the Thomas back to Charlie! You can play with it in five minutes. You can have a turn. So, Jacob, what’ll it be? Give Charlie his toy back or we will take it from you.”

We waited. Jacob, after what seemed like a long pause and a long silence, finally resentfully gives the toy to Charlie.

**Dr. Rick:** “Thank you Jacob. You’ll get a chance to play with the toy soon.”

**Mom:** ‘That was amazing. That would have been a meltdown for sure.”

**Dr. Rick:** “It took us a while but so what? Look at everything we accomplished by reflecting the boys’ feelings:

- Jacob understood his own feelings.
- He understood Charlie’s feelings.
- He seemed to understand the rule—*No taking without asking*—and the reason: ‘It made Charlie unhappy.’
- He made the choice to behave *on his own!* (Even though he was a little reluctant).
- He understood the consequences. Now he will get to play with the toy later instead of having to sit in the chair.”

I said all this loudly in front of Jacob to let him know how well he did.

**Note:** In *Chapter 24, Visit 14: Siblings With Rivalry!* we’ll go over the ‘rules for sharing’ that guided me in this interaction.

So, just to summarize the ‘Mirror Technique’:

1. **Recognize** the feelings of the child.
2. **Mirror** or reflect those feelings (or behavior or language) back to the child in a way that really joins the child and shows that you understand his feelings. (Pause. Don’t rush past the feelings by using the ‘I know, but’ method: ‘I know you feel mad but you have to give the toy back.’)
3. **Use statements** not questions. Children’s feelings are not in the form of questions, i.e., ‘Am I mad?’ No. Their feeling are in the form of statements, i.e., ‘I’m mad!’

4. Then go back to the **rules, reasons, and consequences** approach.

Parents are amazed at how effective this simple method is in improving misbehavior. (See Resources & Websites: How to Talk So Kids Will Listen and Listen So Kids Will Talk). Of course, feeling reflections don’t always work. As we saw with Jacob and Charlie, they must be combined with the rules, reasons and consequences approach.

*The Never, Ever, Ever, Ever, Ever, Ever, Ever Rule.* While it may be most important to ‘nurture, nurture, nurture’, reflect feelings, pay attention to good behavior, etc, it also very important to be clear about the rules and to discipline consistently. Children with autism will get confused if you are not clear, predictable, and consistent.

So, let’s return to the Do’s and Don’ts and focus on one of the most important don’ts.

*Don’t give the child what they want for misbehavior. I call this the Never, Ever, Ever, Ever, Ever, Ever, Ever Rule.* You must say all seven ‘never evers’. Children will remember it and it will become a mantra. ‘Jacob, you will never, ever, ever, ever, ever, ever, ever get what you want for hitting (bad behavior), tantrums, threatening, yelling, whining, or pestering (all ugly behaviors).”

And yet we give in all the time.

We give the crying child some candy so they will be quiet in the store. We let them play their video after they’ve pestered us and whined for half an hour. “Here. Now stop your darn pestering.” We are unfair to sibs: “Just let him have the toy. I can’t stand his whining.” We cave in. We break rules. We do what’s easy. We just want them to be quiet!

In the behavioral sciences this is called ‘intermittent reinforcement’—giving the child what they want sometimes, i.e., reinforcing them every once in a while (i.e., intermittently). And according to behavioral studies—even with animals!—this is the most powerful way to keep the bad behavior going! If a child cries for an hour and then you give in, you have just reinforced (rewarded) crying for an hour. You can be sure the next time they want something they will cry for an hour (and one minute!) to get it.

Sometimes, especially when you are in public, it’s the better choice to give them what they want even for ugly behavior. *If you are going to give in though, give in right away.* Do not give in after long periods of whining, crying, or tantrumming.

**Note:** In the next few visits I am going to provide the Grants a parenting protocol about how to handle public misbehavior, car misbehavior, and other forms of embarrassing behaviors.

A corollary to the ‘never ever’ rule is ‘an ounce of prevention is worth a pound of cure’. Practice prevention. Prevent ugly or bad behavior by reasoning with your child early in their upsets or better yet before they get upset and teach them (give them permission to use) the best way to get things from you.

“So Jacob, if you want to keep watching TV, no yelling. You will never, ever, ever, ever, ever, ever get what you want for yelling at me. But you can make a deal. Say: ‘Mommy, please, five more
minutes. Please?’ Maybe I will let you watch until the next commercial. But if you yell or especially if you hit, no TV. Remember: When you hit you NEVER get.”

If Jacob does this type of if-then negotiating I probably would reward his good behavior—making a deal—by letting him watch TV. But I’d make sure the TV is off in five minutes or at the next commercial! (There’s more of this in the next visit: Dr. Rick’s 20 Transition Tricks).

Of course the child must be must be high functioning enough to reason with him in this way. I felt that Jacob, who is functioning at Greenspan FDL V-VI (See Chapter 15, Visit 8: Rich Pretend Play) could understand this. For children who have lower functioning capacities, parents will have to simplify their message and/or limit explanations but the major rules—no hitting, no throwing, listening, etc.—apply to everyone no matter how high or low functioning they are.

The take home lesson is that you should teach your child appropriate ways to get what they want but they should ‘never, ever, ever, ever, ever, ever, ever’ get what they want for misbehavior.

Rule by the Rules!

Mom: “But what if he doesn’t stop watching TV after five minutes.”
Dr. Rick: “You tell me. What if he doesn’t?”
Mom: “I tell him and I tell him and I tell him until I’m blue in the face and he still won’t listen to me until I start yelling and warning and threatening. Then he might get off and finally come to dinner.”

Dr. Rick: “That’s because you are not ruling by the rules. Jacob was ignoring and broke the ‘We listen to each other’ rule. He was not following the ‘We eat dinner together rule.’ He was breaking at least two rules. You should rule by the rules. After he ignores you once or twice you go over to him and tell him which rules he has broken and have him sit in a chair like we talked about earlier until he is ready to sit at the kitchen table. Use the mini time out method.”

Mom: “But he won’t listen; he won’t go to the kitchen table.”
Dr. Rick: “But you said he does eventually. You have to get furious with him first, right?”
Mom: “Actually that’s true. He does finally listen after I get really upset.”
Dr. Rick: “This is what I call ruling by emotions. Here’s how Jacob understands the rule: ‘When mom gets really upset I will stop what I’m doing and listen.’ This is a very bad rule because it means that you have to get angry before the children will listen. This means that there is going to be a lot of yelling going on.”

Dad: “You got that right. I can’t stand the yelling.”
Dr. Rick: “And once you are upset and ruling by emotions it’s easy to get carried away and say things you regret. For instance, you might get so angry that you make up rules or consequences that you can’t enforce.”

Dad: “You mean like getting so mad you tell him he’s grounded from the iPad for weeks?”
Dr. Rick: “Exactly. Part of ruling by the rules is not making rules up on the spot. Each rule has its consequences that are determined ahead of time and shared with the boys. You can even have the kids help you. They should know what’s going to happen to them.”

Toe over the Line. Children with autism especially need to know clearly and precisely where the rules start. The best way to be clear about the rules is to enforce the ‘Toe over the Line Rule’. As soon as Jacob has put even a toe over the line, that’s it. He suffers the consequences and learns that you are going to rule by the rules.
The ‘toe over the line rule’ applies to bad behavior—hitting, throwing things on purpose, not listening—and usually provokes the most response from the child because ‘toe over the line’ is the bottom line. It is the final ‘No’. The child has broken the rule and will now suffer the (predetermined) consequences.

Dr. Rick: “So you count to three, creating the line, and Jacob has to stop watching TV. No more discussions, no more reasoning or talking, no more deals. You tell him to get up and if he doesn’t get up then you firmly take his arm and lift him up...”

Mom (interrupting, clearly anxious): “OK, I admit I yell. I make deals until I’m blue in the face but eventually I turn off the TV and he will just sit there and scream and call me names and threaten me. I go to take him to his room...”

Dad: “...But when I’m not home, Jacob will resist. He’ll flop to the floor. He’ll have a fit. He hits her!”

Mom (turning to me): “What if he attacks me?”

Dr. Rick: “Has he?”

Mom: “Yes. It’s happening more and more.”

Dr. Rick: “What do you do?”

Mom: “I go to my room and lock the door. And he pounds on the door and kicks it to the point where there are holes in the door and it’s getting loose on its hinges.”

Dr. Rick: “Mom, I’m starting to see why all this is so hard for you...”

Mom: “The idea of having to fight with my own son really upsets me.”

Dr. Rick: “You feel sorry that it has to come to this.”

Mom (nodding through tears.): “I just wish he would behave!”

At this point, the whole room feels sad. Even the boys have noticed mom crying and Charlie (not Jacob) comes to her side to make her feel better.

Charlie: “Mommy, stop crying.”

Dr. Rick: “Yes mom’s crying because she feels sad when Jacob hits her.”

Jacob meanwhile continues to play but he is paying attention and seems to be affected by his mom’s feelings.

A Message of Competence.

Dr. Rick: “The problem with putting yourself in time out is that it empowers Jacob. He senses that you are sad and afraid of a physical confrontation with him. And, perhaps most importantly, it doesn’t give him a message of competence.”

Mom: “A message of competence?”

Dr. Rick: “What message is Jacob getting when you avoid discipline? When you feel sad for him? When you let him dominate and misbehave?”

Mom: “That he is stronger?”

Dad: “That being a brat is OK?”

Dr. Rick: “No, worse than that. Actually the subliminal message you are sending him is that he is ‘a poor little boy with autism who doesn’t have to behave himself’. You are telling him (even though you don’t mean to) that you don’t believe in him.”

Mom: “I never thought of it that way. We expect Charlie to behave. It’s like we don’t expect Jacob to.”
Dr. Rick: “And can I tell you that giving Jacob the power to not listen and not follow the rules that everyone else follows is actually scary for Jacob. It’s too much power and of course it’s not real power. It’s really immature behavior.”

Mom: “I’m really getting this. I’ve been a terrible mom.”

Dr. Rick: “Stop. You’re a great mom. I am not going to reflect your feelings! (Everyone laughs.) You’ve got a kid with high functioning autism who knows how to push your buttons, who is stubborn, and who is going to push you to the max. As soon as you are ready to assert your parental power you will get him under control. You ready?

Mom: “I still don’t understand what to do when Jacob comes after me.”

Dr. Rick: “There are only two choices. Take him to his room or hold him. We’re getting back to that bottom line of discipline. You must win these battles. You have been kind and loving and fair (and a bit of a wimp!) but now it’s time to rule by the rules and not let him put his toe over the line. Give him a message of competence. Jacob I believe in you so much that I’m going to expect you to follow the rules. Are you ready to learn how to hold him?”

Mom (reluctantly): “I guess I don’t have a choice.”

Dr. Rick: “You do. You can let him run the house and hit and destroy.”

Mom: “I don’t want that.”

Dr. Rick: “OK. Here’s exactly how you do it.”

Safe Holding Methods. Breaking rules has consequences. The most severe consequence is to physically stop the child from doing a destructive behavior. We have been heading here the whole time with Jacob’s family and it’s time to teach them ‘Safe Holding Methods’.

There are two basic methods. One involves a so-called ‘basket hold’ where the parents hold the child in their lap with the child’s back to the parent’s chest. The child’s arms are crossed in front with the parent holding the child’s hands from behind. The parent then wraps his or her legs around the child’s legs. The danger of this hold is head butting and often the child can squirm out of this hold.

The other method is described below and involves having the parent calmly but firmly holding the child safely on the floor. These methods are officially approved by government agencies to help out-of-control children and adolescents get under control.

I walk over to Jacob and ask him to lie on the floor on his back. He looks a little confused but he does it. I tell him I just want to show mommy a trick. I straddle him, putting my legs on either side of his legs and hold his arms out so I am looking him in the face. My bottom is gently sitting on his thighs. I ask Jacob if I am hurting him and he shakes his head no. I tell him to try to get out and he can’t. He’s immobilized and stuck. He even says, “I stuck.”

Dr. Rick (turning to mom): “Here are the words I want you to say to Jacob: ‘Jacob, I love you very much but I will not tolerate this behavior. You may not hit! (or throw, or destroy, etc.)’ I want you to state the rule firmly and clearly. Then you are to hold him like this for three minutes by the clock or until he is calm enough to let him go whichever comes first. This will seem like a long time for both of you. During this time do NOT talk to Jacob at all except every once in a while repeat the rule ‘No hitting!’ OK, mom your turn. I want to show you that you are stronger than he is.”
Mom, with an embarrassed smile, gets off her chair and assumes the same position on top of Jacob who is being a very good sport. We ask him to try to get out and he can’t of course. Mom IS stronger.

**Dr. Rick:** “I just wanted you to see that you are stronger. In the heat of battle, though, Jacob is not going to cooperate like this. You are going to have to quickly wrestle him down in order to sit on him. The first time you do this I want dad to be there.”

**Mom:** “I’m starting to understand the whole idea behind the good, the bad, and the ugly. We’re really teaching Jacob the reasons for rules but if he’s not ready yet to truly understand we use consequences to help him understand and that means using force if we need to.”

**Dr. Rick:** “By George I think she’s got it.”

**Dad:** “Yeah, for good behavior they’re rewarded and for bad and ugly behaviors they never, ever, ever, ever, ever, ever get what they want.” (We all laugh.)

**Dr. Rick:** “By George I think he’s got it.”

**GOYA**

**Dad:** “But what is this GOYA listed here on the Do’s and Don’ts?”

**Dr. Rick:** “It stands for ‘Get Off Your Ass—Butt.’

**Dad:** “Very funny.”

**Dr. Rick:** “It’s my dramatic way of saying that disciplining is not a spectator sport. I don’t really have to tell you guys to GOYA. You know already that you can’t sit on your La-Z-Boy and shout from across the room when the boys are fighting. You have to be there, enforcing the rules, reasoning with the boys, carrying out consequences. (Looking at mom) You have to be ready, willing, and able to take Jacob to his room.”

**Mom:** “OK, OK. I get it. I have to win the battles.”

**Dr. Rick:** “Not against Jacob but for Jacob.”

**Conclusion: The Impulse Sandwich**

It is a fact: Jacob, due to his autism, has an under-connected brain (See Chapter 1, Visit 1—Part 1: Jacob has autism), which causes him to act immaturely. This is not an excuse for him but an explanation. While we should be sympathetic—it is much harder for Jacob—and patient, we must also expect Jacob to become more mature. This means we have to be persistent in using all the parenting protocols we’ve discussed in this visit.

Neurologically speaking when an impulse—to hit or throw or get upset—reaches Jacob’s brain, he acts—hits or throws or gets upset—without thinking. Impulse—action. Impulse—action. His impulses never make it to the frontal lobe.

For those of us who are (relatively) mature thinkers and feelers, when an impulse arises in our emotional brain we control that impulse because our frontal lobes process (i.e., recognize and reason through the consequences of) our impulses and feelings.

In short we have in our brain an impulse sandwich made up of an impulse and an action (See Figure below).

Recent brain research locates emotional control in the **cingulate gyrus**. It’s the part of the brain that ‘decides’ whether the impulse will go to the action cortex (where bad and ugly behavior happen) or whether it will go to the frontal lobe (where mature thinking happens).
An intriguing possibility is that the cingulate gyrus may do this by 'recognizing' (i.e., labeling, and being aware of) feelings as they arise. Sound familiar? Yep, the 'The Mirror Technique'. When we reflect Jacob’s feelings back to him we are helping him send his feeling impulses to the frontal lobe.

The Impulse Sandwich: Sibling Rivalry

- **Impulse**: Smack your brother now! He is taking your toy!!!
- **Thought 1**: I'm so mad that he took my toy, I feel like smacking him.
- **Thought 2**: If I hit him though, mom and dad will be angry.
- **Thought 3**: They’ll take the toy away and I’ll have to go to time out.
- **Thought 4**: If I just call them to get him out of here they’ll come and I can play.
- **Action**: Hey mom, Charlie's taking my toy would you please get him out of here now?!

This (above) is an example of a mature impulse sandwich. It’s a variation on the argument that Charlie and Jacob had earlier. The first thought in an impulse sandwich is **awareness** of the feelings. The next set of thoughts help us cool our feelings down (notice the shades in the impulse sandwich going from dark to light?).

The ultimate goal of *The Good, The Bad & The Ugly* approach is to help Jacob develop a mature ‘impulse sandwich’ for all kinds of impulses. Over time—and sometimes the process can take months!—he will internalize the rules, reasons, and consequences. He will behave without our having to tell him to. He will learn that rules are designed to keep us safe, take care of ourselves, and be considerate of others. Mature behavior leads, hopefully, to empathy and better social skills. This would be quite an accomplishment for a child with autism! This is an achievement at Functional Developmental Level VI. When parents are battling bad behaviors, it’s hard to see the light (i.e., maturity) at the end of the tunnel. But it is not only possible; I have seen it many, many times.

**Dr. Rick**: “If you stick to the plan, I feel very optimistic that Jacob will grow up to be a thoughtful, considerate, well behaved, and *competent* boy.”

**Dad** (tongue in cheek): “I’ll believe that when I see it.”

**Dr. Rick**: “I have a lot of faith in Jacob and you. You are both wonderful parents.”

**Dad**: “Well, Jacob’s got so many ‘bad’ behaviors . . .”

**Mom**: “…we’ll need help with the specifics.”

**Dr. Rick**: “Funny you should mention that. What I’d like you to do for the next time is have you do two things: make a list of your family rules and make a detailed list of all of Jacob’s behavior problems, starting with waking up and ending up with going to sleep.”

**Mom**: “I want to work on his tantrums over TV.”

**Dr. Rick**: “Done. Who wants a sucker?”

The boys run out to get a sucker from Amy. I get a warm good-bye with a hug from both Jim and Julie. I feel good about Jacob’s prognosis. With these parents, he's going to become a robust emotional thinker. Now it’s a matter of working on specifics. We set up a meeting for the next available time to talk about 'transition tricks'.

<Insert 1.9 JPEG GBU here>
Summary
- Jacob is becoming a ‘little stinker’, breaking the rules, and pushing his parents’ buttons.
- Jim and Julie Grant each have their own buttons from their families of origins. Jim gets angry and Julie feels sad when faced with conflict.
- Charlie is suffering because of all of Jacob’s aggression. The whole family is stressed.
- We have a long discussion about ‘Rules, Reasons, and Consequences’, and the parenting rules that will guide Jacob to learn to control his aggressive impulses.
- Through the process of using misbehavior Jacob will become a more mature emotional thinker—we hope!

Resources & Websites

Websites
- University of Michigan Your Child Website, Parenting Resources: http://www.med.umich.edu/yourchild/topics/parent.htm

Books
- *Autism Solutions* (2011) Ricki Robinson MD

Coming up
- Jacob’s parents bring in their house rules and a long list of behavioral difficulties. We focus on how to manage transitions, sleep issues, morning routines, public misbehavior, toileting resistance, sibling rivalry, and how to most effectively use consequences like ‘time out/time away” and loss of privileges.
Jacob and Charlie come storming into the playroom and want to pick up our sword fight where we left off from the previous visit. They locate the long soft pipe insulators and wield them ominously at my face.

Jacob: “I going to get you, guy!”
Dr. Rick (grabbing a ‘sword’ and standing up): “Oh yeah, you think you can get me? Ha ha. I’m going to get you both. En garde!”
Jacob: “You not gonna get me now.”
Charlie: “I hit you hard!”

They whack me. I whack them back. I sing the theme song from Star Wars while we sword fight for a good five minutes with me intermittently falling down and then needing a ‘life shot’ (a pretend syringe from my play medical kit) to bring me back to life. Finally I ‘give’.

All the while I’m watching Jacob and noticing just how much he ‘gets’ the play, how his interactions are continuous without fragmenting, and how well he’s stringing words together (“I going to get you, guy!”). Even though he’s driving his parents nuts with his behaviors, I am so pleased with his progress.

Dr. Rick: “OK, OK you win you win. All done you guys. I have to talk to your mommy and daddy. All done.”
Jacob (demanding): “Play again! Sword fight!”
Dad (in a deep loud voice): “Dr. Solomon said ‘all done’. That’s it. Find something else to do."

Jacob’s head immediately goes down in shame; his face starts to cloud up.

Dr. Rick: “Dad, you missed it.”
Dad: “Missed what?”
Dr. Rick: “Jacob’s feeling. Look at him.”

Now Jacob is starting to get upset, lip quivering, the storm coming but I say . . .

Dr. Rick: “Jacob, you want to play swords some more. You don’t want to stop. You don’t like daddy to tell you ‘No!’ swords!”

As quickly as it came, the storm clears to a sunny sky. Jacob’s face relaxes and he and Charlie get hopeful.

Dr. Rick: “I tell you what. I got an idea. Let’s play for one more time and then we’ll stop. Just one more time, OK?”

They both nod vigorously. We play swords for another minute; I die; they revive me.
Dr. Rick: “OK you guys. Now it’s time to play. I have to talk to your mommy and daddy.”

Without complaining they dig in to the toy boxes and find my new Buzz Lightyear from Toy Story with the pop out wings who speaks both Spanish and English and they’re happy.

Dr. Rick (to dad): “You saw what just happened?”
Dad: “They weren’t listening to you.”
Dr. Rick: “True but Jacob wanted to play some more and you missed that. You just jumped to what he should do, not how he was feeling, what he wanted. I know you wanted them just to listen to me but I’m also making a point here. If you don’t ‘hear’ his feeling, two things happen. First, he’ll more likely get upset instead of listen; and second, he won’t learn how to process his feelings. It’s a missed opportunity.”
Dad: “I’m still working on the ‘mirroring’ thing. I just want him to listen and do what he’s supposed to do.”
Dr. Rick: “I know. It’s not really natural to ‘mirror’ his feelings and I know you want him to behave for me but this is what you have to do if you want him to have less upsets.”
Mom: “I’ve been trying to do what we talked about last visit but he’s a tough one.”
Dr. Rick: “It takes time.”

Jacob’s Overwhelming World: Anxiety. At the end of the last visit Julie Grant almost couldn’t wait to come back and talk about Jacob’s problems with transitions. As Jacob has become more and more functional and emotionally astute he is becoming more aware. It’s as if the blinders are coming off and he can see just how big the world is. He is making every effort to keep it all under his control but it’s too much for him. He is becoming obsessive. His anxiety is skyrocketing which affects his ability to handle even small changes and challenges.

Mom: “Everything has to be ‘just so’.”
Dad: “He gets upset over nothing! Let Dr. Rick look at this list.” (Mom gives it to me.)

The Transition Problem List
I had asked Julie and Jim Grant to make me a problem list and did they ever! Here it is:

- Wakes up whining. Trouble getting ready in the morning (See Chapter 20, Visit 12—Part 2: Jacob’s Terrible, Horrible, No Good, Very Bad Mornings). From bed to dressing (hates rough clothes), to brushing teeth (hates brushing his teeth!), to eating (often difficult, very limited diet), to leaving.
- Car rides. Hates if we go the ‘wrong’ way. Doesn’t want to stop at lights! Tantrums/get violent in the car—pulls mom’s hair! (See Chapter 21, Visit 13: Outings and Eating)
- The bus ride to school is noisy. He rocks in his seat (only when he’s anxious).
- Preschool teacher says Jacob has trouble transitioning from the bus to the building and from the building to the class. Hates all the noise in the hallways.
- Started pushing other children to be first in line. (See Chapter 24, Visit 14: Siblings With Rivalry)
- Holds it together at school then lets it all out at home.
- Can’t stop what he’s doing without throwing a big fit. Tantrums when he has to stop watching TV or computer.
- Restaurants and malls are getting very hard. Won’t sit. Yells. (See Chapter 21, Visit 13: Outings and Eating)
• Sharing with Charlie is terrible! (See Chapter 24, Visit 14: Siblings With Rivalry)
• Bedtime. Comes out ‘a dozen times’. Every little thing—bath, teeth brushing, etc.—is a hassle or an argument. (See Chapter 19, Visit 12: The Stone in Your Shoe: Sleep)

If the child with autism wants to “keep the world the same” then **transitions**—the change from one activity to another—are going to mean trouble. And to look at this list, Jacob is having trouble with almost every kind of transition.

Dr. Rick (looking it over): “Wow. Quite a list. This is a job for Dr. Rick’s 20 Transition Tricks!”
Mom: “Would you be sure to record this discussion. It’s so helpful to go back and listen.”
Dr. Rick: (starting to record our discussion): “This is Dr. Rick Solomon making an audio recording for Jacob Grant on February 9th, 2015.”
Dad: “We’ve been using **The Good, The Bad & The Ugly** approach—with occasional slips—and it’s been helping some but were here to tackle the specifics.”
Dr. Rick: “Nice list, Julie.”
Mom (embarrassed): “I’m a bit OCD myself.”
Dr. Rick: “I’m not saying a thing. I love your lists. But it’s like Jacob’s whole day is stressful.”

As I read the list I realized just how hard life had become for Jacob (and mom, dad and Charlie)! Poor guy. The better he does, the more the demands. The more the demands, the more the anxiety. The more the anxiety, the more upsets leading to tantrums and aggression. I seriously thought about anti-anxiety medication (See Chapter 22, Visit 14: Medications?) but a solid developmental and behavioral approach might help us avoid meds and, in my view, should always be tried first.

Mom: “It’s gotten much worse over the last few months, since the Christmas break.”
Dr. Rick: “In looking this over it looks like the big five **triggers** for Jacob seem to be:
  • Transitions, changing activities
  • Not getting what he wants
  • Stopping fun activities
  • Broken expectations
  • Overwhelming environments

Mom: “Speaking of ‘broken expectations’, we just came from a teacher conference.”
Dad: “We’re getting ready for our IEP end of March. By the way, I caved on the part time aide (See Chapter 16: The Seven Habits of Highly Effective Kindergarteners). I think you and Julie were right. Jacob might need some help in kindergarten.”
Dr. Rick: “You’re a reasonable man, Jim. Better safe than sorry.”

*When the Brain Controls the Mind.*
Mom: “Anyway Jacob’s preschool teacher said Jacob had a major meltdown. He wanted to use the red crayon for a coloring assignment (he’s fixated on the color red these days) but his tablmatate got to it first. So he climbed under the table and wouldn’t come out. When his teacher told him to come out, he went wild and had to be removed—yelling at the teacher then screaming all the way to the principal’s office. It took him 20 minutes to calm down.”
Dad: “That was the only one that bad this year and it just happened. Mostly he just shuts down at school and refuses to do things. They leave him alone and he comes around, eventually. He can be so stubborn. But when he comes home he’s cranky and irritable.”
Dr. Rick: “This is very common. Jacob still can’t process his stress and anxiety very well. So all the little upsets add up. He doesn’t have the psychological tools to resolve his feelings. His brain controls his mind.”

Mom: “I never thought of it that way but that makes perfect sense. He acts out and then he feels bad. It’s like he knows what he should do but he can’t, so he gets cranky.”

Dr. Rick: “Right, I say he gets dysregulated.”

Dad: “Out of control is more like it.”

Dr. Rick: “So a big part of what we’re doing with these Transition Tricks is helping Jacob develop a better control system. We have to help him truly make sense of his world and his feelings so he doesn’t get so overwhelmed. On the one hand we’re going to find that unit of control so he feels secure but on the other hand we’re going to teach him how to process his feelings, problem solve, and put things in perspective so he doesn’t have to freak out over minor stresses. We’re going to help his mind control his brain.”

Mom: “He’s been spiraling out of control so much lately that I’m really worried about him.”

Medication?

Dr. Rick: “The thought of medications crossed my mind but I think we can avoid them.”

Dad: “Good because I don’t want Jacob on any meds, he’s only five years old.”

Dr. Rick: “I agree but when the child is suffering a lot, when every little thing sets them off, and they can’t help themselves, sometimes meds can be very helpful.” (See Chapter 22, Visit 14: Medications).

Dr. Rick: “Let’s go over these Transition Tricks and see if we can help Jacob without meds. What do you want to work on most? What’s first from your list?”

Mom: “Either the morning routine or turning off the TV and coming to dinner or the violence in the car. That’s driving me nutso.”

Dad: “I want to talk about going out in public. We can’t take him to a restaurant.

Mom: “. . . or to the mall or grocery shopping.”

Dr. Rick: “We’ll get to each of these but let’s take the most common situation like stopping a preferred activity and transitioning to a new, non-preferred activity. This happens all the time both at school and at home. What do you say?”

Mom: “Sounds good.”

The Transition Tricks (TT)

Dr. Rick: “There are three groups of tricks:

- Five Principle Tricks
- Three Strategy Tricks and
- Twelve Technique Tricks

The principles will help Jacob expand his worldview so he’ll become more mature. Transitions won’t be as threatening and he’ll cope better with less whining and tantrums.”

Mom: “That would be nice.”

Dr. Rick: “You’re probably already familiar with the strategies but they’re important ways to prep Jacob for change. And the techniques are specific tricks that will help us find the unit of control and can be used throughout the day in specific situations. There are some very cool techniques. My long-term goal is to give Jacob a ‘message of competence’ so he handles the challenges of a changing world without a lot of unnecessary anxiety.”

Dad: “That would be a big step forward. He’s bothered a lot by little things.”
Principles

Dr. Rick: “So let me review the five principle tricks and three strategic tricks first because they form the foundation of a child’s ability to cope with change. Then we’ll use the best Technique Tricks to help Jacob with stopping what he wants to do, to do something he doesn’t want to do.”

Dad: “Sounds like a plan.”

Transition Tricks: Principles

1. Most important! Mirror back/reflect feelings (of anxiety, anger, upset, etc.)
2. Give m&m’s: Meaning and Motivation
3. Give perspective: Is this really something to get upset about? What is important?
4. Philosophy of ‘Can’: Can he do it?
5. Keep your sense of humor and use humor to defuse tension

TT#1: Mirror Feelings

Dr. Rick: “The first principle is an old friend of ours but it’s worth repeating. Recognizing Jacob’s feelings and mirroring or reflecting those feelings back to him is an art form that you can always work on. It’s the most effective trick. (See Resources & Websites: How to Talk So Kids Will Listen) I want Jacob to express his bad, negative feelings in a good way. Remember the ‘good negative’?”

Mom: “You mean use his words to tell us that he’s mad?”

Dr. Rick: “Yes, I’d even pound hard on the table and shout what he’s feeling as a form of mirroring. “No daddy. No dinner!!” It teaches him to reflect on his own feelings, turn his feelings into words, and problem solve in a mature way instead of lashing out.”

Dad: “Definitely not there yet.”

Dr. Rick: “So, we have to keep mirroring back his feelings using a statement (not a question). Simply telling Jacob how he feels will reduce his anxiety by half. The problem is that parents often miss the feeling in the first place.”

Dad: “Like I did earlier.”

Dr. Rick: “I wasn’t going to rub your nose in it but now that you mention it...yes. He didn’t want to stop sword fighting. It’s natural. Feelings are easy to miss. They fly by fast. And we want to jump in and solve the problem logically without ‘processing their feelings’.”

Dad: “It’s still a little unnatural for me.”

Dr. Rick: “It is a bit unnatural for most people but Jacob (and almost every child) responds beautifully to this ‘mirroring trick’. You have to use your judgment though. Some behaviors and feelings you ignore, like whining. Others you process.”

Mom: “How do you know which is which?”

Dr. Rick: “The biggest mistake I’ve seen is when parents have already processed feelings or stated the rules a couple of times and it’s not working. If you feel that you’re talking until you’re blue in the face, it’s time to stop talking.”

Mom: “I feel that way a lot.”

Turn Off the TV!

Dr. Rick: “So let’s say that it’s time for Jacob to stop watching TV or get off the computer and he yells at you. What are you going to do?”
Dad: “I know what I usually do. I tell him to ‘Turn off the TV!’ again and again and after he’s ignored me totally, I get mad and turn off the TV and tell him to get his butt to the dinner table.”

Mom: “That’s when he has a total meltdown and it ruins dinner almost every night. We’ve just let him watch TV to keep the peace and he eats dinner later. But Charlie doesn’t think that’s fair. He wants to watch TV too.”

Dr. Rick: “So when he threatens to have a tantrum he gets rewarded?”

Mom: “That’s not good.”

Dr. Rick: “And dad, you broke the ‘No sudden no’s trick’ which I’ll talk about and Mom you can’t let Jacob get away with this. So, what are you going to say next time?”

Dad (mocking me, using his fingers to quote): “I’m going to ‘reflect his feelings’ Dr. Rick. Something like ‘Jacob I know you want to watch TV but it’s time for dinner.’”

Dr. Rick: “No ‘but’. Simply ‘You don’t want to turn off the TV. You want to keep watching your favorite show’.”

Dad: “I know but it is time.”

Dr. Rick: “I know what you want but this first principle is about what Jacob is feeling and nothing more. We’re going to get him to do what you want but if you don’t want him to freak out you first have to reflect his feelings.”

Dad: “OK, fine.”

Dr. Rick: “Besides, if we set up the situation right, you might not have to go through this at all.”

**TT#2: Give M&M’s**

Dr. Rick: “The next trick is to give him m&m’s—not the candy of course but ‘meaning’ and ‘motivation’. We must always make the world’s meanings apparent—the why of rules, the why of feelings, the why of behavior. Everything must have a reason. So you want him to eat dinner with the whole family. Why?”

Mom: “It’s the only time of the day when we’re together.”

Dr. Rick: “So, make the argument. Make the reasons explicit to Jacob. And be passionate about your love for him and for the family. This is a great chance to express your deepest feelings.”

Dad: “You think he’ll understand the idea of family time and being close?”

Dr. Rick: “Even children who don’t completely understand the words will understand the tone of voice, the love that goes with an explanation of why he should join the family for dinner.”

“I suggest you have this discussion with Jacob before he sits down to TV and say something like (and I say this very loud so Jacob hears me): ‘Jacob I know you love your TV show but (you can use ‘but’ for explanations), but after this TV show is over we are going to have dinner together. We love talking with you and your brother at the dinner table. It’s family time. We love, love, love you and we want to be together as a family’.”

**Explanations.**

Dr. Rick: “Listen to your voice when you explain things. Explanations have a ‘feel’, a certain sound. There’s the feeling of patience and/or compassion, of exhorting and/or warning, which sink deeply into the child’s psyche over time. Eventually the world comes to make sense, feelings make sense, because you took the time to explain things and make life meaningful, heartfelt, and logical.”

Dad: “But what if he understands and still doesn’t want to do it anyway?”

Dr. Rick: “Then he’ll have to learn the hard way—by suffering the consequences.”

Mom: “You mean like ‘time outs’?”
Dr. Rick: “Like ‘time outs’ or other unpleasant consequences. The TV will be turned off and he’ll go to his room and won’t eat until later. But the power tricks come later. I want to cover the gentler, kinder persuasion tricks first.”

Note: Even children with low functioning autism will learn from this Transition Tricks approach. Certain ‘tricks’ will be more effective than others depending on how much the child can understand. As we go through Jacob’s transition issues, I’ll mark the methods that will be most helpful for the children who can’t understand as well as Jacob can.

Rewards vs. Reasons.

Dr. Rick: “The other half of m&m’s is motivation. Sometimes the meaning is not motivating. For instance, Charlie might be motivated by pleasing you or by the idea of ‘family time’. Jacob might not.”

Dad: “Charlie seems to get it.”

Dr. Rick: “It is a measure of Jacob’s progress that meaning motivates him. Until then you might have to search for the right motivation like prizes or consequences—the carrot and stick approach. You could say to Jacob, if you cooperate you’ll get a prize. Children with autism, regardless of level of functioning, are highly motivated by rewards. You can almost always find a reward they will like. This is Transition Trick #15: Bribes, a specific technique that usually motivates.”

Dad: “I really don’t like the idea of giving prizes too much. Jacob will think he should do things for a prize when he should do things because…”

Dr. Rick: “…it’s the right thing to do? (Dad nods.) I agree, but if doing the right thing for the right reason is not motivating, then what? It’s true that rewards are not reasons. Reasons are more important in the long run but rewards will motivate in the short run. You get paid for work. Getting paid is a big reward.”

Dad: “But I enjoy my work too.”

Dr. Rick: “Right. You’ve got meaning and motivation.”

Dad: “Got it. You get him going with motivation…”

Dr. Rick: “…and add the meaning later. Actually I am ruthless in giving big rewards to get children with ASD to be motivated in the beginning. I will go ‘to infinity and beyond’ to find that unit of control.”

Mom: “Unit of control? You’ve mentioned that a couple times.”

Dr. Rick: “Every child has power to control a behavior if you find the right combinations of meaning and motivation. That’s the unit of control. It also means reducing demands until he can do it. This is related to Trick 8: Desensitization where you reduce the demand to the smallest step that the child is capable of doing. Whatever it takes to motivate is my motto. Whatever Jacob can imagine, I will help him to get. (To Jacob) Hey Jacob, hey Jacob.”

Jacob (looks up): “What?”

Dr. Rick: “What toys do you like? What’s your favorite toy?”

Jacob: “Thomas.”

Dr. Rick: “I tell you what? When it’s time to turn off the TV and come to dinner, if you turn off the TV and come to dinner without crying we’ll give you a Thomas train.”

Jacob: “Emily.”

Dr. Rick (to the parents): “The little stinker is negotiating! (To Jacob) You want an Emily for coming to dinner without crying?”

Jacob: “Emily.”

Dr. Rick: “OK, Emily it is—the little green train with the little green tender. So TV off, get Emily, come to dinner. No crying. Right, Jacob? Right?”
Jacob: “OK. Emily.” Jacob returns to his play.

Dr. Rick (to his parents): “The guy wants Emily.”

Mom: “You know how much those trains cost?”

Dr. Rick: “How much is it worth for him to stop tantrumming?”

Dad: “A lot, he’s been ruining dinner time for months.”

Dr. Rick: “I’d just get him a few trains, for a few days. Plus, we’ll set this up so he ‘gets’ it by making him a picture schedule (that’s another strategy coming up, TT #6: Structure) that includes Emily and once he’s motivated he’ll develop a new (and better) set of habits. And ‘a good habit in motion stays in motion’. This new habit works better and makes the child feel better which leads to improved self-esteem.”

Dad: “You’re a tricky doctor.”

Dr. Rick: “That’s why we call them Dr. Rick’s Tricks. Jacob doesn’t really like misbehaving. Being aggressive, angry, out of control, impulsive, and immature feels bad.”

Mom: “That is so true. He feels guilty. He comes up to me after a tantrum and asks me ‘Mommy happy?’”

Dr. Rick: “We are showing Jacob a new way to handle stress as well as strong emotions by motivating him to make good choices for the right reasons. This way he won’t feel guilty as much.”

**TT#3: Give perspective**

Dr. Rick: “The next thing we work on is putting things in perspective. I mean really, is going to the bus, or stopping the TV to eat, or brushing his teeth or whatever transitional activity that big of a deal?”

Mom: “You’d think it was the end of the world the way he carries on!”

Dr. Rick: “Here again, if you notice the tone in your voice when you put things in perspective. There is a quality of ‘Seriously? Jacob, it’s just TV. You don’t have to cry when it’s turned off. You can watch TV after dinner again.’ There’s a tone like: ‘Get your act together. Grow up. Get mature. It’s not the end of the world’.”

Mom: “I say first we’ll do this, then we’ll do that. Is that what you mean?”

Dr. Rick: “That’s a good example. You’re giving him perspective on time. And you can give him perspective by talking about his tantrums. Let’s say when Charlie wants one of his toys. You could say something like ‘Jacob, you don’t want Charlie to have your toys. OK, OK. No crying. Talk to mommy and tell me that you want Charlie to leave your toys alone. Use your words. Say ‘No Charlie. My toy.’ and mommy will listen.””

Mom: “And that will work?”

Dr. Rick: “Over time.”

Dad: “I gotta see this.”

Dr. Rick: “One of the main perspectives we are teaching is what I call delayed gratification. Don’t throw a tantrum. Use your words to problem solve and wait for help. It works better than having a fit. ‘When you have a fit’, . . .”

Dad: “. . .you never get.”

Dr. Rick (high fiving dad): “In a way, though, I’m talking out of both sides of my mouth here. On the one hand I’m saying pay attention and mirror Jacob’s feelings. Join his feelings. Honor his feelings. And on the other hand I’m saying don’t give those feelings too much power. Otherwise you’re going to be ‘walking on eggshells’ worrying about his reactions. Put feelings in perspective. It is related to having a sense of humor.”

Dad: “We could use a little sense of humor.”
(Shhh, don’t tell The Grants this but it’s also my way of telling Jim and Julie to lighten up and not get so upset about Jacob’s upsets. In other words I’m also trying to give parents perspective! As I said in *The Good, The Bad & The Ugly* (See: *Chapter 17*), if you are yelling, angry, and/or upset you are doing something wrong. When you feel neutral, almost professional, in handling your child’s upset, you’re getting closer to the right perspective.)

**TT#4: Philosophy of Can**

Dr. Rick: “I believe in Jacob. I call this the ‘philosophy of can’. Can Jacob get his act together? Can he delay gratification? Can he use his words? Can he become more mature? Can he behave better? You have to literally ask yourselves, *Can* Jacob turn off the TV without crying, come to dinner table, sit and eat with us?"

Mom: “I think so.”

Dad: “Me too.”

Dr. Rick: “Me too. So *if he can then we should expect him to*. The philosophy of ‘can’ is also transmitted in body language and in tone of voice to give a message of competence. It says, ‘I believe in you. I expect you to behave and I’m not going to settle for less.’ *Families need to be reality oriented, uphold common sense rules, and expect the child to comply.* Here again, I’m talking out of both sides of my mouth. I’m saying that once you’ve processed the feelings; once you’ve explained the reasons; once you’ve warned the child about the consequences, then enough! It’s time to get real.” (See TT #19: Time Outs and #20: Just Do It).

‘**No elbows on the table!’**

Dr. Rick: “I have to tell you about a patient I’ll call Ian. Smart, high functioning guy, eight years old, in regular third grade. Very obsessive and controlling (sound familiar?). Get this: He didn’t like it when anyone put their napkin on the dining room table! If they did, he’d start whining and yelling. His mother wanted to keep the peace (just like you Julie) so she made Ian’s brother and sister take their napkins off the table. Soon it was the salt and pepper shakers. Then, no elbows on the table! Ian’s OCD, his obsessive-compulsive disorder, was turning him into the table tyrant.”

Mom: “So what happened?”

Dr. Rick: “I was flabbergasted. I couldn’t believe they were letting him get away with that. I thought he could do better (*philosophy of ‘can’*). With mom’s permission of course I made a *rule*, with *reasons* and *consequences*. I said: ‘Ian, I have bad news for you. I’m afraid you’re done being the *table tyrant*.’ You can do what you want with your part of the table but you can’t tell others what to do (*the rule*). It’s not fair to tell people that they can’t put things on the table (*the reason*). In fact it’s ridiculous Ian (I was giving him *perspective*!). Starting tonight your family can put whatever they want on their part of the table and if you don’t like it you can go to your room and miss dinner (*the ‘stick’*). But I have good news. If you stop being the table tyrant you can have a prize (*the ‘carrot’*). What would you like?” He wasn’t happy but, after a pause, he said he wanted a new video game for his Nintendo DS. Mom thought that that prize would be worth the peace.”

Dad: “Did that stop him?”

Dr. Rick: “His mother called me two days later to say that after he went to his room (I should say he was dragged kicking and screaming to his room) one day without dinner, the next day there were no problems at the dinner table. He got his video game. She was amazed. It had been going on for months. I wasn’t amazed; I thought he *could* get control over his OCD (*TT#4: Philosophy of ‘Can’*) and besides it just wasn’t right, there was no reason (*TT#2: Meaning and Motivation*). It’s amazing what families will put up with.
“When it comes to the ‘philosophy of can’ I have only one warning. You have to be accurate about your child’s ability. If your child really can’t do something then over time it will only cause more frustration and further misbehavior. That’s how you’ll know. We would have to back off and find a more accurate unit of control.”

Dad: “That happened when Jacob was younger. I spanked him when he didn’t listen to me.”
Dr. Rick: “But he wasn’t ignoring you. He really didn’t understand, right?”
Dad: “Right. I spanked him and it didn’t help him listen. He just avoided me. I felt bad.”
Dr. Rick: “That was then and this is now. Jacob can turn off the TV and come to dinner.”
Mom: “Well he’s not.”

**TT#5: Sense of Humor**

Dr. Rick: “Last principle, Sense of Humor. This one’s as much for the parents as the child. It’s closely related to giving perspective. By sense of humor, I don’t mean teaching your child jokes of course. I mean taking the long view, having faith that these behavior problems will be solved, and using sense of humor to get things done or diffuse tension.

“I suggest, when Jacob won’t turn the TV off, that you throw a temper tantrum screaming ‘Turn off the TV, turn off the TV’. Lie on the floor and kick and turn in circles.

“Or you could say, ‘First one to the dinner table wins a prize’ or you could say ‘Don’t you turn off the TV. Don’t you sit at the dinner table.’ Reverse psychology.”

Mom: “I would never have thought of those. I’ve totally lost my sense of humor.”
Dr. Rick: “You and Jim could hold hands, dance in a circle while singing ‘Jacob come to dinner. Jacob come to dinner.’”
Dad: “In fact, she’s worried and stressed to the max. Me, I’m getting frustrated and mad too. To tell you the truth I’m fed up with his constant whining and crying.”
Mom: “Then we feel guilty because our yelling isn’t making it any better.”
Dr. Rick: “Patience and persistence are virtues.”
Dad: “I took Jacob to the grocery store and didn’t give him the candy he saw on the shelf and you would have thought I was torturing him.”
Dr. Rick (laughing): “Really? Over a piece of candy?”
Dad: “Yep.”
Dr. Rick: “Sorry for laughing but the image of Jacob throwing a whopping temper tantrum in the grocery store over a piece of candy—now that’s funny.”
Dad: “Actually I was furious.”
Mom: “That happens to me all the time. Everyone in the store must think I’m the worst parent.”
Dr. Rick: “You know you’ve arrived when you shrug, throw Jacob over your shoulder like a sack of potatoes and take him out to the car while singing Hi ho hi ho, it’s off to work I go.”
Dad: “I haven’t arrived.”
Dr. Rick: “Well we’ll have to get you there. Seriously folks, most of these behavioral issues can get resolved typically within days to weeks with the right strategies.”
Mom: “We’ve been dealing with them for months and it’s wearing us out.”
Dr. Rick: “OK. I hear you. You’re not ready to laugh yet but a sense of humor that ‘this too shall pass’ also gets transmitted through body language, attitude, and tone of voice. Jacob will realize he cannot push your buttons easily and he’ll give up his ridiculous behavior sooner.”
Mom: “Once when we were visiting a farm, Jacob wanted ride a tractor he saw in the field.”
Dad: “When we explained that he couldn’t ride the tractor, he threw such a fit over something so impossible that we all found it hilarious.”
Mom: “He saw us laughing and stopped tantrumming.”
Dr. Rick: “See, that’s what I’m talking about. Sometimes it’s so bad you just have to laugh!”

Jacob and Charlie have been so good for so long. It always amazes me how well behaved children are when the adults are talking about important things. I thank them for playing so nicely together (I reward their ‘good’ behavior.), I tell them NOT to scare me with the Jack in the Boxes (I have two of them,) and they immediately bring them over and proceed to open them up. When the clowns jump out of the box I act scared and scream and tell the clowns to go away. They love this game of scaring the adult and we play this for a while until it gets old and I’m not scared anymore. I send them out for their first sucker and we return to our discussion.

Strategies

Dr. Rick: “Before we get into more specific Technique Tricks let me just talk about the three most important and amazingly effective Strategy Tricks (Tricks 6-8):

**Transition Tricks: Strategies**

6. Create structure:
   a. Use calendars (for month and week)
   b. Schedules (for day)
   c. Lists (for hour)
   d. Sequences (for minute)

7. Social stories and Fables

8. Desensitize by successive approximations & repeated exposures: use countdowns, breathing/relaxation

**TT#6: Create Structure**

Dr. Rick: “If kids with autism want to ‘keep the world the same’ then creating a predictable structure is crucial. This is where ‘calendars, schedules, lists, and sequences’ come in.”

Mom: “We’re using a calendar but not really a schedule.”

Dad: “And Jacob is a stickler for knowing what’s coming next.”

Mom: “We have a white board. He can see the big events coming for the month and week.”

Dr. Rick: “But this TV issue calls for a schedule, a list and maybe even a sequence. Here’s an example of a schedule with a list of activities and prizes/consequences (I draw it out):

<Insert 2.0 JPEG TT here>

- *Schedules* can be helpful at home for daily and/or hourly events.
- *Lists*—for events that happen over minutes.
- Last and most specific are sequences, which can be used for activities that happen second to second like brushing your teeth, e.g., get toothpaste, toothbrush and a paper cup, etc.

You can make little boxes and check off the actions listed to get prizes (See Chapter 19, Visit 12: The Stone in Your Shoe—Sleep).”

Mom: “That’s easy enough.”

Dr. Rick: “For now this schedule and list should work. Just make sure you show him the chart before he sits down to watch TV.”
TT#7: Social Stories and Fables

Dr. Rick: “I know you are both familiar with Carol Gray’s Social Stories™ but it’s worth repeating here (See Resources & Websites) that social stories are fundamentally a form of self-talk and a great way to help children on the spectrum think maturely and cope with events, feelings, and stresses. Jacob is well suited for social stories. He can follow not only routines consistently but he’s got his 1-2 step spontaneous commands down.”

Note: For children who cannot follow routines or one step spontaneous commands to ‘get’ or ‘give’ things, social stories will not be effective.

Dad: “I can tell him to go to the kitchen and get silverware and he’ll do it.”

Dr. Rick: “You really need that level of receptive language for social stories to work well. Here’s a social story for this situation and should be accompanied by pictures (drawn or found):

- When I come home from school I love to watch TV (picture of a boy watching TV)
- And I don’t want to stop even when it’s dinnertime. (Mom with a cartoon balloon coming from her mouth saying “Jacob it’s time for dinner” but the boy is still watching).
- It makes me mad to stop TV but dinnertime is family time and I have to stop. It’s a rule. (Show a family sitting around a dinner table having fun.)
- Besides, if I don’t stop my parents will turn off the TV and I won’t be able to watch TV. I’ll have to go to my room. And no TV for the rest of the night. (Show boy in time out).
- But if I eat dinner with my family and behave myself I will get an Emily train and can watch TV after dinner. (Picture of a train.)
- Eating dinner with my family is fun (show a picture with a happy family sitting around the dinner table.)

“For the higher functioning children, I use fables a lot.”

Mom: “He loved your fable about the Bear who wouldn’t brush his teeth.”

Dr. Rick: “The ‘No Brush Bear’ whose teeth started falling out?”

Mom: “He listened to that recording over and over again.”

Mom: “We drew a picture of a bear with no teeth to go along with the story and he asked if his teeth would fall out for a long time.”

Dad: “We said if you brush your teeth they won’t fall out, they will be ‘strong and white’ and now he brushes them twice a day and says ‘Strong and white!’”

Dr. Rick: “If we have to, we can make up a fable about the ‘No Dinner Dog’ who wouldn’t turn off the TV to come to dinner. But I think a simple schedule, the social story, and a few other tricks will do the job.”

Mom: “I might be calling you for a fable.”

TT#8: Desensitize

Dr. Rick: “Most families already know something about creating structure and using social stories but many families are not as familiar with the idea of desensitization even though they use the idea naturally all the time.”
“In one of my previous jobs, I used to help children with cancer through their painful medical procedures like bone marrow aspirations and lumbar punctures. I convinced them—through the use of desensitization—that they could get through these painful procedures.”

Mom: “That sounds like a hard job.”
Dr. Rick: “These kids were amazing. I used a step-by-step approach. First I introduced them to just the idea that they could learn self-control. That was the unit of control. Just thinking about it. Then we’d practice for the procedure without needles; then we’d practice with needles but not poking; and then I’d poke them with the cap on the needle to get them as close as possible to the real deal.”
Dad: “I’m starting to get this idea of unit of control. You set it up so the child can be successful by starting with what they can do and then increasing the demands slowly.”
Dr. Rick: “I couldn’t have said it better myself. And all the while with these kids who had cancer I had them use breathing, relaxation and mental imagery to help them control their bodies. It worked! Through repeated and increasingly realistic exposures to the scary event, these children were able to desensitize themselves to very painful procedures (See Appendix I: Breathing, Relaxation, and Imagination)

“What we are doing with Jacob by talking to him, explaining the reasons, making a schedule, prepping him for change—all of this is a form of desensitizing him, giving him successive exposures to the event and preparing him to handle the anxiety in a more productive way.”

Mom: “I remember when you did that for brushing his teeth. Besides the fable, we started off by just brushing one stroke. I thought it was nuts.”
Dad: “Then one tooth.”
Dr. Rick: “The unit under his control got bigger and bigger.”
Mom: “Then we gave him prizes for each tooth.”
Dr. Rick: “Until he was raking it in! It took a week to ‘desensitize’ him but it worked.”
Dad: “So a schedule is also a form of desensitizing?”
Dr. Rick: “Absolutely. A schedule, talking about it, counting down, whatever prepares Jacob for the transition is desensitizing.”
Mom: “Should we teach him to use breathing?”
Dr. Rick: “I recommend that you do this at bedtime so he gets into the habit. Some kids take to it and some don’t. I can give you a handout that describes the process. It’s really easy. (See Appendix I: Progressive Relaxation for Children on the Spectrum).
Mom: “So when he comes home from school but before he gets on the TV...”
Dr. Rick: “...we are going to desensitize him. (I say this loud again so Jacob hears me) You tell him: ‘Jacob, I know you love the TV and you hate to stop when it’s dinner time.’ (Pause here after ‘reflecting his feelings’). Then you state the new rule: ‘Today we are starting a new rule: Everybody eats dinner together so we can have family time (you’re giving the rule with reasons) so you will have to stop the TV at 5:30 and come to dinner with us or you will have to go to your room.’ That’s when you show him the schedule and the social story. ‘See Jacob. TV. Turn off TV. No crying! Go to dinner. Get Emily.’ All this desensitizes him and gets him ready psychologically for coming to the dinner table. If he doesn’t come to the dinner table and sit nicely you can add a negative consequence. If you like, you can add that step to his schedule.” (See Transitions Tricks: Schedule above)
Dad: “So if he fights us and won’t sit nicely and yells his head off, he goes to his room.”
Dr. Rick: “Right. Transition Trick #19: Time Out and/or #20: Just Do It. And he loses TV for the night.”
Mom: “But won’t that disrupt the whole evening?”
Dr. Rick: “For a few days it might but if you keep ‘giving in to keep the peace’ then he’s winning the battle and, most importantly, you are not expecting him to act maturely. You are giving him a ‘message of incompetence’—you poor little boy with autism, you can’t stop watching TV, come to the dinner and act civilized.”
Mom: “Oh my gosh. You’re right. That’s no good.”
Dad: “So I could take him to his room and keep him there while Julie and Charlie eat?”
Dr. Rick: “Or vice versa. You could take turns. Isn’t he getting used to time-outs?”
Dad: “Lately he has been tolerating them better. We tried your time out sequence starting with mini time outs and then increasing the time depending on how much he cooperates (See Chapter 17: The Good, The Bad & The Ugly) and he’s getting the idea that the more he fights the worse it is for him.”
Dr. Rick: “You guys are really giving him a strong message! But before we get to the Time Out Trick and Just Do It stage let’s go back and try to avoid conflict with some of my trickier tricks.”
Mom: “I’d like that.”

Transition Tricks: Techniques
9. No sudden No’s
10. Tussle, negotiate, argue, debate: get lots of circles!
11. Preview and Review
12. Video modeling
13. Talk about transitions at the right time
14. Use a game or competition to motivate: ‘Game Show’ mode

**TT#9: No sudden ‘no’s’**
Dr. Rick: “Let’s start with the No Sudden No’s trick that I mentioned earlier.”
Dad: “I know about ‘No sudden no’s’. I shouldn’t just turn the TV off. That’s a sudden ‘No’.”
Dr. Rick: “Correct. So when your child wants something he can’t have, let’s say candy in the grocery store, you can say, ‘Oh, you want candy (TT#1: Mirroring). I’ll tell you what. I got an idea. We’re done & I’ll get you some candy.’ That’s one way to avoid a sudden ‘No’. You can use the: ‘I’ll tell you what. I got an idea, the negotiating approach.’”
Dad: “What if Jacob keeps whining and demanding.”
Dr. Rick: “Then I’ll use TT#10: Tussling.”

**TT#10: Tussling**
Dr. Rick: “Let’s take our situation. Jacob doesn’t want to stop watching TV or get off the computer. Let’s say you’ve done everything right—prepped him, showed him the schedule, offered rewards, given him warnings, etc.”
Mom: “I’ve given him five-minute and one-minute warnings but that hasn’t worked.”
Dr. Rick: “Warnings are great. Warnings use:
- **Structure (TT#6)**
- **Desensitizing (TT#8)**
- **Avoid sudden ‘no’s’ (TT#9), and**
- **Talking about transitions at the right time (TT#13)**
“But, when warnings don’t work tussling might. Tussling means ‘getting into’ the tug of war.”
Dad: “Like we do with our dog and a towel. He growls; we wiggle the towel; he growls some more.”
Dr. Rick: “Exactly. That’s tussling. It involves having an argument that includes processing feelings, discussing reasons, warning about consequences, having a sense of humor—the kitchen sink.”
Mom: “Can you give an example?”
Dr. Rick: “It would go something like this (and as I record, I say Jacob’s name loudly to get his attention):

“So Jacob you don’t want to stop TV! (With a joking tone) Oh yeah? (Wait for eye contact and reaction.) Come on Jacob, turn it off and come to dinner. (This is tussling, getting into the argument and stretching it out. Wait for eye contact and reaction: let’s say Jacob frowns.) ‘Come on, Jacob. Dinner is fun. We talk. You’ll get a prize. (In a tempting voice) You’ll get Emily. (Let’s say he says firmly ‘No dinner. No Emily.’) No? I tell you what. I got an idea. When you come to dinner you’ll get Emily AND after dinner we’ll wrestle. We’ll have fun. (Let’s say he’s being completely stubborn. and starts to cry.) Oh, you’re so sad. But Jacob, if you don’t turn off the TV and come to dinner, you’re going to go to time out. (Changing tone) Come on Jacob, come to dinner and have family time, prizes, and then more TV.’

“So you’re tussling, arguing, negotiating, discussing with him like this and. . .”

Dad: “What if he comes to dinner but he’s crying.”
Dr. Rick: “That’s a victory. As long he’s not being too disruptive. He can change his mind at any time and come to dinner.”
Dad: “Even when he’s in time out?”
Dr. Rick: “Sure. You can make a time out that says ‘Go to your room until you are ready to come to dinner without crying.’ Time out is not a punishment; it’s a consequence. As long as he’s truly ready to sit and not be disruptive he can come to the dinner table any time.”
Dad: “I don’t know if have the patience for this.”
Dr. Rick: “You don’t have to. You could just turn off the TV and send him to his room with no discussion and that would work to improve his behavior. But patience pays off because he’s learning to think and feel more maturely.”
Mom: “But tussling will improve his understanding too, right?”
Dr. Rick: “Eventually. It takes a lot of exposures sometimes but I think it’s worth it.”

**TT#11: Preview and Review**
Dr. Rick: “I don’t know if you noticed but I added another technique while I was demonstrating tussling called Preview and Review into the tussling process. Preview and Review paints a picture not only of the coming events but also of the coming feelings both positive and negative:

“OK, Jacob. Listen. If you don’t turn off the TV and come to dinner, you know what’s going to happen? (Preview the negative consequences) You’re going to cry, we’re going to fight, and then you’re going to go to your room. No prizes, no Emily train, no dinner. Go to your room. And no TV. You will feel very sad.”

“If you do turn off the TV (Preview of positive consequences), you will eat with mommy and daddy and Charlie. We will have family time. You will get a prize and you can watch TV after dinner. You will be happy. Mommy and daddy will be happy. Come on now, turn off TV and come to dinner.”

“The other half of Preview/Review is Review. It’s important to look back on a situation and summarize it, especially successes but also failure. ‘Jacob, you did so well! You turned off TV; you came to the table and ate nicely. Now you get to watch TV. No time outs, no crying . .’
“Both Tussling and Preview/Review have elements of social stories, m&m’s, sense of humor, giving perspective—the whole enchilada.”

**Dad:** “But the idea behind *tussling* and *preview/review* is to make the discussion last, open lots of circles, and kind of get into the argument without really getting mad.”

**Dr. Rick:** “Right. Get into ‘discussion mode’. Have lots of back and forth interactions and keep your sense of humor. Like mom said, it’s a way of desensitizing Jacob. It’s a very cool Trick. So is this next one.”

**TT#12: Video Modeling**

**Dr. Rick:** “A high tech version of *Preview/Review* is **TT#12: Video Modeling.** (Here I make a square with my fingers to simulate a picture frame.) You get your cell phone or one of those cheap video cameras and you say into it: “This is the wrong way (cry and yell into the camera): ‘I want to watch TV. No dinner. No family. TV, TV, TV!! Wa-a-a-a-a-a-a’.” And you act out a tantrum. Jacob will find this very funny.

“Then move your face out of the picture fame. Wait a second and then move your face back into the picture and say: “This is the right way: (use a thoughtful voice) ‘I don’t want to turn off TV but it’s time for dinner. If I go to dinner I will have family time with daddy and mommy and Charlie. I will get a prize and I can watch TV later. OK daddy, OK mommy I’m going to dinner.”

**Dad:** “Jacob loves watching videos.”

**Dr. Rick:** “This way he could watch it over and over and get the message.”

**Mom:** “I see what you’re going for. We’re teaching Jacob to think things through. Would these techniques work with any transition?”

**Dr. Rick:** “Absolutely. Many of my families have tried them with lots of different transitions and they work. Really, they are very practical. Look at this next one.”

**Transition Trick #13: Talking about the Transition at the Right Time**

**Dr. Rick:** “Transition Trick #13 is about talking about the transition at the right time. There are two aspects to this. Talking too soon or not talking soon enough. This Trick is mostly for events that are far in the future like going to the doctor’s or dentist or even going to the store. You don’t want say ‘Next year we’re going to the dentist’. I have some children who would fret for a year. So just remember to discuss events in a timely fashion—usually an hour ahead of time for small events and a day ahead of time for bigger events.”

**Mom:** “Even fun events?”

**Dr. Rick:** “Even fun events. The other point here is to make sure you talk about *everything* (within reason) that is going to happen so there are no surprises.”

**Dad:** “So calendars, schedules, the discussion, the countdowns. . .”

**Dr. Rick:** “. . .are all part of Transition Trick #13. These tricks overlap.”

**Transition Trick #14: Use a Game or Competition to Motivate**

**Dr. Rick:** “**TT #14 is using competition or a game to motivate Jacob.**”

**Dad:** “So we could say: “First one to the dinner table gets a prize.”

**Mom:** “That would work for Charlie. He’s competitive but I’m not so sure about Jacob.”

**Dr. Rick:** “I might try to make Jacob jealous of Charlie by having fun with Charlie as you get ready for dinner. Make it loud and make it sound like so much fun that Jacob will get curious. You might say something like: ‘Yay. Charlie gets a prize!! Yay.’ See if you can woo Jacob into the kitchen.”

**Mom:** “But what prize.”

**Dr. Rick:** “I don’t know. Maybe stickers.”
Dad: “Charlie likes Batman stickers.”
Dr. Rick: “There you go. This Trick is also about making games out of any type of transition. If you are going to the store you could make it a game to see how many things you buy in each aisle and count them. ‘We bought two things on this aisle. How many are we going to buy on this next aisle?’”
Mom: “Jacob loves to count. That’s very ingenious. Can we give him a prize at the end of each aisle?”
Dr. Rick: “Sure, but don’t get into over-doing rewards. Our ultimate goal is to have him behave in the store because it’s the right thing to do. But counting, naming, creating mystery like ‘let’s see what we can find next from the list...’ can make transitions familiar and fun.

“I like to use game show mode. I turn my voice into an announcer’s voice and say: ‘And now contestants, let’s see if you can find the forks for the dinner table. Forks for two hundred (a la Jeopardy). On your mark, get set, go go go. Find the forks and put them on the dinner table. Hurry hurry hurry. Yay!! Get it?”
Mom: “Got it.”
Dr. Rick: “Good. OK. Let’s finish up.”

Transition Tricks Techniques
15. Offer bribes and prizes. Start very big and go smaller, then wean
16. Hold a favorite object during transitions
17. Sensory blinders (headphones & hat)
18. Threaten to put limits: “1-2-3 Magic”
19. Time out or natural consequences
20. Use of force--just do it!

TT#15: Bribes
Dr. Rick: “We’ve already talked about Bribes and Prizes. The only other thing to say here is that you want to start big and wean down.”
Dad: “How do you know when to wean?”
Dr. Rick: “The short answer is: ‘As quickly as you can.’ First you want to be effective in creating a new habit. Give him an Emily the first day and then maybe one other train the next day. The third day I might use the Thomas Come to Dinner Toy Bag Trick.”
Mom: “Toy bag?”
Dr. Rick: “Get a brown grocery bag and put some cheaper Thomas toys like a book, a craft set, some train track extras, etc. There are so many cheap things you can buy. Put them in the bag to create some mystery and suspense and let him reach into the bag and take a toy. Make sure Charlie gets prizes too.”
Dad: “This is getting more expensive all the time.”
Dr. Rick: “I call it ‘Christmas in July’. Isn’t it worth it?”
Mom: “If we can have some peace, definitely.”
Dr. Rick: “You have to be fair to Charlie.”
Dad: “So when do you wean him off?”
Dr. Rick: “Maybe by the 5th or 6th day. Use your judgment. There may come a point when he might say or act as if to say: ‘If I don’t get a prize, I’m not going to sit at the table.’ Then I’d tussle and negotiate for a couple of more prizes over another day or two with an agreement that there’s not
going to be any more prizes for sitting at the table because he should sit at the table because ‘it is family time.’"

Dad: “That’s what I said in the first place!”

Dr. Rick: “True but look at all the reasoning we’re doing in the mean time.”

**TT#16: Hold a Favorite Object during Transitions**

Dr. Rick: “I have one more for you before we get out the stick: Transition Trick #16. Give him Emily to hold when the TV goes off as he’s going to the dinner table.”

Dad (incredulous): “Now you want me to give him a prize before he comes to the table?”

Dr. Rick: “Whatever works. He gets Emily only if he comes to the table without whining or crying. Otherwise he won’t get it.”

Mom: “He could get upset twice.”

Dr. Rick: “It’s a risk we could take but it could work just fine. This trick of holding a transition object also works well for transitions like going from home to the bus or from bus to school. Give him something to hold like his DS Video game or a favorite book or a favorite toy.”

Mom: “Will the school allow Jacob to take things on the bus?”

Dr. Rick: “If they’re smart they will.”

**TT#17: Sensory Blinders**

Dr. Rick: “Another good Trick while transitioning to different places is to teach Jacob to wear headphones. Have you ever tried that?”

Mom: “He loves music.”

Dr. Rick: “Well, get him to wear headphones to your iPod or other music device. Put a hat or hood on him. Pull his collar up. Create a micro-environment for him.”

Dad: “That might be good for stores and restaurants. The noisy big public places can really trigger him.”

Mom: “He likes to wear hats already.”

**Transition Trick #18: Threats and 1-2-3 Magic**

Mom: “I have one more question though about getting him to come to dinner. Let’s say we’ve tried everything, all the tricks, and he still won’t come to the table.”

Dr. Rick: “Then he’s done with the carrot and all that’s left are the sticks. Tricks 18, 19 and 20 are the sticks: Warning and threats, Time outs and, when time outs are not appropriate, the Use of force, just doing it. Like putting him in the car or on the bus.”

Dad: “I get it. He can’t really win unless he cooperates.”

Dr. Rick: “Exactly. We give him every chance to cooperate by reasoning and motivating him because it helps his emotional maturity. But if he won’t be reasonable then that’s it. Threats work! And, Julie, don’t wait too long to do it. Don’t over-talk!”

Mom: “That is my problem. What if he comes to the dinner table but he’s whining a lot.”

Dr. Rick: “I’d use Transition Trick # 18: Threats and/ or 1-2-3 Magic. You can use this at each step if you have to. Remember we talked about the ‘toe over the line’ in the last visit (See The Good, The Bad & The Ugly)? This is ‘the line’. You’ll say to Jacob ‘I’m going to count to three and you have to:"

- Turn the TV off and come to dinner or else (you threaten) time out: 1-2-3
- You have to stop whining or go to your room: 1-2-3
- You have to sit in your chair and eat or go to your room: 1-2-3’

“Whatever he has to do you draw the line. And when you say ‘3’ you have to act and know what you are going to do. You have to have your parenting protocol clearly in your mind.”
**Transition Tricks #19: Time Out and #20: Just Do It**

**Dr. Rick:**“And then you follow through and just do it. If you have to, you physically take him to his room—Transition Tricks #19 and #20. Jacob must have a bottom line. He must lose this battle over the rules. Why?”

**Mom:** “Because he can do it.”

**Dr. Rick:** “Right. Because we believe in him.”

**Dad:** “Do we have to go through all these tricks every time?”

**Dr. Rick:** “On the contrary. If he knows the rules; you’ve given explanations; and he’s playing you and thinks he’s the boss. Don’t over explain. You must be very clear and that’s what Tricks 18, 19 and 20 are all about—threaten, count, send him to time out or, if he forces you, physically take him to his room and make him stay there.

“If you want to be gentler with time out, use graded time outs:

- A mini time out if he can get it together and come to dinner and sit nicely at the table
- A five-minute time out in the chair, on the steps, or in his room
- Or a ten-minute time out if he fights you”

**Mom:** “What if he goes wild in his room and starts tearing the sheets from his bed, pulling all the clothes out of his drawers, kicking the door, pounding the wall and trying to get out of his room repeatedly?”

**Dr. Rick:** “Make sure his room is safe. Time outs start when the crying stops. Jacob must stay in his room whether you put him back in there repeatedly, hold the door handle, or put a lock on the door. When time out is done he has to clean up his room and he has likely missed dinner.”

**Dad:** “You’re tough.”

**Dr. Rick:** “I’m really fair. I’d tell Jacob ‘I don’t want to fight Jacob but you are not following the rules.’ I’m tough and clear about the rules. Otherwise it will be confusing. You can’t be wishy-washy with the rules, especially with kids on the spectrum. It’s actually reassuring. Children need to know that there is a predictable structure.

“Over time, these Transition Tricks will work 100% of the time because, Jacob always loses when he breaks the rules. He will see that it’s in his interest to cooperate. It makes sense. It’s fair. It promotes maturity. And, in the long run, it’s really better for the child and family. It makes everyone truly happier.”

**Mom:** “I get it Dr. Rick. I just hope I can do it.”

**Dr. Rick:** “You can do it, Julie. I have faith in you because you know it’s best for Jacob and you always want what’s best for your boys.”

**Dad:** “And I can see how these tricks will help with lots of transitions.”

**Mom:** “But what about the other situations like getting up in the morning or going to the grocery stores or driving in the car?”

**Dad:** “Or the fighting with Charlie?”

**Mom:** “Or getting him toilet trained?”

**Dr. Rick:** “The natives are getting restless.”

Charlie and Jacob are pushing each other over my new dragon toy that shoots gold coins from his mouth. The room is totally trashed. Our time is up today.
Dr. Rick: “Why don’t you try these tricks out and then we’ll get back together to cover these other issues. Call me. (To the boys) OK guys, we’re done here. (I start singing the clean up song.) Time to ‘clean up, clean up, everybody clean up’.”

I promise them another sucker. The room is clean in no time. I keep my promises.

Dr. Rick: “Who wants another sucker.”
Charlie: “I do!”
Jacob: “I do!”
Dad: “I do. I need one after all this.”

Dr. Rick: “It sounds like a lot but you’ve got our recording. I’ll email it to you. You’ve got the list of tricks and you have the phone. Give me a buzz. I really want to hear how Jacob does with turning off the TV and coming to the dinner table. Call me.” (See Phone Follow-up below).

Mom: “I like that Preview/Review trick. Along with the chart I think that will work.”
Dr. Rick: “And Emily.”

Jacob’s head turned at that. I think we may have found his m&m’s.

Phone Follow Up: One week later... Julie called a week after the appointment to say that the plan worked like a charm—at first.

- They mirrored Jacob’s feelings
- Made him a chart/schedule/list
- Pictured and told him a social story
- And gave him an Emily and other Thomas toys from a big brown bag for coming to the dinner table
- They even videotaped a silly dad doing things ‘the wrong way’ and ‘the right way’; Jacob loved the video
- They previewed and reviewed feelings
- And told him how much they loved having him and Charlie together at the dinner table for ‘family time’

Mom: “Everything worked amazingly well for four or five days until yesterday, Dr. Rick. Then, I don’t know what it was but he wanted to watch TV and there was no way he was going to stop.”

Dr. Rick: “So what did you do?”

Mom: “Jim wasn’t home. He had to work late. I tried all the positive tricks. Jacob just didn’t care. I even waited until his show was over but he wanted to watch the next show.”

Dr. Rick: “Had Jim been bringing Jacob to the table?”

Mom: “You know, you’re right. Jim took it on. Maybe it was because Jim wasn’t home.”

Dr. Rick: “Jacob was testing you, Julie. You’re the one who backs off when he gets mad.”

Mom (firmly): “Well, I didn’t back off. Because of our plan I knew just what to do. I got down to the power tricks, ‘1-2-3 Magic’, threats, and time out so fast it made Jacob’s head spin. I took him by the arm and sat him in the chair for a short time out and I think Jacob was shocked. He whimpered a little, got up and sat at the dinner table. I let him and Charlie pick from the bag (which is down to little prizes from the dollar store—which they still love) and we had a very nice dinner.”

Dr. Rick: “Way to go Julie! How did you feel about it?”
Mom: “Great. Instead of feeling anxious I felt great. Having a plan really helped me give him a clear message.”
Dr. Rick: “A message of competence!”
Mom: “We had a very nice dinner thank you.”
Dr. Rick: “Congratulations! I am so glad.”
Mom: “Now we have to deal with the terrible morning routine. We've got an appointment coming up.”
Dr. Rick: “See you then. Way to go Julie! High five.”

Summary
- Jacob won’t turn off the TV to come to dinner. In fact, he’s having problems with nearly all the transitions in his life. They make him anxious and upset.
- We review Dr. Rick’s Twenty Transition Tricks to give the Grants principles, strategies, and techniques to help Jacob understand that transitions are not the ‘end of the world’.
- We use transitions and upsets to work on Jacob’s logical and emotional thinking, to help him delay gratification, and to use his words. We believe in him and, by making appropriate demands we give him a message of competence. In short we are helping Jacob to become more mature.

Resources & Websites
- Carol Grey’s Social Stories
- 1,2,3 Magic (5th Edition, 2014), Thomas Phelan
- Autism Solutions (2011) Ricki Robinson MD

Coming Up Next
- Sleep routines have become a nightmare with bedtime resistance and night waking. We help Jacob go to sleep without a big hassle and stay asleep in his own bed.
Chapter 19  
Visit 12: Part 1  
The Stone in Your Shoe: Sleep

Jacob has steadily become a behavioral terror in the Grant household. He wants what he wants when he wants it and he wants it now! In a bad way, this is a good thing—Jacob is making developmental progress. If only I could get the parents to appreciate it. Of course, it’s easy for me. I don’t have to live with him 24/7.

During the last two visits we covered the behavioral basics by distinguishing between ‘good, bad, and ugly’ behavior (See Chapter 17, Visit 10: The Good, The Bad & The Ugly) and talking about ‘transitions’ (See Chapter 18, Visit 11: Dr. Rick’s 20 Transition Tricks). In a follow-up phone conversation with Julie, I was relieved to hear that the very worst behaviors—hitting, biting, kicking, throwing things in anger, purposeful ignoring, and terrible tantrums during transitions—are (slowly but steadily) getting better.

Mom (on the phone): “For a while there he was spending a lot of time in his room and losing some privileges. The rules helped a lot. We put them on the fridge and Jacob actually looks at them. It’s funny. He can’t read yet but we’ve gone over them so many times he can recognize ‘No hitting.’ ‘No throwing.’ ‘No ignoring.’ by sight. And we’ve been teaching him how to ‘use his words, and get his controls’ if he wants to get what he wants. You’d be proud of him—he now has a lot of ‘good negative’ behavior. He yells at us in an angry voice instead of hitting. He’s learning to negotiate. When he says “Please, mom” he’s so cute I can hardly deny him. So, overall he’s doing much better—on the big things...”

Dr. Rick: “But...”

Mom: “...but now from the time Jacob wakes up to the time he goes to sleep every little thing is an issue.”

Dr. Rick: “There is a Chinese saying that ‘it’s not the mountain ahead but the stone in your shoe that gives you the most problems’.”

Mom: “And every time I take out one stone I find another one. He’s throwing tantrums at the mall and in the grocery store. If we drive the ‘wrong way’ he kicks the seat and tries to pull my hair. He won’t get dressed in the morning. He...”

Dr. Rick (interrupting): “Julie, sorry to interrupt but, do me a favor please, and make a list of your daily hassles so we can deal with them one at a time and we can talk. I’d love to talk now but I’ve got to return a bunch of calls.”

Mom: “Sorry, Dr. Rick.”

Dr. Rick: “No, I’m sorry. Let’s get together soon to talk things through.”

Jacob was challenging her authority and fighting almost every demand. Dad was supportive but he wasn’t there when a lot of the worst behavior was happening. The transition trick ideas helped some but there were so many situations where things weren’t going well!

Mom: “It’s just that I’m becoming ‘a screamer’ and ‘a nag’. I’m starting to feel like I’m not a good mom.”

Dr. Rick: “Julie, you’re a great mom. We just have to talk the issues through. I have confidence in Jacob and you.”
I invited her in for a consultation (without the boys). After I hung up the phone, I felt bad for her. We needed to create some parenting protocols for each of the daily hassles she was facing and she needed some emotional support. She was getting frazzled. We had to get Mr. Jacob more under control.

When she walked into the office, she was prepared and handed me her list of issues.

_Jacob’s Daily Problems_

- Bedtime routines/night waking
- Morning routine/getting ready for school
- Self-help—dressing, brushing teeth
- Car misbehavior
- Meltdowns in public: grocery shopping
- Dinnertime & Eating problems
- Toileting Issues
- Sibling rivalry & sharing

Mom: “You know, Dr. Rick, this is the first time I’ve had an adult-to-adult conversation without at least one of the boys in...I can’t remember...how long. My mom is watching them.”

Dr. Rick: “You don’t get much alone time these days, do you? Well, it’s nice to be with you too.”

After I looked over the list I looked her right in the eyes.

Dr. Rick: “Julie, can I just tell you something important? What you are experiencing is really common with kids on the spectrum. I hope you know that this is not about you. These behaviors are not your fault. You are a wonderful mom.”

Mom (starting to tear up): “Well, I don’t feel like a wonderful mom. It’s gotten so bad. I feel like I’m arguing with him constantly.”

Dr. Rick: “Not much fun.”

Mom: “He’s ruining our family life. I’m worried for Charlie who is starting to imitate Jacob. The sharing issues are horrendous. I’m so stressed. I’m not much fun to be around for Jim.”

Dr. Rick: “Is everything OK with you two?”

Mom: “I think so, but this autism thing is taking its toll on our family. Jim and I don’t go out anymore. I’m feeling pretty depressed, Dr. Rick. It’s been years...”

Dr. Rick: “I hear you. It’s so hard being the one who has to hold it all together. All I can tell you is that it’s going to get better. Emotionally, even though he’s five, Jacob is in the terrible twos to threes stage. Let’s just take it step by step and set it up so Jacob learns to cooperate (or else). I don’t want you screaming and nagging and feeling like a bad mom.”

Mom: “It’s just one thing after another.”

Dr. Rick: “Where do you want to start?”

_Sleeping and Waking Hassles_

Mom: “We could probably start at the beginning. Mornings have become a nightmare.”

We laugh at the pun.
Mom: “Jim says it’s total chaos out there but I’m trying the best I can.”

Dr. Rick: “What do you mean ‘out there’?”

Mom: “He’s in the bathroom getting ready for work and from 6:30 to 7:00 before the kids get up, it’s quiet and peaceful. At 7:00 all hell breaks loose ‘out there’ in the house.”

Dr. Rick: “Mornings should be peaceful.”

Mom: “Charlie and Jim are bright and cheery. Jim actually sings in the morning (which is really annoying!). But Jacob is not a morning person. And to tell you the truth I’m not either.”

Dr. Rick: “So what’s the routine?”

Mom: “Jacob’s got to catch the bus by 8:00 and I’ve got to take Charlie to preschool three days a week. By the time I leave the house I’ve got a headache that lasts hours.”

Dr. Rick: “Don’t tell me. They don’t listen; they dawdle; they won’t turn off the TV; they won’t eat. You’re arguing, yelling, constantly herding. By the time you’re done with the morning routine you don’t feel like a good mom and you’re exhausted.”

Mom: “Have you been spying on us?”

Dr. Rick: “I have a lot of families with these problems. Kids on the spectrum don’t like to move fast. They don’t like to transition and mornings are all about transitions—wake up, eat, get dressed, go out the door, get on the bus—it’s so hard for them and that makes it hard for you. It sounds like you put a lot of pressure on yourself.”

Mom: “If I don’t, I feel so guilty.”

Dr. Rick: “Well, hopefully, when we’re done you might not sing like dad but at least mornings should be better. That will help your guilt. The key is planning, planning, planning.”

Mom: “I need a plan.”

Dr. Rick: “But before we get to morning routines, let me ask you first, how is Jacob sleeping?”

Mom: “Terrible.”

Dr. Rick: “Trouble falling asleep or staying asleep?”

Mom: “Both. But again it’s been mostly recently, the last month or so.”

Dr. Rick: “Maybe we should nip the sleep problems in the bud. If he’s tired from lack of sleep, he’s going to be cranky in the morning and that alone can make your mornings miserable. If it’s OK with you, I’d like to talk about sleep first.”

Mom: “OK with me.”

First, Good Sleep Hygiene

Here’s the history I obtained from mom regarding Jacob’s sleep. Jacob has a lot of energy and doesn’t go to sleep easily. He and Charlie share a room and go to bed at the same time around 7:30 to 8:00 pm, which is a good bedtime for a five year old. Dad is usually home by dinner and has developed a good routine with the boys. After dinner the boys watch a little TV. Then dad plays with them, gets them washed up, into their p.j.’s and ready for bed with a ‘night-night’ story. Mom, meanwhile, gets a needed break. Both boys have a little ‘blanky’ with a soft, silk border that serves as a ‘transition object’. There is a little nightlight that chases away the darkness (and any lurking monsters!). Jacob has a stuffed ‘Cars’ movie character—Lightning McQueen; Charlie takes a soft little bunny to bed (more ‘transition’ objects). Dad briefly lies down with each of the boys and rubs their back a little, then gets up before they fall asleep and gives them a kiss good night. Charlie, thank goodness, is a robust sleeper and practically falls asleep as soon as his head hits the pillow. Dad leaves the door open a crack so the boys feel connected to the rest of the house.

So far so good. The Grants were demonstrating what I call ‘good sleep hygiene.’
Good Sleep Hygiene

- Appropriate bedtime for age. Child should be tired. Bed should be associated with tiredness.
- Calm and soothing routine
- A parent who is calm and loving
- 'Transition objects' like a 'blanky' or stuffed animal to keep the child company in the absence of the parent
- A nightlight and open door
- An emphasis on falling asleep on their own in their own bed.

Falling asleep is the child's job.

Mom: “Jacob likes to talk to himself for a while before he falls asleep.”
Dr. Rick: “That’s OK. I don’t care if he’s up as long as he stays in his bed. It’s his job to put himself to sleep. It’s your job to stay out of it. Leave him alone and if you must interact keep it short and make it boring—no talking, no stimulation of any kind.”
Mom: “Even if he talks to himself for a long time?”
Dr. Rick: “Yes. Leave him alone. No telling him to ‘go to sleep’ unless he’s disturbing Charlie.”

Trouble Falling Asleep, Trouble Staying Asleep

Mom: “I hear what you’re saying but Jacob’s been getting out of bed supposedly to pee but it’s turning into a habit. He’s also been asking for water because he figured out that being thirsty gets attention too.”
Dr. Rick: “I told you he was smart!”
Mom: “Finally, he’s discovered ‘monsters’ in the dark after a bad dream. We put the nightlight in and went around the room to show him that there were no monsters. That worked for a while. But between peeing, drinking and monsters, he was getting up so many times a night I lost count before he finally fell asleep way after his bedtime.”
Dr. Rick: “So what did you do about it?”
Mom: “Jim and I tried reasoning with him, then threatening him, and then yelling but Jacob made such a commotion that Charlie started waking up.”

Jacob, it appeared, had them between a rock (a stone in the shoe?) and a hard place.

Mom: “So I gave in and started lying down with him.”
Dr. Rick: “And don’t tell me. After he got what he wanted, he promptly fell asleep.”
Mom: “Yep. It worked. Kind of. Jacob went to bed better but then he started waking up in the middle of the night, calling for me. At first all I had to do was lay down with him again and he’d fall asleep. But just this last week he started coming to our bed.”
Dr. Rick: “You didn’t let him sleep with you I hope.”
Mom: “Well... we’ve been trying to get him back to his bed but the other night when he made a fuss, we were so tired and, well...”
Dr. Rick: “He got his way. He’s got it all figured out!”

So much for good sleep hygiene! Mom is now getting a terrible night’s sleep. Jacob is restless and bumps into her. Exhausted, she is now falling asleep in Jacob’s bed. Jacob’s sleep is interrupted several times a night. Now, he is sneaking into his parents’ bed and dad is now not sleeping well! But if they try to put limits, he yells and wakes up Charlie who used to be a good sleeper. What a mess!
Sleep Onset Association. There is a term—sleep onset association—that is key to understanding most of children’s sleep problems. It means just what it says. If I associate mom sleeping with me at the onset of sleep then I will need mom to fall asleep. Get it? Mom lying beside me is my new sleep onset association. Being in your own bed and falling asleep on your own is good sleep hygiene, because your sleep onset association is your bed only (maybe your pillow and a blanky type object—not mom).

Whatever is associated with the onset of sleep is what you will need to fall back asleep if you wake up at night too.

Over the last month Jacob’s new sleep onset association is: ‘falling asleep with mom by my side’. The reasons are clear. Developmentally and emotionally, Jacob now experiences sleep as a separation from his parents and it is scary. He’s showing some separation anxiety. That’s where the monsters come in. That’s also where delaying sleep by asking for water or going to the bathroom comes in. When mom sleeps with him his separation anxiety goes down and he falls asleep. When he wakes up in the middle of the night, he gets anxious, remembers his sleep onset association and calls for mom or goes into his parents’ bed. He’s also smart enough to figure out that when he makes requests, uses delaying tactics, and makes noise he gets what he wants—his mom. He is learning to manipulate the situation. This is a sign of intelligence.

In short, Jacob’s sleep problems are developmental and behavioral. There is nothing wrong with him physically. I know what we need to do to fix the problem and we need to fix the problem as soon as possible before it becomes too much of a habit.

Dr. Rick: “We have to get back to good sleep hygiene again. Here’s what I recommend:

• First, talk to Jacob. Use a simple social story: Tell him “I sleep all night in my own bed; daddy sleeps all night in his own bed; Charlie sleeps all night in his own bed. When we get a good night’s sleep we feel good in the morning. Jacob, you need to sleep all night in your own bed so you feel good in the morning.”

• Give him a message of competence. Be strong, be clear, have faith that Jacob can do it.

• But be understanding and fair. Tell him he can get up three times only to pee, or get a drink or you will get mad because he needs his sleep. Say “Mommy loves you and will lay down with you for a little while and will see you in the morning.”

• No sleeping in mommy and daddy’s bed.

• Tell him that if he sleeps in his bed all night you will give him a prize.

• If he gets out of bed more than three times—no prize. If he comes into your bed—no prize. If he screams—no prize.

• Make a small chart. Determine the prize.

Mom: “A Cars movie character. He’s into Cars, the movie, big time.”

Dr. Rick: “The prize is just to motivate him in the beginning to get him back to good sleep hygiene. The real reason is that he needs his sleep and everyone else needs their sleep. And if you want him sleeping in his own bed then always, always take him back to bed if and when he gets into bed with you. We have to re-establish the right sleep onset association.”

Out of Bed at Bedtime Protocol
Mom: “What if he keeps coming out of his room a dozen times to pee or get a drink.”
Dr. Rick: “You want to be kind and understand at first. Separation from mommy is a scary thing. But after three times, your voice should get firm and clear and tell him ‘No more coming out.’"
Mom: “And when he does it again?”
Dr. Rick: “Well here you have various options from gentle to not-so-gentle. The gentle approach is to sit in his room for a while and let him get sleepy with you in the room.”
Mom: ‘I tried that and it just kept him up. And I didn’t talk except to say ‘Go to sleep’ and I was in there for an hour. It got to be way past his bedtime.”
Dr. Rick: “It’s very important that you put him to bed when he’s tired. 8:00 to 8:30 is good for a five year old.”
Mom: “I tried putting him to bed at 7:30. I figured if it was going to take an hour, I’d start an hour earlier. But that didn’t work because he wasn’t tired and Charlie wasn’t tired either.”
Dr. Rick: “Too early is not good and you tried the gentle approach by sitting with him but it only make things worse.”
Mom: “So what’s the not-so-gentle approach? Jim thinks I should just lock him in and let him cry it out but that seems so mean.”
Dr. Rick: “I have a step wise plan that is firm but not mean. First, you threaten to keep him in his room and hold his door shut.”
Mom: “Then he’ll scream and wake Charlie up.”
Dr. Rick: “Just a threat when he comes out the fourth time. Don’t actually hold the door shut. Then, when he’s come out the fifth time, you hold the door shut for a very short time, like one minute.”
Mom: “Then he’ll scream and wake up Charlie.”
Dr. Rick: “Charlie is a good sleeper. If you need to you can move Charlie (while he’s asleep) in your bed (until your battle with Jacob is done). This will be another threat for Jacob: ‘If you cry, Charlie will have to sleep in our room.’ Then you should hold the door shut so Jacob cannot come out. You must win this battle.”
Mom: “He’s going to freak out.”
Dr. Rick: “Correct. Then after one minute of holding the door you go in and say to him, ‘Are you ready to go to sleep without coming out or do you want me to close your door?”’
Mom: “I get it. It’s mostly a threat.”
Dr. Rick: “Mostly, but if he keeps coming out you will hold his door then check on him at increasing intervals—three minutes, then four minutes, then five minutes, etc. Get it? And every time you check on him tell him in a firm voice: ‘I’m here. I love you buddy but it’s bedtime. Now go to sleep.’ Don’t give him any other kind of attention. Just those same words. Eventually he will get tired and will fall asleep on his own.”
Mom: “That could take hours.”
Dr. Rick: “The first day it takes, in general, about an hour. Day Two about a half hour. Day Three, fifteen minutes. By Day Four most kids realize they’ve lost this battle. They know you’re there and that you love them but the message is clear. Go to sleep! So just to summarize, here’s your handy dandy chart.”

Out of Bed at Bedtime Protocol

- Talk to Jacob about the plan: you can come out of your room only three times or no prize
- Be aware of his separation anxiety but give him a message of competence
• Sleep onset association: If you lie down with him, leave before he falls asleep
• If he keeps getting out of bed, threaten to close the door
• If he persists, then close and hold the door and check on him in increasing intervals of time until he gets tired and falls asleep

Note: This is a variation on the Ferber Method (See Resources & Websites: Books) I highly recommend this book for families whose child has night waking problems.

Mom: “You’ve done this before.”
Dr. Rick: “Only about a hundred times and it’s never easy because you have to put limits; it hurts your child’s feelings; it’s pretty miserable.”
Mom: “Won’t this make him feel . . .”
Dr. Rick: “. . . insecure? No. He understands the plan. You should even say to him: ‘Jacob, I don’t want to fight with you. I love you but you have to sleep in your own bed. You need your sleep.’ He knows you’re there. He knows you love him. You let him get up three to four times. You lay down with him. You reason with him. You’re being totally fair, kind, and loving. So, he’ll be mad for not getting his way, but not insecure.”
Mom: “Okay, I’ll try it.”
Dr. Rick: “Don’t try it. Do it. The most important thing I can tell you is that you must give him a message of competence. If he picks up that you feel sorry for him or are weak in your resolve; if he figures that you’re going to cave in, he will resist. You have to be committed to it. The only time this method fails is if the parents feel sorry for their child and give in. I have parents who let their kids fall asleep watching TV, lift them up and put them in bed and then, when the kids wake up in the middle of night, allow the children to sleep with them in their bed. I think these kids are at risk for long-term sleep problems. But I’m really OK with whatever the parents want. Personally, I wanted my kids to sleep in their own bed on their own. By the way, both of my kids are robust sleepers.”
Mom: “So when he finally falls asleep in his own bed, he’ll be back to the right sleep. . .”
Dr. Rick: “. . . onset association. By George, she’s got it! And this should help with the night waking too because when he hits a light sleep, he’ll have the right association. Given that Jacob is just starting these bad sleep behaviors we should be able to get him back on track pretty easily.”
Mom: “I hope so. These last three weeks have been terrible. No one is getting good sleep except Charlie.”
Dr. Rick: “Oh, one final suggestion for problems falling asleep. I recommend melatonin, an over the counter sleep aide that is safe and not habit forming. Give that a half hour to an hour before Jacob’s bedtime and it can really help him fall asleep. The dosage range is 1-6 milligrams. So start with 1 mg, but 3 mg is the right dose. There are stronger sleep medications like clonidine and trazadone but the melatonin should do it for now.” (See Resources & Websites: When Kids Need Meds)

Out of Bed at Night Protocol
Mom: “All right. I think I’ve got it for getting out of bed at bedtime but what’s the protocol if he gets out of bed at night? I can’t hold his door or he’ll scream and definitely wake up Charlie. What if he keeps trying to sleep in our bed?”
Dr. Rick: “The protocol is similar. Explain the plan. First, promise him an even bigger prize for staying in bed. Get or draw a picture of the prize and put it up where he can see it. If he comes to your room you take him back to bed. If he only comes in once he can still get a prize but if he wakes you up twice—no prize.”
Mom: “He’s sneaky. He’ll sleep at the foot of the bed. We’ll wake up in the morning and he’ll be there.”

**Out of Bed at Night Protocol**

- Talk to him about the plan: Sleep in your bed all night and get a really BIG prize (picture it)
- No prize if he wakes you up more than once
- *Never* let him sleep in your bed (lock your door) and do not fall asleep in his bed!
- Keep taking him back to his bed. You may lie down or sit in his room but leave before he falls asleep.
- If he yells, put Charlie in your bed and no prize.
- If there is a danger of his roaming the house gate or lock the door.

Dr. Rick: “Lock your door.”
Mom: “Then he’ll pound on the door.”
Dr. Rick: “Then take him back to his room and tell him: ‘Jacob you have to sleep in your own bed like mommy and daddy and Charlie. If you get up again, no prize.’ I’d give him one chance. If you like you can lie down with him in his bed for a short time or you can even sit in his room in a rocking chair until he starts to fall asleep but make sure you get up and leave the room before he falls asleep.”
Mom: “I tried that. But when I got up he followed me.”
Dr. Rick: “Take him back over and over until he’s exhausted and falls asleep in his own bed on his own. And no prize. And don’t let him sleep in your bed. Not once. And don’t fall asleep in his bed.”
Mom: “This is going to be exhausting.”
Dr. Rick: “Make sure dad and you take turns by the night. It will take about 3-5 days to get him back to good sleep hygiene. You take Monday. Dad takes Tuesday, etc.”
Mom: “This is going to work right?”
Dr. Rick: “No. . . Just kidding. Yes, it will work. Eventually he will fall asleep on his own in his own bed and then he should be a solid sleeper but. . .”
Mom: “But what?”
Dr. Rick: “If you’re going to do it, do it! If you stop putting Jacob back in his bed after a couple of days of struggle, he will go that much longer the next time.”
Mom: “The reason I gave in in the first place is because of Charlie. If Jacob doesn’t get what he wants, he yells and screams and I’m afraid he’s going to wake up Charlie.”
Dr. Rick: “Well, for the nights you’re working on it, I would tell Jacob that if he yells you are going to put Charlie in your bed which will upset him plenty and be a good natural consequence (‘When you scream it wakes up Charlie; so Charlie is going to sleep in our bed. When you are quiet then Charlie will go back in his own bed.’)”
Mom: “Won’t that make Charlie want to come into our bed?”
Dr. Rick: “Charlie is a good sleeper. I’d transfer him back as soon as Jacob is sleeping. I’m betting that with the big reward system in place, the threat of Charlie sleeping in your bed, and never letting him sleep in your bed, he won’t yell—much. But if he does, he does. If he wakes up Charlie then you can get really angry. ‘See, now look. You woke up Charlie and he’s crying and he’s not sleeping. Jacob, no yelling or screaming.’ Make a big deal of it. These are the consequences. Plan on staying up until Jacob goes to sleep in his own bed or the sun rises. Get into it.”
Mom: “Easy for you to say.”

Dr. Rick: “I’m OK with Jacob sleeping with you. I have a number of families who enjoy co-sleeping and I’m fine with that, truly. For my wife and I, we wanted our children to sleep on their own in their own beds.”

Mom: “That’s what Jim and I want. But it just sounds so hard.”

Dr. Rick: “I never promised you a rose garden. You’re darned if you do and darned if you don’t but you’re more darned if you don’t get Jacob to sleep in his own room.”

Mom: “OK, OK, I’ll just plan for it.”

Dr. Rick: “It’s going to be easier than you think. One last thing. If Jacob starts roaming the house you may have to gate or lock his door for safety purposes.”

Mom: “He never roams. He’s afraid of the monsters.”

Dr. Rick: “That’ll work. I wish I had a couple of monsters to rent out to some of my families!”

Note 1: For children who do not understand consequences it may be necessary to gate the door, get a baby monitoring system so as to hear if the child wakes up, or use one of the new laser systems that sounds an alarm if the child leaves the room. As a last resort to keep the child from roaming the house at night you may need to lock the bedroom door for safety purposes.

Note 2: For children who have developed a long established habit of coming into their parents’ bed I will sometimes recommend a more gradual approach where the parent starts by lying down in the child’s bed until the child falls asleep just to get the child used to sleeping in their own bed again. Then the parent sleeps in a cot by the child’s bed. This changes the sleep onset association. Then the parent sits in a chair and gradually gets out of the chair before the child falls asleep. Then the protocol is the same as for Jacob.

Postscript
Julie and I continue our discussion of morning routines in the next half of this visit (See Visit 12: Part 2, Jacob’s Terrible, Horrible, No Good, Very Bad Mornings) but a couple of weeks after the visit I heard back from her. Jacob was a little more stubborn than I had anticipated. Julie Grant, in a series of follow up phone calls, reported that there were times when she was cursing my name and wondering what she had gotten herself into. My words kept ringing in her ears ‘If you’re going to do it, do it! If you stop putting Jacob back in his bed after a couple of days of struggle, he will go that much longer the next time.’ It took five long and hard days with Jacob yelling and long sessions of putting him back to bed, holding the door for progressive periods of time, and loss of sleep for both parents (and Charlie woke up a couple of times!) but eventually Jacob fell asleep in his own bed on his own and won his prize. He has stayed in his bed now for over two weeks and is ‘sleeping like a baby’. The parents won the battle (at some cost!).

Summary
- Over the last month Jacob has been resisting sleep. He’s been getting out of bed to avoid going to sleep and he’s been waking up at night and getting into his parents’ bed. When his parents try to get him back to his own bed he screams, threatening to wake up Charlie. He had them where he wanted them! Because he was tired, mornings were terrible too.
- I help the Grants develop a parenting protocol that gets Jacob back (eventually) to being a robust sleeper.
- The key is ‘sleep onset association’ plus a clear, consistent, fair, kind, loving, and tough approach that gives Jacob a message of competence: ‘You can fall asleep on your own and stay asleep in your own bed. You are safe. We love you.’
Resources & Websites

Websites
- *Your Child* website: http://www.med.umich.edu/yourchild/topics/sleep.htm

Books

Coming Up Next
- With Jacob sleeping better the Grants are ready to tackle the ‘horrible, no good, terrible’ morning hassles.
Chapter 20
Visit 12: Part 2

Jacob’s Terrible, Horrible, No Good, Very Bad Mornings

Dr. Rick: “Let’s not stop now, Julie. We have a plan at least for Jacob’s sleep. Let’s talk about Jacob’s terrible, horrible, no good, very bad mornings.”

Jacob’s Daily Problems

- Bedtime routine/night waking
- Morning routine/getting ready for school
- Self-help—dressing, brushing teeth
- Car misbehavior
- Meltdowns in public: grocery shopping
- Dinner time and eating problems
- Sibling rivalry & sharing
- Toilet Training

Mom: “Judith Viorst, the children’s author, right? I loved that book when I was a kid.”

Dr. Rick: “Exactly! Good children’s literature touches on our deepest emotions. I have a whole library of books I refer to. Now that Jacob is becoming an emotional thinker, it would be a good list for you.” I hand Julie the list. (See Resources & Website, Books about Feelings)

Mom: “Thanks Dr. Rick.”

Dr. Rick: “So what’s your morning routine?”

Mom: “If you can call it that. It’s more like morning chaos! I wake Jakey up around 7:00. We have to catch the bus by 8:00 on school days. The bus stop is right outside the door. But if I am not on him constantly it’s like he gets lost and starts playing with his trains or he starts fighting over the TV with Charlie and it starts with waking up.”

Dr. Rick: “So he dawdles, gets distracted, and you nag. The classic ‘dawdle-nag’ phenomenon. I see it all the time.”

Mom: “I feel like a constant nag.”

Dr. Rick: “Well at least your timing is good and timing is everything. An hour from waking to out-the-door is about right. Some families have to give an hour and 15 minutes depending on long it takes for their child to ‘wake up.’ Does Jacob wake up easily?”

Mom: “He’s a bear to wake up and cranky when he’s up.”

Dr. Rick: “This may sound weird, but try using a warm wash cloth while he’s still in bed. Be loving and soft and gentle and say, ‘O Jacob, it’s time to get up my sweet boy. Mommy’s got a nice warm wash cloth to help you feel good in the morning.’ Some kids love the feeling of warmth. It brings blood to the head and neck and helps them wake up. Some kids hate it but it’s worth a try.”

Mom: “I really want their mornings to be better. In fact, that should be your mantra to the boys: ‘I’m not going to yell or argue any more boys. Let’s have a great morning. AND I have prizes in a Big Boy Bag when you dress yourselves and take care of yourselves.’”

Mom: “I really want them to be independent. This sounds good.”
Dr. Rick: “What else gets your morning off to a bad start?”
Mom: “No one listens. I have to constantly nag the boys—mostly Jacob—to do anything. He yells at me. I yell at him.”
Dr. Rick: “Can Jacob get out of bed on his own? Can he dress himself on his own? Can he eat on his own; brush his teeth on his own?”
Mom: “You mean can he? Yes he can. He’s capable.”
Dr. Rick: “You must be sure he can do it, otherwise you are setting yourself up for failure.”
Mom: “Except he needs some help with hard zippers and he sometimes gets his shirt on backward. So yes he can do almost everything but will he? No he won’t.”
Dr. Rick: “That’s when the nagging and yelling start?”
Mom: “Right. But I’m not going to yell any more.”
Dr. Rick: “You can nag if you want to. Nagging does work. I even prescribe systematic nagging.”
Mom: “You mean I actually use nagging as a method?”
Dr. Rick: “Right. You get into it. I have the mother say, ‘OK children I’m going to nag you constantly until you get ready.’ Then you become very annoying.”
Mom: “I’m very good at nagging. I get it. Then I could use not nagging as a bargaining chip.”
Dr. Rick: “Right. You say, ‘If you don’t want mommy to nag then get dressed’.”
Mom: “I’d like to try a more positive approach first and then use nagging if I have to.”

A Foolproof Morning Structure. The keys to success, I explained to Julie, are, first, to have a foolproof morning structure that makes life easier, not harder, and helps the boys achieve the goal of independence. And second, Julie needs to give a strong message to the boys.

For some families any old sequence will do: get up, eat, watch TV, get dressed, get your back pack, and go. And if it works I’m all for it. But for families where there is a lot of dawdling, the sequence of the morning—and the message—must motivate the children to cooperate or else they suffer consequences, not the parents. We will promote maturity, functional development, independence AND (after some initial testing to see if the parents are serious!) making mornings more pleasant.

The structure must be designed for success. It should reward and support cooperation and discourage resistance. The best sign that there is something wrong with the structure is parental frustration and upset.

Dr. Rick: “I tell parents that if they are yelling and frustrated and exhausted by 8 o’clock they are probably doing something wrong.”
Mom: “Then I’m doing something wrong.”
Dr. Rick: “Tell me more about your terrible, horrible, no good, very bad mornings.”
Mom: “Well, I wake the boys up, which isn’t easy. I’m their snooze alarm. It takes several times to get them up. (I’m going to try your washcloth trick.) Then they get distracted and start to play with their toys or Charlie will jump on Jacob’s bed and usually someone gets hurt or mad. I have to break that up.”
Dr. Rick: “Actually that’s ugly behavior and I’d try to ignore that as much as possible. Remember, whatever you pay attention to will increase.”
Mom: “I don’t want that to increase. It’s bad enough already. I’ll have to keep reminding myself—ugly behavior should be ignored, ugly behavior should be ignored’. Anyway, once they’re up, I herd them into the kitchen to eat. They watch cartoons while they’re eating and usually there’s an argument. Jacob likes Bob the Builder. Charlie likes Fireman Sam or Blues Clues. And then I can’t break them away from the TV to get them dressed.”
Dr. Rick: “That’s a big unnecessary fight. TV should come last.”
Mom: “Charlie wants to dress himself, thank goodness. He still needs help with front and back and which shoe goes on which foot. But Jacob—I’m trying to get him to be more independent—he’s almost five already. I’ll go make lunch or clean up breakfast but when I check on him, he’s still in his pajamas playing with his trains.”
Dr. Rick: “Maybe he really needs help with sequencing.”
Mom: “Sequencing?”
Dr. Rick: “The sequence of getting dressed—underwear, socks, shirt, pants.”
Mom: “He stalls because he can’t ‘sequence’? I never thought of that.”
Dr. Rick: “We could give him a picture sequence to help him (See Jacob’s Dressing Sequence below). But go on, please. Then what?”
Mom: “Then we have a fight about getting dressed because… I don’t know… because he just doesn’t like to change clothes. Or maybe it’s the ‘sequence’. Oh, and there are only certain clothes he will wear. Or he’s playing and he doesn’t want to stop. Or he whines he wants to watch TV.”
Dr. Rick: “Getting him dressed sounds exhausting.”
Mom: “By the time I get them to brush their teeth, wash their hands, get them dressed, pack Jacob’s book bag, get their shoes and coats on, I’m drained. And they’ve figured out that as soon as I’m not right there, they run to the TV or they start wrestling with each other.”
Dr. Rick: “Where’s Jim in all this?”
Mom: “Lucky guy, he’s out the door by the time we wake up. But when he is at home they listen to him more of the time but I hear him yelling plenty.”
Dr. Rick: “The deep voice makes a difference. It gives a strong message.”
Mom: “He’s no nonsense and they know it.”
Dr. Rick: “You have to give the boys a strong message too. That’s a big part of this structure. You can’t lose. Do you miss the bus a lot?”
Mom: “Not any more. We missed it a few times and Jacob was upset. Jacob loves the bus.”
Dr. Rick: “So that’s a motivator. Good to know. We can use that as a threat.”
Mom: “I do that already, ‘Jacob get dressed or no bus’.”
Dr. Rick: “Then why is it so hard?”
Mom: “Mostly because they don’t listen. It’s almost like they like it when I yell. They actually laugh and think it’s a game. Let’s see how much we can get away with not doing what mom wants. That really burns me up.”
Dr. Rick (with a fake evil laugh imitating The Count on Sesame Street): “Ah, ah, ah! Ve vill get even vit dem! Ah, ah, ah.”
Mom (with an evil smile, rubbing her hands together): “I’m all for that.”
Dr. Rick: “I’m just half joking. If they don’t cooperate, they’re going to pay the price, not you. What do you do when they don’t listen?”
Mom: “I just keep herding and nagging, herding and nagging.”

Guilt The Gift that Keeps On Giving.
Dr. Rick: “They’ve got you over the guilt barrel.”
Mom: “What do you mean?”
Dr. Rick: “If you don’t take good care of them in the morning then you’ll feel guilty. They push your ‘soft heart’ button. You’ll feel like a bad mom. You feel like you have to do all these things before you leave in the morning.”
Mom: “I don’t think of it as having to do it.”
Dr. Rick: “What if they didn’t eat?”
Mom: “They have to eat.”
Dr. Rick: “See. You said they have to eat. Actually they don’t. They’ll be hungry but they don’t have to eat.”
Mom: “I couldn’t do that.”
Dr. Rick: “Because it’s your job as mom to feed your boys, right?”
Mom: “Right... ah, I see what you mean. I guess I do feel that I have to take care of my boys. Is that bad? I feel like it’s my job.”
Dr. Rick: “No. It’s good. It’s great. You’re a great mom. I’m not saying you shouldn’t feed them. But I want you to feel a little space here. This is part of a strong message. I want you to start giving the boys some of that responsibility that you feel. I want to convince you to set up the morning for success. But if they give you a hard time, they suffer the consequences not you. Don’t let them push your ‘soft heart’ button.”
Mom: “I have a feeling you’re going to make my life harder.”
Dr. Rick: “Much easier. But. . .you will have to let them suffer the natural consequences if they don’t cooperate. It’s not just the deep voice, it’s the ‘I’m not going to take any crap attitude’, excuse the expression.”
Mom: “That’s his attitude. So I have to be willing to let them suffer the consequences?”
Dr. Rick: “Yep, like not getting to watch TV or not having time to eat their usual breakfast.”
Mom: “That’s why you were talking about guilt.”
Dr. Rick: “Trust me. I want them to eat, watch TV, and have a good morning as much as you do. When you hear my proposal you’ll see that the new morning routine will support what we want. But your morning routine is not working.”
Mom: “You can say that again.”
Dr. Rick: “Your morning routine is not working.”
Mom: “Not funny.”

**Jacob’s Morning Routine: The Carrot**

Dr. Rick: “First, I want you to talk to the boys about the new routine. Tell them you’re done with fighting, yelling and nagging. Tell them they are going to get prizes when they cooperate.”
Mom: “I’ve tried rewards. They don’t work.”
Dr. Rick: “That’s because the boys have been rewarded for NOT cooperating. Your current morning routine is very rewarding for them. They get a lot of your attention (though negative), get to watch TV, do whatever they want, and you take on all the responsibility so they don’t have to take care of themselves because they know you will.”
Mom: “I’ve been doing it all wrong.”
Dr. Rick: “No, you’ve just been doing what mom’s all over the country do. You herd, you nag, you yell and it works, kind of. But maybe there is a better way. The rewards are just incentives. The most important things are the morning structure, a strong message, and natural consequences. At the end come the rewards. Then they’ll work, I hope. So let me lay out the structure of the morning routine.

**Jacob’s Morning Routine: The Carrot**

- Refuse to argue, nag, or yell; be kind & patient
- Promote cooperation and independence
- Provide visual support: calendars, schedules, lists & sequences
- Chart success; reward with stickers & prizes
- Do as much the night before as possible: clothes, book bag, lunch
• Critical—The Morning Sequence:
  1. Wake up 
  2. Dress 
  3. Brush teeth 
  4. Eat 
  5. Watch TV 
  7. Leave/get on bus 

• Be prepared for ‘ugly’ and ‘bad’ behavior...

Dr. Rick: First things first. I want you to do everything you can the night before.”
Mom: “I could make lunch. Lay out the boys’ clothes.”
Dr. Rick: “Right, but make sure they help pick out their clothes. Remember, we’re promoting independence. I have some parents who actually dress their child for school at night.”
Mom: “They sleep in their school clothes? Gross! I don’t think so. But I get the idea. I could have his book bag ready to go too.”
Dr. Rick: “The flaw in your morning routine, as I’ve said, is your sequence (See Morning Sequence above). You allow the boys to eat and watch TV before they get dressed (which, by the way, is OK if they cooperate). But they aren’t motivated to get dressed and get ready to go and they fight over TV a lot. TV should be the last thing they get IF they cooperate and are ready. Otherwise, no TV or free play.”
Mom: “They’re not going to like that but it makes sense. TV would be a built-in reward. I’m starting to see what you mean by a good morning sequence. They eat after they get dressed. They watch TV or play after they eat. That way, if they don’t cooperate, they suffer not me.”
Dr. Rick: “Your message is getting stronger! I recommend you go to the Internet and find some good pictures that show the morning sequence in pictures (See below) and put the pictures on the fridge with a magnet so they can see exactly what they need to do to get stars and prizes.

Incentives: The Big Boy Bag.
Dr. Rick: “Five stars equals a pick from the Big Boy Bag. And, in the beginning, the bag should be loaded with really fun, motivating toys. What would they love?”
Mom: “Jacob and Charlie both love the ‘Cars’ movie cars and the ‘Thomas the Tank Engine’ trains but those little characters are expensive.”
Dr. Rick: “Is it worth it to have a good morning?”
Mom: “I’ll go out and buy a bunch immediately.”
Dr. Rick: “And don’t let them know what’s in the bag. Create suspense. Just tell them that they are going to love the toys.”
Mom: “They will. They love those characters.”
Dr. Rick: “Make the charts together. Go buy stickers together. Make it a project. Then put the charts where the boys can see them:
  • Calendar on the fridge
  • Morning schedule in the bedroom
  • Dressing sequence by the dresser
  • Bathroom sequence in the bathroom, etc.

<Insert 2.1 JPEG DailProb here>
“I would emphasize here that you should only do what you have to do. If all you need is a master schedule for the morning then that’s good enough, but if you need a dressing sequence for example then at least you have that as an option. You could even have a tooth-brushing sequence.”

Mom (laughing): “I have enough to do. I’ll just follow the morning sequence.”

Dr. Rick: “Come on Julie. It’s not that hard. Here’s a dressing sequence example I have as a handout.”

<Insert 2.2 JPEG DailProb here>

Start with a Walk Through.

Dr. Rick: “Each night and each morning, at least in the beginning, take the boys to the schedules to preview what is going to happen in the morning. Give them lots of positive attention—hugs, kisses, praise—and walk them through the process of getting stars/stickers and prizes. In the beginning from 7:00 to 7:15 or 7:20 you support them.”

Mom: “So I sit there and supervise them getting dressed?”

Dr. Rick: “Don’t help too much. Just tell them that you want to see how good they can get dressed so they can get a sticker. We want to get them into the routine first. Give them positive attention. Remember you’re changing their routine. Promote ‘The Good’. Plus you get to see how they get dressed and where the problems might be, like sequencing.

“Make it like a video game, make success noises—bing bing bing, yay!—every time they succeed and move to the next level until they are successful. Then wean yourself out of the picture and keep praising them for becoming independent.”

Mom: “How many days do I do this?”

Dr. Rick: “One or two is all. I can tell you Jacob and Charlie will both love this. Let Charlie model for Jacob.”

Mom: “Charlie is much less of a problem.”

Dr. Rick: “Make it fun (as much fun as you can have in the morning!). Adding a little competition between the brothers as to who gets a star sticker first could help too.”

Mom: “Oh, they’re competitive. Too competitive. It could backfire.”

Dr. Rick: “Use your judgment. I trust you to figure out the best way to motivate but I just want you to see the principle at work here: planning, positive motivation, incentives, practice.”

Mom: “I’ll try to be positive and strong but what if they don’t cooperate?”

Dr. Rick: “We are getting to the . . . stick! It does take effort in the beginning but it’s worth it. As I always say, ‘A habit in motion . . .’

Mom: “. . .stays in motion.”

Dr. Rick: “And when they get all their stars for getting dressed or brushing their teeth they get to pick from the Big Boy Bag!”

Mom: “Jim would say that’s bribing?”

Dr. Rick: “I call it an incentive. An incentive is not a reason. The reason they should do all this is because they are growing up and becoming independent. Just tell Jim that sometimes you need a short-term incentive to achieve your long-term goal. We’ll wean down the prizes. Just let them pick from the bag each time they get all their stars.”

Mom: “When do I wean?”

Dr. Rick: “Give it a week. After the pattern is established, wean down the size of the prizes.”

Mom: “Like Matchbox cars instead of Lightning McQueen?”
Dr. Rick: “Exactly. Give that ‘strong message’ attitude, the expectation that this is going to happen! And keep emphasizing that they are growing up and getting big.”

Mom: “So no prizes after a while. But what if they aren’t motivated enough?

Dr. Rick: “Well, we have...the stick!”

Mom: “The stick?”

Dr. Rick: “THE STICK!”

*What to Do With Dawdling: The Stick!!*

Dr. Rick: “In the beginning, no matter how much you set it up right and offer them the ‘carrot’, there is a fair chance that the boys (especially Jacob) are going to buck the new routine, especially after you wean yourself out.”

Mom: “We could go back to square one; but maybe the ‘carrot’ will work.”

Dr. Rick: “It really could. You get them into the new routine, they love the stickers and rewards, they are motivated to be independent and their behavior will be perfect forever and ever.”

Mom: “Sounds like a fairy tale.”

Dr. Rick: “A Grimm fairy tale. There’s always a troll somewhere. You have to be prepared to use ‘the stick’. First of all it’s a new routine and Jacob doesn’t like change. Second, you are not going to fight, badger, nag, yell or give him attention like you used to. He could return to dawdling. There’s a lot to be said for dawdling.”

Mom: “Nagging and yelling worked, kind of. I was miserable but eventually they did what they had to.”

Dr. Rick: “And you can always go back to that.”

Mom: “No thanks!”

Dr. Rick: “Plus they won’t get to watch TV first thing. So Jacob, for instance, might come down the stairs in his p.j.s and head for the TV.”

Mom: “And if he does, I just send him back upstairs to get dressed, right?”

Dr. Rick: “Gently and kindly but only two times. He has until 7:15 to get dressed on his own and get stickers. Go over the picture schedule. Be supportive. Say ‘Jacob, mommy loves you so much. It’s time to get dressed on your own and get stickers. Go up and get dressed, eat, brush your teeth and then TV. You can do it, Jacob. Get dressed and get prizes! Yay!’ Cheerlead. Shepherd. Do the same for Charlie. But then, no nagging from you.”

Mom: “And if he comes down undressed?”

Dr. Rick: “If comes down undressed more than twice sit him on the stairs in time out until 7:15.”


Dr. Rick: “By George, I think she’s got it. The rule is: When you are dressed, you can eat.”

Mom: “Can I give him reminders?”

Dr. Rick: “Sure, give him two reminders. You can yell up the stairs or go up in person and say: ‘Jacob, it’s time to get dressed on your own and then come down to eat. If you dress on your own you get STICKERS and PRIZES!”

Mom: “That would be a switch. I’m usually nagging him every two minutes.”

Dr. Rick: “See, your morning is getting better already!”

Mom: “So I warn him, I mean ‘remind’ him. And what if he dawdles?”

Dr. Rick: “He gets to play a little but he’s dawdling his TV time away. And you get to relax. Until 7:15.”

Mom: “Natural consequences. I’m starting to see the benefit of this.”

*Timing Is Everything.*
Dr. Rick: “We are working by the clock:

*Timing is Everything*

- **7:00-7:15**
  - Jacob dresses on his own. Maximum two reminders. Help him if he needs it. Success=Stickers/Big Boy Bag.
- **7:15-7:30**
  - If not dressed, he sits on the stairs until he dresses. You may help him if he needs it. No stickers.
  - If he resists he sits on the stairs in time out.
- **7:30-7:45**
  - If he is still not dressed you dress him by force if necessary.
- **7:45-8:00**
  - Brush his teeth, get his coat, book bag, etc., and go!

“So at around 7:15 if he is not downstairs and dressed, bring Jacob and his clothes downstairs and say the following words: *Jacob you did not get dressed on your own. Do you want to eat and play? Then you need to get dressed right now, otherwise you have to sit in time out.*”

Mom: “So if he doesn’t get dressed in his room...”

Dr. Rick: “. . .then you bring him and his clothes downstairs starting at 7:15.”

Mom: “Then he sits until he gets dressed?”

Dr. Rick: “On his own.”

Mom: “But he could get dressed at any time and not go to time out on the stairs.”

Dr. Rick: “Right. Or he can choose to fight you and then he has no choice but to sit on the stairs until he gets dressed on his own.”

Mom: “I think he’s going to fight me.”

Dr. Rick: “Maybe, maybe not. Just plan on putting him in time out on the stairs from 7:15 to 7:30 and keep him there by force if necessary.”

Mom: “I just keep bringing him back?”

Dr. Rick: “Calmly and coolly. Just plan on it.”

Mom: “You call this a good morning?”

Dr. Rick: “He will remember this the next day and you can use it as a threat. ‘Jacob, remember yesterday? You didn’t get dressed so you had to sit on the stairs.’”

Mom: “Shouldn’t I warn him?”

**Use a Social Story.**

Dr. Rick: “I like that idea. Let’s say he has a bad morning. Then that night you could do a little social story for the next morning with a puppet or stuffed animal.”

Mom: “We have a Lightning McQueen puppet.”

Dr. Rick: “Perfect. You could talk to Lightning and say: *Poor Lightning you didn’t get dressed this morning and had to sit on the stairs. You were sad. I love you Lightning so I’m not going to argue or yell. I want you to get dressed on your own like a big car. Can you do that? (Lightning nods.) I think you can too. Then you’ll get stickers and get to pick from the Big Boy Bag! Get dressed, come downstairs, eat, brush your teeth, play and watch TV. But if you don’t get dressed you will have to sit on the stairs and no stickers and no Big Boy Bag. Tomorrow morning you can get dressed like a big car.”
“Then Lightning can say: ‘OK mommy. I want to watch TV and play. I want to get stars and pick a prize from the Big Boy Bag because I’m getting to be a big boy.’ Get it?”
Mom: “Got it, but I can see him agreeing then getting up and dawdling anyway. He can’t resist sitting on his bed looking at his Thomas trains.”

Work by the Clock.
Dr. Rick: “That’s why we work by the clock and have the stick. At 7:15, dawdling is not allowed—that’s the rule. Jacob must start getting dressed downstairs now at 7:15. No star stickers or prize unless he dresses on his own. And he has to keep getting dressed.”
Mom: “So he gets a second chance to get a prize? Jim will think that’s babying him.”
Dr. Rick: “I disagree. If you bring his clothes downstairs and he dresses himself—why not? What’s wrong with giving him more chances? Keep it positive and fun. You could even try my trick to tell him he can’t get dressed. ‘No dressing, Jacob!’ And let him ‘disobey’ you and get dressed just to show you who’s boss.”
Mom: “And if he doesn’t get dressed?”
Dr. Rick: “No problem. You have a plan. Then he’s on the stairs until 7:30. No nagging, no talking, nothing except putting him back on the stairs.”
Mom: “Definitely no sticker here.”
Dr. Rick: “Right. But I wouldn’t rub it in. He can change his mind at any time to get dressed. Then he can eat.”
Mom: “What if he gets up off the stairs to test me.”
Dr. Rick: “I’d ignore as much ‘ugly’ behavior as possible. If he stays around the stairs, I’m OK with that. But if he actually gets up and tries to leave the area, then bring him back to time out until 7:30. And please don’t give him attention or talk to him too much! Just the words I’ve recommended: ‘Jacob you are not listening. Now you have to sit in on the stairs (or time out chair).’”
Mom: “This could take up the rest of the morning.”
Dr. Rick: “Nope, just from 7:15 to 7:30. And he missed his usual breakfast.”
Mom: “Now I see why you were talking about guilt. I don’t know how I feel about letting him go to school without eating.”
Dr. Rick: “Use hunger as a motivator. Tell him: ‘Jacob if you want to eat, get dressed!’”
Mom: “He likes his breakfast.”
Dr. Rick: “If he misses his usual breakfast, give him a granola bar to eat on the bus.”
Mom: “That makes me feel less guilty.”
Dr. Rick: “This should last one or two days at most. Once he ‘gets’ the new routine, mornings will be pleasant (See Postscript). Hope for the best but be prepared for the worst. And keep in mind that this is really about Jacob taking care of himself and growing up.”

The Bottom Line.
Mom: “OK. So he doesn’t get dressed; he doesn’t eat and it’s time to go. What then?”
Dr. Rick: “Dress him. Plan on it. Just dress him between 7:30 and 7:45. Be firm and not happy and say ‘Jacob I am very disappointed in you. You did not get dressed so I have to dress you so you can get on the bus. You get no stars, no prize, no TV, and no breakfast.’”
Mom: “Should I point out that Charlie got all these things because he cooperated?”
Dr. Rick: “Absolutely.”
Mom: “I could even see him undressing himself as I get him dressed.”
Dr. Rick: “He’s a real stinker isn’t he? You’ll just have to dress him again. And again if necessary until time runs out. Remind him that he’ll miss his bus. That would make it a really horrible, no good, very bad morning indeed! You have until 7:55 am.”

Mom: “He loves his bus ride.”

Dr. Rick: “I had one child recently who had to be driven to school in his underwear. We handed him off to the school personnel and they dressed him. While his mom was driving him he was so angry, he took his seat belt off and attacked his mom while she was driving.”

Mom: “What did she do?”

Dr. Rick: “Pulled the car over repeatedly; put him back in his seat belt every time. She was furious. They had a terrible, horrible, no good, very bad morning but it only happened once. Just be prepared to fight and win this battle. The bottom line is he gets no attention, no breakfast, no TV, no prizes; he’s been in time out most of the morning and then he has a big fight with his mom. Believe me, the next day he will remember this. The question I have for you is: What are you going to do with all your free time when the mornings are easy?”

Mom: “I hope I’m tough enough to go through with this.”

Dr. Rick: “You don’t have to. If you want to do it the old way it’s OK with me.”

Mom: “I hate our mornings.”

Dr. Rick: “You’re darned if you do and you’re darned if you don’t but you’re more darned if you don’t establish a new routine. This is ultimately about helping Jacob grow up and take care of himself and having at least a decent start to the day. It’s also about your attitude. Once the boys push your ‘soft heart’ button and you back off, you’ve lost the battle.”

Mom: “Jim sounds tougher, like a military sergeant. I’ll have to keep that in mind.”

Dr. Rick: “Here’s a handy dandy summary:

**Jacob’s Morning Routine: The Stick**

- Night before: Rehearse time outs with a puppet
- Next morning 7:00-7:15: Two reminders to dress on his own
- 7:15 Not dressed? Bring Jacob downstairs to dress on the stairs.
- 7:15-7:30 Time Out on the stairs or chair
  - Remind Jacob to get dressed on his own and he still gets a prize
  - If he gets off stairs bring him back until 7:30
- Natural consequences: No eating, no play/TV
- At 7:30-7:45 you dress him for an 8:00 am departure
- He will remember this the next day!!

Mom: “There are still two problems on my checklist that I really want to get to and both of them are problems that start in the morning and go on all day.”

Dr. Rick (looking at the list): “You mean the toileting and the sibling rivalry?”

Mom: “Changing Jacob’s poopy diapers is really getting old. He’s ready; he’s just stubborn.”

Dr. Rick: “I have a lot of good tricks for toileting. I think he’s ready too.”

Mom: “The other big issue is going out together. Jacob and Charlie are getting into it. There is so much fighting over sharing, in car rides. We can’t go anywhere without problems.”

Dr. Rick: “Sounds like ‘outing’ are trouble.”

Mom: “Grocery shopping, restaurants, driving—all of them are driving us nuts.”

Dr. Rick: “No pun intended. Let’s see how the morning plan works first. Then let’s get together to talk about the outings, toileting and the sibling issues. How does that sound?”
Mom: “I want Jim to be here for those discussions. Jacob’s behavior has been so bad even Jim is talking about medications. I’ll let you know how the morning goes. Wish me luck!”

Dr. Rick: “You won’t need it. Be kind but be tough.”

Postscript
As opposed to the problems Julie and Jim had with Jacob’s nighttime routine, Julie reported good news about the morning routine. The boys were surprisingly motivated by the carrot approach to get prizes from the Big Boy Bag. At first they tested her and they did have one terrible, horrible, no good, very bad day where Jacob went without breakfast, sat in time out the whole time and had to get dressed by force but he seemed to get the fact that his mom was going to win the battle. She was determined! She was tough!

After that Jacob loved the structure of the calendars, schedules, lists and sequences. He liked putting stars on for every accomplishment. It didn’t hurt that Charlie was all about getting prizes and he was a model of independence. Now Julie gets to read the news online in the morning with her cup of coffee. Mornings are busy but much more peaceful. She was very grateful for the new morning routine.

Summary
- Jacob has been having terrible, no good, horrible, very bad mornings for months. There’s dawdling, yelling, resistance, and, recently, outright disobedience. Mom is frazzled by 8:00 am.
- We make a morning routine plan that includes helping Julie Grant give a strong message by creating a better morning structure that uses a ‘carrot and stick’ approach with rewards and prizes for success, and time outs, no TV, and delaying breakfast, which are the natural consequences of severe dawdling and misbehavior. It’s tough love but it works!
- In the process I provide the Grants with a number of handy dandy charts and plans.

Resources & Websites
- Autism Solutions (2011) Ricki Robinson MD
- Books about feelings: http://www.aadl.org/user/lists/59337

Coming Up
- Dad calls! Despite good behavioral strategies, Jacob continues to have serious problems with outings, eating, car travel, aggression towards Charlie, etc., etc., and now dad is re-considering medications. We schedule a visit to talk about misbehavior in public.
- Things are getting so bad for the Grants that it might be time to consider medications.
Chapter 21
Visit 13
Outings and Eating

At the end of a long day, I see Jacob Grant's chart with a note from Amy that Jim Grant called. “Jacob’s behavior is getting worse.” This is a bad sign especially after all the work we’ve already done on Jacob’s behavioral issues. Jim Grant is pretty unflappable. I call him on his cell.

Dad: “Dr. Rick, I’m sorry to bother you after hours but at one of our visits you mentioned medications. I was the one against it but Julie and I have been talking. We think Jacob might need it.”

Dr. Rick: “Why the change of heart?”

Dad: “You said something that stuck in my head, that meds were not for treating a label but to help Jacob feel better and be happier. And he’s been...well...miserable. And to be honest, we’re all pretty miserable these days. Everything puts him on edge. Little things. Nothing. He won’t eat what we eat. And going out to eat is a nightmare. We’ve practically stopped going to restaurants altogether. Do you think he might have ADD?”

Dr. Rick: “I doubt it but that’s something we can talk about.”

Dad: “His car behavior is horrible. You go the ‘wrong’ way and he’s crying the whole time and the sibling rivalry with Charlie is constant.”

Dr. Rick: “I thought things were going better.”

Dad: “They were. They are. Sleeping is better and we thought maybe if Jacob got more sleep, he’d be better during the day but these outings are kicking our butts. Maybe it’s sensory. We can’t go anywhere without Jacob having embarrassing meltdowns, yelling, pushing, you name it. Oh, and Julie wanted me to mention that Jacob is getting pickier and pickier about what he will eat at home and at restaurants. We need to do something. Meds. Something.”

Dr. Rick: “Sounds terrible. Okay, let’s get you guys in tomorrow at the end of the day, at 5:00. Bring your list. I’d like to avoid meds but the poor guy sounds like he’s not a happy camper.”

Dad: “And you know how it is. When Julie’s stressed everyone’s stressed.”

Dr. Rick: “I’ve been married 40 years and if there’s one lesson I’ve learned, it’s ‘happy wife, happy life’. Do me one favor? Make sure the boys get a good snack before they come in. I don’t want them being hungry while we talk.”

Dad: “Will do. See you tomorrow at 5:00.”

The Layers of the Onion

When a family has a child with ASD, they peel away the top layers of the onion, the big problems—like dealing with the autism itself—and come to another layer and yet another. In terms of his autism, Jacob has made tremendous progress over the last 2½ years, but progress has brought transition issues, sleep problems, and difficulty with morning routines. His brain is still maturing.

It’s been my consistent experience that as children with ASD get better, their behavior often gets worse. Why? Two reasons.

• First, as they become more aware of everything, the world becomes bigger, more overwhelming, and more anxiety provoking. There’s just so much to deal with and their coping skills are still immature.
And second, they are getting smarter; they have more wishes and expectations. So they want more and they can’t always get what they want.

This combination of anxiety, poor coping skills, and more demandingness show up as constant daily hassles—the stones in your shoe—that wear even solid families down over time unless families work with their child to help improve the child’s coping skills and maturity. All children go through the terrible two’s stage but children with ASD go through them for a longer period of time.

As I finish my phone call with Jim Grant, I realize again how important is to deal with these daily hassles, these layers of the onion. They offer a vital opportunity to help Jacob become a much better, more mature emotional thinker, which has profound long-term implications for his life. I’m looking forward to the discussion.

The Visit

As Julie and Jim Grant arrive for their 5:00 pm visit, I can feel the tension, see the stress in their serious faces. They want to get down to business. It’s been a long day but I want to start the visit off on a positive note.

Dr. Rick: “So tell me something good about Mr. Jacob.”

Jacob and Charlie are hanging out, waiting for me to have some fun with them.

Mom (holding her list): “Things are better at night and in the morning. Jacob’s even getting himself dressed and is brushing his teeth most of the time. Sometimes I have to joke or make up a game or use reverse psychology with him.”

Dad: “. . . and tell him not to do something.”

Mom: “. . . but he knows the consequences if he doesn’t cooperate.”

Dr. Rick: “Strong message mom! Way to go Jacob. Give me five. (He does.) Ouch! Don’t hit so hard! (He laughs.) Charlie, you been a good boy? (He nods.) Way to go and give me five. (He does.) Ouch. Don’t hit so hard. (Both boys laugh.)”

Of course after the ‘ouches’ they want to give me harder and harder high fives. So we spend a minute slapping with me yelling “ouch”. I shoo them away to play while I continue the discussion with Jim and Julie.

Dr. Rick: “So sleep is better and Jacob’s getting himself dressed at least mostly on his own.”

Mom: “I have to help him with his zippering and buttoning but it’s not bad. What’s bad is going out. I can’t figure out what the consequences should be. Not going out is OK with him. He likes it at home and the threat of losing privileges doesn’t matter enough to change his behavior when we’re out, so he’s got us over a barrel. I get the evil eye from strangers almost every time I’m out with him in public.”

Dad: “That really burns me. They give you that look like ‘Why can’t you control your kid?’”

Dr. Rick: “I know. I have so many families that have embarrassing moments in the grocery store or wherever and people in the stores just don’t get it.”

Mom: “When Jacob’s having even a minor meltdown we get ‘the look’.”
Dr. Rick: “I have just the thing. (I reach for a business card from my shelf). Here, take a few of these. On the front of the card it says: ‘My child has autism. Thank you for understanding.’ and on the back there’s a space where you can write in ‘You Jerk!!’” (We all have a good laugh.)

Dr. Rick: “This card is no joke. One of my families just told me that they used the card in the grocery store the other day and the woman who was glaring and judging actually apologized and had a whole different attitude. Within seconds she became a lot more compassionate. I really believe in educating the public. We need to be more tolerant as a society.”

Dad: “But I don’t want Jacob to get a pass on behaving himself.”

Dr. Rick: “I agree. We should expect Mr. Jacob to behave, right Jacob? (I hold my hand up and he gives me another high five.) I’ve got a lot of ideas for making outings better, Julie, but you still might face some embarrassing moments.”

Mom: “I’ll take a few of those cards.”

Dr. Rick: “I’ve got some practical ways to reduce Jacob’s upsets in public. It really has to do with helping him cope better, to understand that he can’t always get what he wants.”

Dad: “And he wants what he wants when he wants it.”

Helping Jacob Cope and Mature

Dr. Rick: “So let’s talk about outings. Oh, and eating. Jim, you mentioned that Jacob is getting pickier and pickier. Didn’t we talk about the survival of the tastiest? (See Chapter 10, Visit 5: Moving On Up?)

Dad: “He was doing better but lately he’s narrowed his food choices again. I think we need a booster about his diet.

Mom: “That’s important but can we please talk about Jacob’s car behavior?

Dr. Rick: “All these behaviors are connected. I see it all the time. When children make progress in their overall development they regress in their behavior.”

Dad: “Why is that?”

Dr. Rick: “As the children make progress, the world can feel very overwhelming on the one hand and cause anxiety which leads to upsets; and on the other hand they start to project their desires into the future. They know what they want.”

Mom: “So in a way, this is all progress?”

Dr. Rick: “Yes, but we still have to help Jacob mature, cope and learn that there are better ways of getting what he wants than throwing a tantrum. He needs to get his controls.”

Dad: “I hope so because it’s getting very hard for Julie to do anything outside the house. Do you think we’ll need to medicate him?”

Dr. Rick: “We’ll talk about it, I promise. But first I have to take care of some business.”

The shooping didn’t work. The boys are chomping at the bit, waiting to play. They locate my popper buttons.

Jacob: “Do poppers. Shoot ‘em.”
Charlie (pointing to the ceiling): “Pop ‘em up.”

Dr. Rick: “Mind if I play a little with the boys and then we can get down to business?”

Jacob, Charlie and I pop a few popper buttons (small half spheres of rubber that jump really high when you deform them) off my bald spot, which they find hilarious; I shoot poppers at them off my fingertips like a gun. Then, we sword fight until I’m mortally wounded. Then we play ‘yuck frog’ where I put on a big mouth frog puppet who tastes and then spits out the plastic food while saying
‘Yuck!!’ Finally, the boys settle in with my Thomas the Tank Engine set with wooden tracks, while we adults settle in to peel back more layers of the onion.

**Dr. Rick:** “So, outings, car behavior and picky eating. What else is on your list?”

Julie hands me the list.

**Jacob’s Daily Problems**

- Bedtime routine/night waking
- Morning routine/Getting ready for school
- Self-help—dressing, brushing teeth
- Car misbehavior
- Meltdowns in public: grocery shopping
- Dinner time and eating problems
- Sibling rivalry & sharing
- Toileting Issues

**Outings: ‘Driving’ Us Nuts**

**Dr. Rick:** “You are organized!”

**Mom:** “I feel like I’m a hostage in my own home Dr. Rick. First of all, driving anywhere has become a nightmare.”

**Dr. Rick:** “How’s the process of getting into the car going?”

**Mom:** “We’ve been using some of your transition tricks and they seem to be working okay.” *(See Chapter 18 Dr. Rick’s 20 Transition Tricks)*

**Dad:** “We let the boys know what’s coming and make it sound like fun. We let them bring a toy. . .”

**Dr. Rick:** “A transition object.”

**Dad:** “. . . and if they’re good we give both boys a little prize—like a superhero sticker—for getting in the car without a hassle.”

**Mom:** “We praise and cheerlead a lot.”

**Dad:** “So, actually getting in the car goes pretty well. I had to fight with Jacob a couple of times to put on his seatbelt but when he realized I meant business I haven’t had much trouble lately.”

**Mom:** “But sometimes he holds a grudge. Then the problems start on the road when Jim’s not with us, which is most of the time. If I don’t go the way Jacob thinks I ought to go he’ll scream and try to get out of his seatbelt. It’s like he’s got OCD.”

**Dad:** “He even attacked Julie and pulled her hair. We don’t let him sit behind her while she’s driving anymore.”

**Dr. Rick:** “Putting the child in the right seat is important.”

**Dad:** “He knows better when I’m in the car. That burns me; that’s just downright dangerous.”

**Mom:** “Or if Jacob wants Charlie’s toy or game, he tries to get out of his seat belt to get it. Then the boys start fighting. And I’m driving!”

**Dr. Rick:** “OK. Let’s start there with driving hassles. I have a wonderful tactic for you but the first principle for dealing with outings of all types is ‘You must have a plan’. You have to expect the best and set things up for success but be ready for the worst behaviors.”

**Mom:** “Well I need a plan. Driving is driving me nuts.” *(See Driving Us Nuts below).*

**Dr. Rick:** “So once you’re in the car and going somewhere and the boys or Jacob start acting up, what have you been doing so far?”

**Mom** (half-joking): “Praying.”
Dr. Rick: “My dad use to say that God helps them that helps themselves.”

Mom: “I’ve tried ‘telling Jacob how he feels’.”

Dr. Rick: “You mean like ‘Jacob you don’t want mommy to go this way; you want mommy to go that way.’”

Mom: “Exactly but when he’s upset about the direction I’m going (the boy could make maps for Rand McNally) it seems like he’s beyond help.”

Dr. Rick: “I have one more variation on ‘telling him how he feels’ that might be helpful here. I want you to actually act like Jacob and get really mad at going the wrong way.”

Mom: “Like what?”

Dr. Rick (demonstrating loudly): “No! No! No! Mommy. I don’t want to go this way!!” (I mock cry out loud.)

Driving Us Nuts: The Plan

- Join him in his feeling. Be dramatic.
- Use a social story/fable (Right-Way Rabbit).
- Plan for 20-30 minutes of extra time to your trips initially for one to two weeks.
- Use the same phrases, i.e., I can’t drive with crying and hitting, I’m pulling over!
- For car misbehavior, pull over quickly (but safely) for 15 minutes and read a big novel.
- In the future threaten to pull over.
- Give praise & rewards for successful trips

This gets the attention of the boys who look at me with concern because they think I’m really crying.

Dr. Rick: “See how fast that works.”

Mom: “That’s a good one. I haven’t tried that.”

Dr. Rick: “But the timing has to be right and you have to be dramatic.”

Dad: “Oh she can be dramatic.”

Jacob: “No crying Docker Rick.”

Dr. Rick: “I’m sad when mommy goes the wrong way.”

Jacob: “I like my way.”

Dr. Rick: “You want mommy to go the right way.”

Jacob: “The right way. 96. Yes.”

Mom: “That’s I-96. He knows all the highways between home and here and can list them. We have to go exactly the right way. Where do we go after 96 Jacob?”

Jacob: “23.”

Dr. Rick: “That’s right! You go 96 to 23. Amazing map cognition. That’s one way to keep the world the same.”

Dad: “He knows exactly—and I mean exactly—how he wants to go and if he doesn’t go that way, it’s all over. He just loses it.”

Mom: “Like last week, our usual ramp was closed so we had to use another exit. He got so upset, crying, then screaming, he got out of his seat belt and started hitting me and pulling my hair.”

Dr. Rick: “We can’t have that. So the question is how do we help Jacob become a better emotional thinker—more flexible, more in control of upset—by using these types of daily conflicts? Right now he’s rigid and not
thinking flexibly. And he sounds to be a bit obsessive compulsive/OCDish. Remember our discussion on the impulse sandwich? (See Chapter 17, Visit 10: The Good, The Bad, & The Ugly)

Dr. Rick: “Good memory, dad. We want to put more meat and cheese and tomatoes in his impulse sandwich by reasoning with him and connecting ideas. So what’s the basic idea here?”

Dad: “Sometimes we can’t go the way Jacob wants us to.”

Dr. Rick: “Right, dad. That is the social story.”

Mom: “And you can’t always get what you want.”

Dr. Rick: “That too, but ‘if you try sometimes you just might find...’”

Dad: “...you get what you need’. Rolling Stones.”

Dr. Rick (high fiving dad): “You are so cool dad! So how can we teach Jacob to think more flexibly?”

Mom: “Talk about it!”

A Fable: The Right Way Rabbit.

Dr. Rick: “Yes, but not when he’s in the heat of the moment. And of course it has to be in terms he can understand... I think it’s time for a fable.”

I quickly get a little toy car and put a mommy doll in the front seat and, among my toys, I find a miniature Piglet and Rabbit from Winnie the Pooh for the back seat. I talk into my audio recorder and start recording a fable. I speak loudly and dramatically.

Dr. Rick: “Once up a time there was a rabbit called ‘The Right Way Rabbit’. (I push the re-play button, which totally attracts Charlie and Jacob to my table.) You know why he was called Right Way Rabbit? Because he only wanted to go the right way in the car.”

“One day his mommy was blocked (I put some large Legos in the way of the car) and she had to go the wrong way. Uh oh, watch out!! You know what Right Way Rabbit did?”

Jacob: “Cry?”

Dr. Rick: “Right, Jacob. He was so mad. He was so sad. He cried, he screamed, he HIT his mommy! Oh no! He said, ‘I’m the Right Way Rabbit and I have to go the right way in the car! And if you don’t go the right way I’m going to scream and cry and hit, hit, hit’!”

At the word ‘hit’ Jacob, Charlie and I exchange wide-eyed looks at how bad Right Way Rabbit was being.

Dr. Rick (talking to the character): “Right Way Rabbit no hitting!”

Charlie: “No hitting.”

Right Way (I role play Right Way Rabbit and sound very self righteous): “If I don’t go the way I want then I will hit because I am Right Way Rabbit and I have to go the right way in the car.”

Dr. Rick (to the boys): “What is the mommy going to do with Right Way Rabbit? Uh, oh. Oh, oh! Look what’s happening. Mommy is pulling over and stopping the car. Screeeeeeeeeee.”

Mommy Doll (I hold the mommy doll and speak for her): “Right Way Rabbit, I can’t drive when you scream and yell and hit. It’s dangerous! I’M PULLING OVER. I’M PULLING OVER.”

Dr. Rick: “And you know what she did? She PULLED OVER. Screeeeeeeeeee! She stopped the car and they didn’t go anywhere.”
Piglet (I wiggle Piglet): “Go mommy go.”
Right Way Rabbit: “Go mommy go.”
Jacob: “Go mommy go.”
Dr. Rick: “But mommy did not go. You know what she did? (Long dramatic pause. The boys are totally into the story and hanging on every word.) She sang a song! And here is what she sang (to the tune of London Bridge):

Mommy Doll: “Some of the time the road gets blocked, the road gets blocked, the road gets blocked. Some of the time the road gets blocked, and I can’t go the right way.”

Dr. Rick (summarizing the social story): ‘Sometimes the road is blocked and the mommy can’t go the right way.’ If Right Way Rabbit screams and hits, the mommy can’t drive. It’s dangerous.”

I rewind the tape recorder and play the song again which the boys love.

Dr. Rick: “And then (my voice gets very sad sounding) the mommy sang a sad, sad song to Right Way Rabbit” (again to the tune of London Bridge):

Mommy Doll: “I can’t drive when you scream and hit, scream and hit, scream and hit. I can’t drive when you scream and hit, my dear children.”

Dr. Rick: “So, they sat on the side of the road and sat and sat and sat. . . and sat. And Rabbit and Piglet said ‘Come on mommy let’s go!’ And you know what the mommy did? Nothing! And Piglet and Rabbit were sad. They wanted to go to the store but mommy wouldn’t go until. . . . Rabbit and Piglet (I wiggle the characters) said together: ‘Mommy even if you go the wrong way, we won’t scream and hit. We will be good. Please go go go.’”

“So mommy got back on the road to go to the store and, you know what? They had to go the wrong way again. You know why? You know why they went the wrong way again? Because the road was. . .”

Jacob: “. . . blocked.”

Dr. Rick (I could tell that he was getting this): “Right, Jacob, the right way was blocked so mommy had to go to the store in a different way, not the right way and Right Way Rabbit got very upset.”

Right Way Rabbit (I speak in an internal monologue while wiggling Rabbit): “I don’t want to go a different way; I want to go the right way. I’m mad. I want to cry and hit but then mommy will pull over. Besides if I hit I won’t get what I want. The road is blocked. We have to go a different way to get to the store.”

Dr. Rick: “He was so sad not to go the right way but he wanted to go to the store and have fun. And guess what? Good news! Even though they went a different way to the store, Piglet and Right Way Rabbit had fun and got toys. (I play the happy ending again.) The end!”

Charlie: “Play it again!”
Jacob: “Play it again, Docker Rick!”

So I replay the moral of the story one more time.

Dr. Rick: “Sometimes you can’t go the right way because the road is blocked and you have to go a different way.”

Dad: “That was amazing. I think they really got it.”

Dr. Rick: “The point is to help Jacob understand why! We are connecting two ideas logically. We are helping him become a more mature social thinker. This will help him cope!”

Car Time Out: Pulling Over
Mom: “So the moral of the story is that you want me to pull over every time the boys start fighting?”

Dr. Rick: “You have to use your judgment. You can try all your tricks but when you’ve given two warnings and they are not responding, yes, you should safely find a place to pull over and pull over. You do this and after one or two times they will start listening to you.”

Mom: “There’s not enough time in the day for this.”

Dad: “Just try it honey. This is such a huge headache for you.”

Dr. Rick: “Give it one week. Plan on taking some extra time. Expect it. Bring your biggest novel.”

Mom: “My biggest novel?”

Dr. Rick: “When you pull over I want you to get out your novel and start reading. I want you to read for 15 full minutes. Enjoy yourself.”

Mom: “The boys will hate that. They want to go...ah, I get it. I get it. Consequences!”

Dr. Rick: “And before you pull over I want you to say the same words every time—loudly and distinctly. Something like: ‘I CAN’T STAND THIS FIGHTING, I’M PULLING OVER!!’”

Dad: “The dreaded ‘I’m pulling over’ phrase. Which means time out on the side of the road totally bored while mom reads her novel. Brilliant!”

Dr. Rick: “Many of my parents have used this and it works. I want you to use the same phrase for two reasons. One, it comes to have meaning. Two, you can use ‘Do you want mommy to PULL OVER?’ as a threat in the future.”

Mom: “I’m almost looking forward to the boys misbehaving in the car. But what if they keep screaming after I’ve pulled over?”

Driving Us Nuts: The Plan

- Join him in his feeling. Be dramatic.
- Use a social story/fable (Right-Way Rabbit).
- Plan for 20-30 minutes of extra time to your trips initially for one to two weeks.
- Use the same phrases, i.e., I can’t drive with crying and hitting, I’m pulling over!
- For car misbehavior, pull over quickly (but safely) for 15 minutes and read a big novel.
- In the future threaten to pull over.
- Give praise & rewards for successful trips

Dr. Rick: “Totally ignore the ugly behavior and act like you can’t hear them. You can even step outside the car if it’s safe. This works for all kinds of car misbehavior, not just going the wrong way. You can use it when they get out of the seat belt or for sibling squabbles, etc. So that’s the stick.”

“But don’t forget the carrot. Try and make the car ride fun and when they behave make sure they get praise or a little prize of appreciation like a stamp or sticker.”

Mom: “We’ve been doing that right along. We bring books, little video games, we play their favorite music and we reward them with stickers and suckers but they rarely get a prize. The carrot is not working. I get the booby prize of crying, fighting, and hitting.”

Dr. Rick: “Hopefully, after you pull over a couple of times and they get the booby prize of boredom, they’ll think twice. Besides, it really is unsafe to drive under those conditions.”
“We’re going to have to look at possible root causes too like sibling rivalry issues because that can fuel the fire. You’ll have to let me know how it goes. What else is on your list?”

### Jacob Won’t Eat Restaurant Food

**Mom:** “Grocery shopping and restaurants.”

**Dad:** “I can’t remember the last time we went out to eat at a nice place and had a good time without some kind of hassle.”

**Dr. Rick:** “But you go out for a nice meal together alone don’t you. Like a date?”

**Mom** (long pause): “We haven’t for a while. With Jacob the way he’s been, it’s hard to find a baby sitter we can trust.”

**Dr. Rick:** “How about your folks, Julie.”

**Mom:** “My mom and dad are good but we don’t like to impose on them just to go out.”

**Dr. Rick:** “Do I need to write a prescription? ‘One date monthly’.”

**Mom:** “I would love that.”

**Dad:** “You always say you’re too tired.”

**Dr. Rick:** “You need alone time or you will be tired. Remember, if you don’t recharge your batteries you won’t have enough energy for them. You just have to plan it and stick to it. Your folks would love to have the boys.”

**Dad:** “They give in to Jacob’s behavior and I think that might be making him worse.”

**Dr. Rick:** “Don’t worry too much about how your parents parent the boys. You will always retain control at your home. You need a break, a monthly date. (I get out my prescription pad and write) ‘One date monthly. Grandparents to babysit.’ (I hand it to mom.) Doctor’s orders. Now, getting back to the restaurant. I assume you bring distractions.”

**Dad:** “Of course. Books, toys, Nintendo DS (the handheld video game), you name it. That works for a while but Jacob is so particular about food…”

**Mom:** “…we’re very limited as to where we can go and even then we have to hurry and worry the whole time. It’s not worth it. We just eat at home more and more.”

**Dad:** “It used to be fun, going out to a nice place and having a good meal.”

**Dr. Rick:** “This is sad! One trick is to go to McDonalds and get a Happy Meal or McNuggets and fries and take that to the restaurant.”

**Mom** (hopeful): “We could do that?”

**Dad:** “Bring food from another place into the restaurant?”

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**Ideas for Eating Out**

- Don’t go out to eat ever (not recommended)
- Get a sitter and go without the boys. Parents need to go out once a month on a date!
- At the restaurant bring distractions and use prizes. Keep a fun attitude.
- Buy fast food and take it to the restaurant.
- Go off hours and sit in a quiet place.
- Have them eat *before* you go. When you get to the restaurant, *they* eat dessert and the parents eat dinner.

**Dr. Rick:** “If it’s for the kids. Sure. A restaurant won’t mind.”

**Mom:** “But that involves another stop, more time.”
Dr. Rick: “True. Ideally they will eat food from the restaurant without any problems.”
Dad: “That never happens.”
Dr. Rick: “So here’s a cool trick that several of my parents told me works like a charm: Feed the boys their dinner before you go out. Do they like desserts?”
Dad: “Charlie likes all desserts. Jacob pretty much only likes ice cream or chocolate cake.”
Dr. Rick: “Perfect. Almost every place has ice cream. Feed them before you go out so they’re not hungry and while you are eating dinner they are eating desert. Make sure you go at off hours, a little early or a little later than the rush hour and find a quiet corner table near an exit or bathroom if possible. The sensory issues can be overwhelming. Did you feed them before you came today?”
Dad: “I made sure of it.”
Dr. Rick: “And look what angels they are.”
Mom: “I love that idea. Honey, we could go to a nice restaurant.”
Dad: “Just like in the old days.”
Dr. Rick: “Stop you guys. You’re breaking my heart.”
Mom: “If you can’t go in the car, can’t go to restaurants, can’t go to the grocery store without worrying and hassling...”
Dad: “...it really affects the quality of your life. It gets old.”
Dr. Rick: “I hear that. Hopefully some of these tricks will help and we’ll get Mr. Jacob back on a better track, so to speak. (Jacob and Charlie are playing very nicely with trains.) Let’s talk about shopping.”

Tantrums in the Store
Mom: “I dread shopping although I’m starting to get used to the stares. I swear I’m going to use those cards. Jim can’t stand Jacob’s store behavior.”
Dad: “He’s much better for me. I can pick him up and carry him out. I won’t take his crap, excuse the expression.”
Mom: “He’s getting heavy and I can’t pick him up like that.”
Dr. Rick: “He is getting big but that’s the whole point. He’s getting big enough to understand that you go shopping so you can eat. We need cereal so we go to the store and buy more. You’re putting two ideas together...OK. So what triggers Jacob’s misbehavior?”
Dad: “Wanting things. He’s always thinking ahead. He’s a collector.”
Dr. Rick: “Ah, broken expectations, disappointment. He has an idea and expectation of how things should go”
Mom: “Right. His expectation is that he always wants me to get him something and I’m not doing that anymore. I made that mistake. I bought him a Thomas the Tank Engine book once and now he wants to go to the book or toy section every time. Those toys are expensive.”
Dad: “He should be able to go through a store without getting something every time.”
Dr. Rick: “Right dad. Though some of my families do promise a little prize like gum, or a small candy bar, or something for a buck or two that can be used as a reward for good behavior. I’m not opposed to a small reward. The point is to reward good behavior. On the other hand, I agree with you Jim. Going to the store is part of life itself. We shouldn’t have to buy him off but that doesn’t mean it can’t be fun.”
Mom: “It is not fun.”
Dad: “Even if he gets one thing, he wants something else. With Julie especially, if he doesn’t get a book or a toy, he’ll whine, cry, tantrum and hit. He acts like a brat.”
Dr. Rick: “You have to follow the ‘never, ever’ rule: You never, ever, ever, ever, ever, ever, get what you want for bad behavior. (See Chapter 17, Visit 10: The Good, The Bad, The Ugly). It will take some training but I believe in Jacob.”
Mom: “As soon as he sees something he wants, he starts to whine. I ignore him and keep going down the aisle. By then he’s in tantrum mode but he doesn’t want me to leave him so he gets up off the floor and chases after me, whining all the way down the aisles.”

Dr. Rick: “That sounds terrible.”

Dad: “It’s bad.”

Mom: “I’m going to hand out cards left and right. I don’t know what else to do. I have to finish shopping.”

The ‘Going-to-the-Store’ Plan.

Dr. Rick: “We need a better ‘going-to-the-store’ plan. Our goal is for Jacob to go through a half hour of shopping without whining, crying, or tantrumming. So let’s make sure we do the basics. Do you make a shopping list?”

Mom: “I do.”

Dr. Rick: “So make sure Jacob has a copy. This will be his schedule. Check off your list.”

The Going-to-the-Store Plan

- Use a shopping list as your schedule
- Have a positive attitude; Expect success
- Keep trips short; Get what you really need first
- Make sure the boys are fed and not tired
- Make it fun and meaningful; Let the child help
- Follow the never, ever rule; Be strict and quick
- Ignore ugly behavior if you can
- Plan an extra half hour for a ‘car time out’
- Use prizes only for great store behavior
- Be careful about too much sensory overload

Mom: “He might like that.”

Dr. Rick: “Next, your attitude matters. If you are expecting a behavioral mess, you will give off an anxious vibe and Jacob will pick up on this.”

Mom: “I’m definitely negative about shopping. The boy can’t handle five minutes let alone a half hour. A half hour without a hassle would be heaven.”

Dr. Rick: “Well maybe that’s where we start. Keep the shopping trip short to start with. Think of this as not shopping but as a practice session to teach Jacob how to go shopping. Only get what you need. Be ready to leave and go out to the car at any time. Give yourself the psychological advantage and just plan on it. Make sure the boys are rested and not hungry. Make it fun and be silly. Make it meaningful, sing a silly song ‘Hi ho hi ho let’s buy some food and go. We want to buy good food to eat, hi ho, hi ho, hi ho.’ Make sure you tell him you are not going to buy a toy.”

Mom: “I tell him that ahead of time but it doesn’t matter. He wants a toy.”

Dr. Rick: “I think you could give him a little prize to give him something to look forward to but only if he has great store behavior. Be strict. Is that OK dad?”

Dad: “I guess.”

Dr. Rick: “Are you up for this?”

Dad: “It can’t get much worse. So at the first sign of misbehavior we should go out to the car for a car time out?”
Dr. Rick: “As always you should mirror back his feelings and see if you can talk him down. One warning should do it but then, if that doesn’t work, you have to act. What words will you use?”

Mom: “Jacob, no whining. If you keep whining we are going to the car.”

Dr. Rick: “Perfect.”

Jacob looks up from playing with the trains.

Mom: “What if he fights me. He can run.”

Dr. Rick: “Don’t be afraid to be tricky. When he keeps whining you could say in a wooing, inviting voice, ‘Come here Jacob I want to show you something.’ Then take him outside and then to the car. If you anticipate him running just keep a good grip on him and get him to the car. Park close. I’ve even had families get a handicap-parking sticker. You’re the boss.”

Mom: “I hope this works. It’s going to take a lot of time.”

Dad: “I’ll go with you the first time.”

Dr. Rick: “That would be helpful, Jim. But I want you, Julie, to do the whole thing. Otherwise Jacob won’t respond to you when you’re alone. It could take a couple of trips to the store before he knows that when you say ‘no whining’ you mean ‘no’. He’s getting smart. He thinks he can wear you down. Your current strategy of ignoring and walking away is actually not that bad behaviorally. It might work eventually. But for me this is about helping Jacob learn to be mature, delay gratification, not always get what he wants. I want him to not only tolerate shopping but even enjoy it.”

Mom: “I’m going to do the car time outs. I’ll just plan on taking more time.”

Dr. Rick: “Call me when you are successful (See Postscript. I have one last question. How is Jacob with the noise and the chaos? Some kids literally can’t handle the sensory overload. I recommend going off hours.”

Dad: “I don’t think he’s that sensory. I can take him to Lowe’s and he loves it because he loves tools and machines and we pretend he’s Bob the Builder.”

Dr. Rick: “OK. Then we’re set. I think Jacob will get it.”

**Picky Eating**

Mom: “One last thing before we go. Any advice on Jacob’s picky eating?”

The boys are starting to fight over some toys and Jacob is pushing Charlie and Charlie is pushing him back.

Dr. Rick: “Whoa, whoa. Who wants a sucker? Go ask Amy.”

They stop fighting and run out.

Mom: “I’m surprised they’ve lasted this long without a fight. The sibling rivalry thing is getting out of hand at home. The issues over sharing are constant.”

Dr. Rick: “I think we should talk about that next time. That’s a long conversation. I’d like to finish this conversation about picky eating, OK?”

Mom: “Sorry, Dr. Rick.”

Dr. Rick: “I’ve had a lot of picky eaters lately in my practice so I put together a handy dandy set of guidelines that can help expand the range of foods that a child eats. (I search through my handouts.) Here you go:
Guidelines for Picky Eaters

• Beware: 'Survival of the tastiest'
• 'It's the parents' job to put good food on the table. It's the child's job to eat.'
• No fighting over eating. No feeding or force feeding. If he doesn't eat then he'll be hungry.
• 20 exposures to adopt a new food!
• Create a 'Just take a taste' plate
• Food should be similar in color, texture, smell and taste to what he eats or what he ate before
• Five Start Chart for touching, tasting, eating, etc.

“Let me go over this quickly and then we can talk about it later if you like. To tell you the truth, I don't worry too much about picky eating because I have rarely seen a child with ASD lose weight or get sick because of dietary matters. If the eating problems are more severe I refer the family for professional help.”

“So, I have a joke about autism and eating: Do you know what Indian children with autism eat?”

Dad: “I'll bite (smiles at his pun. I smile back). What do Indian children with autism eat?”
Dr. Rick: “Indian food.” (We all laugh).

Dr. Rick: “Rice, curry, lentils.”
Mom: “Children will eat whatever they're exposed to.”
Dr. Rick: “Exactly. So the first rule of eating is don’t cave in by giving tastier foods. We talked about this before. Of course they are going to want food that is sweeter, saltier, and/or fattier because these foods taste better. I can’t tell you how many children are on the nuggets and fries diet. They think: ‘I’m not going to eat chicken when I can have nuggets.’ Then they refuse chicken or throw a tantrum. I have some parents who literally run out to McDonalds so their child will eat! The tastiest foods get selected and you have what I call...”
Dad: “…survival of the tastiest.”
Dr. Rick: “This is the main cause of picky eating—parents giving in to the food preferences of their children. I have many mothers who cook multiple meals for dinner.”

Mom: “I do that.”
Dr. Rick: “If American parents would follow the dictum of the most famous pediatric nutritionist, Ellyn Satter, we would be a much better eating nation: ‘It’s the parents job to put good food on the table. It’s the children’s job to eat.’ In other words, if the child does not eat, it’s OK. They’ll be hungry later and can eat the good food that their parents gave them (i.e., you can reheat the food they refused) or they can wait until the next meal.

Mom: “It’s so hard to see them go hungry.”

Dr. Rick: “It is. Seeing you kids go hungry is hard. But for kids with ASD it can be disastrous to keep giving in. I have some children who will only eat five foods total. I had one kid recently who would only eat French fries. Once they narrow their diets they do not want to change.

“Now don’t get me wrong. I think it’s OK to have a simple alternative to the family meal—like peanut butter and jelly or a hot dog or a bowl of healthy cereal—as an alternative to what the family
is eating but if they reject those choices because they want McDonald’s Chicken McNuggets then it’s too bad. If you want to cave and give them tastier foods it’s OK with me. . .”

**Dad:** “. . .but then they keep narrowing.”

**Mom:** “One thing I’ve really learned from you Dr. Rick, is that being a good parent means doing what’s best even if it upsets your child.”

**Dr. Rick:** “Well said, Julie. So that’s rule number one. Put good food on the table and no fighting and no force-feeding. It’s the child’s job to eat.”

**Mom:** “But how do you get them to broaden their diet then?”

*The ‘Just Take a Taste’ Plate.*

**Dr. Rick:** “That’s the next strategy. It's important to understand that it takes up to 20 exposures to a new food before the child will eat it.”

**Mom:** “Wow. 20 exposures?”

**Dr. Rick:** “So what I recommend is having what I call a ‘Just Take a Taste’ plate. This is a separate, smaller plate that you put by the dinner plate that has a tiny, teeny piece of food on it. Here are the guidelines:

- It should be very easy to make (usually what has already been cooked). Keep it simple.
- But, and this is important, it should be very similar in color, smell, texture and taste to the foods Jacob likes.
- In the beginning it could be something he might even like more, something sweet.
- But it has to be different.”

**Dad:** “I get it. He'll get used to trying something new that is easy to like and then he'll get into a habit of trying new foods.”

**Dr. Rick:** “Correct! This way he will get lots of exposures. Tell him that if he will ‘Just Take a Taste’ he will get a reward. I like to have a strip with five stars on it.

- If he just touches the food he gets a star
- If he puts it to his mouth he gets another star
- If he tastes it and spits it out he gets another star
- But if he actually eats it he gets five stars right away and the prize!

“So, no matter how he gets there, if he gets five stars he gets a prize.”

**Mom:** “I see. You make it easy to get stars. What kind of prize?”

**Dr. Rick:** “Whatever will motivate. It could be a sweet treat. I had one family recently give a miniature tootsie roll for trying a new food. It could be a small toy. I have had some parents use the food that’s for dinner as the reward: Take a tiny taste of real chicken and you get a chicken nugget—plus five stars!”

**Dad:** “Charlie could do this too.”

**Dr. Rick:** “Yep, he would be a good model (and competitor). After a while it just gets to be a habit. And a habit in motion… .”

**Mom & Dad** (in unison): “. . .stays in motion.”

*Medications*

**Dr. Rick:** “One last thing, Jim, you mentioned meds.”

**Dad:** “I’m wavering now. Sometimes I think Jacob can’t really control himself and sometimes I think we should give him a chance to cope and be more mature before we give him meds.”
Dr. Rick: “I’ll tell you what. Let’s set up a time to talk about the medication options so you can see what’s possible but if we can avoid them that would be best. I’m happy to do this over the phone because my return appointments are so far out. It’s a pain in the butt to work this hard on all these things but it’s worth it if it works, if Jacob can learn. If he can’t, then that’s another story.”

Mom: “But we need to give him a chance before using the meds, right?”

Dr. Rick: “You need a lot of patience and persistence but I have seen a lot of kids get better without the meds. The meds can be very helpful when you need them.”

Dad: “Let’s hold off for now but I’ll look forward to talking about it with you. With all these new ideas, I think we can help Jacob do better.”

Dr. Rick: “Let’s give it a few weeks to work on all these issues and then talk about the medications.”

Postscript

Driving the Wrong Way. After hearing the Right Way Rabbit fable (with a little booster from mom), Jacob had no problems with going the wrong way (which happened only once). A total success! On the other hand, Jim and Julie did have to pull off the road when Jacob wanted Charlie’s toy and started throwing things in the car. Mom and dad said the magic words: “WE CAN’T DRIVE WHEN YOU ARE THROWING THINGS. WE ARE PULLING OVER!!” They safely pulled over, got out their (big fat) novels, and read for 15 full minutes. As the time dragged on, the boys were begging for them to go. Now all Jim and Julie have to do is threaten to pull over and the boys behave much better!

Restaurants. Jim and Julie were not quite as successful with restaurant behavior. They fed Jacob and Charlie dinner at home, then ordered the boys ice cream at a very nice restaurant while they ate an adult meal. It went well until the end of the meal when Jacob started getting whiny. They warned him once to stop whining, and when he didn’t stop, Jim took him to the car and let Charlie and mom finish their meals in peace. Jacob did not like the car time out (but Charlie did!).

Grocery shopping. Grocery shopping did not go great either but mom planned for the worst. She parked close, kept her shopping list short, and took Jacob out quickly as soon as he started to get upset. She was strong, kept her cool, and imposed a five minute car time out. Charlie was not happy either and cried loudly which Jacob hated. Mom talked to Jacob about going back in to finish shopping because, as she tells it: “We have to buy food so we can eat.” She had to take him out a second time but then he understood when she said that it was “going to take a long, long time if you cry or throw a tantrum”. Third time was a charm. Julie just threatened a ‘car time out’ and he behaved after one threat! She gave him a little treat at the end for being good (the third time).

Picky Eating. Jacob’s eating hasn’t changed that much but the attitude at the dinner table is much less tense. He’s trying a few bites of new things (enough to get a prize) but he hasn’t adopted any new foods yet. Oh well, can’t win them all!

Summary

- Dad calls! While some things have gotten better, Jacob continues to have problems with outings, car travel, restaurants and grocery shopping.
- So we meet and develop a driving plan, an eating out plan, and plan for handling public misbehavior.
• Jacob’s eating has become more and more picky too.
• We schedule a visit to talk about how to use daily hassles and misbehavior to improve Jacob’s emotional thinking, coping, and maturity.

Resources & Websites
• Engaging Autism, Stanley Greenspan and Serena Wieder (2009)
• Autism Solutions, Ricki Robinson (2011)
• Secrets of Feeding a Healthy Family, Ellyn Satter (2008)
• Just Take a Bite: Easy, Effective Answers to Food Aversions and Eating Challenges, Lori Ernsperger (2004)

Coming Up
• On a phone all visit, I discuss medications for Jacob with Jim and Julie.
Despite the fact that Jacob Grant has, over the last two and half years, made wonderful progress in terms of his autism, his behavior has worsened to point where his parents and I are considering medications. Jim and Julie Grant called and our phone visit picked right up where we our last office visit left off.

**Burning Out**

_Dad_: “Thanks so much for agreeing to talk so soon after our visit but with all the chaos in the family we have to settle this issue of meds. I’ve got it on speaker phone and Julie is here with me.”

_Dr. Rick_: “No problem. We ran out of time last visit. But I agree this is important.”

_Mom_: “You said the meds could be helpful if Jacob’s behavior is out of his control.”

_Dr. Rick_: “So what you’re saying is that you think that might be the case?”

_Dad_: “You haven’t seen him when it’s happening. It’s like he loses it completely and there’s no bringing him back. His face goes wild. And he goes from 0 to 60 in a second. He’s gone.”

_Mom_: “Just like we’ve been saying, almost anything can upset him—going out, not getting what he wants, not going where he wants, arguing with Charlie. We’ve tried so hard and done so much you’d think that life would be getting easier.”

_Dad_: “And maybe it is. These new strategies we’ve been implementing have helped some, don’t you think Julie?”

_Mom_: “Some. Maybe. But I’m just getting worn down.”

_Dr. Rick_: “It feels so hard. Jacob’s behavior is still so challenging. It can take a long time for these guys to change. Months and months.”

_Dad_: “She’s burning out, Dr. Rick. Jacob has made really great progress overall. Don’t think we’re not happy with where he’s at. But it’s like why can’t he get himself under control already? Julie keeps saying that she feels like we’re failing him.”

At this I can hear mom starting to cry. I hear Jacob and Charlie in the background.

_Jacob_: “Mommy’s crying.”

_Charlie_ (going to his mom’s side): “Don’t cry mommy.”

_Dad_: “Mommy’s OK. Everything is OK.”

_Mom_: “We just want to be the best we can for Jacob, and Charlie.”

_Dr. Rick_: “You guys are doing great. If you could see the range of families I see you would realize just how wonderful you are. I mean amazing. But that doesn’t mean it’s easy and I know how much you want Jacob to be happy.”

_Mom_: “But the way he behaves now, how can he be happy?”

_Dr. Rick_: “That’s the question. Let me give you a little perspective here. Jacob has come a long, long way. One thing I’ve learned in following so many children on the spectrum is that the phases of their emotional development last longer than typical children. For example, Charlie is three and he’s already able to control his impulses better than Jacob. But he went through a ‘terrible twos’ phase where everything was a ‘no’, true?”

_Mom_: “True, but it didn’t last like this.”
Dr. Rick: “My point exactly. Jacob’s ‘terrible two phase’ as you call it is going to last longer but he will get more cooperative.”
Dad (half joking): “I don’t know if we can survive until then.”
Dr. Rick: “Let’s talk about just how much he’s out of control. Let’s quantify it. From my perspective, and correct me if I’m wrong, he seems basically happy. You’ve met his needs for nurturing. He’s loved. He’s making everyone else miserable but he’s happy.”
Mom (laughing through tears): “Maybe I need the meds.”
Dr. Rick: “Don’t laugh. Many families want medications for their child because they can’t stand the conflict, the upsets, and the misery. It must feel like there’s no end in sight.”
Mom: “It feels endless.”
Dr. Rick: “Let’s talk about meds—for Jacob—and we’ll come up with a decision together.”

Medication Considerations
Dr. Rick: “How strong are we leaning toward meds here?”
Mom: “The more we talk, the more I’m beginning to see that Jacob might be just going through a phase. A long phase but a phase. That maybe if we just hang in there...”
Dr. Rick: “I don’t want you to have a nervous breakdown in the mean time.”
Dad: “Me personally, I’d be happy to wait on the meds but the hassles and fighting are just taking a toll, especially on Julie. It’s hard to watch.”
Dr. Rick: “This is one my considerations. Is the behavior so bad that it’s affecting family functioning?”
Mom: “Jacob’s behavior has been hard on all of us but if you really think this is a phase, that gives me hope.”
Dr. Rick: “I know it’s a phase. I have faith that Jacob has the potential within himself to be more mature but that doesn’t mean meds are out of the question because you can use meds temporarily and then wean them off.”
Dad: “I’m open. I’m just leery about them.”
Dr. Rick: “You should be. I’m not like child psychiatrists—who for the most part these days prescribe meds for a living—but I do prescribe psychotropic medications regularly and I can tell you that these meds are powerful. They change the child’s brain chemistry and there isn’t a lot of research on the long-term effects on the child’s developing brain. I think we as a society are way too quick to give them without first working on the child’s emotional thinking process. Every one of these meds has side effects with some having potentially serious side effects. So for me the important question is how severe is Jacob’s behavior. Is his behavior affecting his functioning, his happiness, and the functioning and happiness of the family so much that we need the meds?”
Mom: “His behavior was getting really bad but lately with all your help it’s been somewhat better. It’s just that it seems like every interaction is a hassle.”
Dr. Rick: “Another fundamental question has to do with the ‘philosophy of can’. Can Jacob learn to be more mature in a reasonable amount of time without meds?”
Dad: “What is reasonable?”
Dr. Rick: “I’d guess 4-6 months. Helping Jacob become a more mature, emotional thinker takes time and persistence, meds or no meds. Look how long we’ve been working. Years now.”
Dad: “Don’t remind me.”
Mom: “It’s almost like the better he’s gotten the worse his behavior has gotten. And once we deal with one behavior up pops another one.”
Dr. Rick: “It’s like peeling the onion. He’s still immature and doesn’t yet understand that you can’t always get what you want; and ‘when you throw a fit you never get’. (Make sure Jacob can hear me!) But let’s quantify this. How often would you say he has major upsets?”
Mom: “You mean like fall on the floor screaming?”
Dad: “Those really bad tantrums are getting a little better. It used to be every day. At one point, both Jacob and Charlie were falling down screaming together. It was almost comic.”
Dr. Rick: “What about hitting, being really aggressive. Are we looking at daily, weekly, monthly?”
Mom: “It’s not daily but I’d say at least two to three times a week. The sibling rivalry thing is bad. That’s daily.”
Dad (returning to the speaker phone): “Julie handles the daily hassles really well. You asked if the big tantrums are daily or weekly. If she wasn’t so good, it would be daily, definitely.”
Mom: “And that’s with a lot of support from Jim.”
Dr. Rick: “You guys are wonderful as a couple. But that’s a factor too. If the husband and wife don’t work as a team, I’m going to be quicker to give meds. If the family as a whole is suffering, I’m going to be quicker to give meds.”

No sooner had we invoked sibling rivalry than Jacob and Charlie were fighting over some toy at home. Jim left the phone to deal with it. I hear Jim settling them down and then he returns to the phone.

Dad: “I bought them off with a TV show so we could talk. But you asked about the family suffering. I think the family as a whole is suffering.”
Mom: “Charlie is really struggling.”
Dr. Rick: “So 2-3 times a week with major breakdowns and lots of little upsets on a daily basis mostly because of sibling rivalry or outings. That’s quite a bit. But before we talk about specific types of meds, I want you to realize that meds are rarely completely effective and they don’t ‘cure’ the condition. They help but you when stop the meds, the symptoms come back most of the time; whereas, if you work on the behaviors successfully, the behaviors resolve. Helping Jacob become a mature emotional thinker is curative.”

Dad: “Even if we give meds Jacob could still have behavior problems?”
Dr. Rick: “Meds might improve his symptoms 50-75% of the time. That can be a big help especially when the symptoms are really bad.”
Mom: “Do you think Jacob’s symptoms are bad enough to need meds?”
Dr. Rick: “Close. We’re walking that line. Let’s take the next step and figure out what specific type of medication he might need. That might help us make a decision.”

**Anxiety, OCD, Depression?**

Dr. Rick: “Would you say Jacob is a worrier in general or that his upsets are more situational?”
Dad: “Jacob makes us worry but I don’t think he worries so much as reacts.”
Mom: “Me either. I don’t think of Jacob as being anxious. Demanding yes. Impulsive yes, but a worrier? Except for going the right way, no. He’s pretty easy going most of the time.”
Dad: “His upsets are definitely situational, predictable.”
Mom: “The car, the store, arguing with Charlie.”
Dr. Rick: “He gets upset when his expectations are broken. So, in a sense, he is worried about getting what he wants. That’s a form of anxiety.”
Dad: “True but he’s not ‘a worrier’. Broken expectations. That’s Jacob in a nutshell. He is obsessed with what he wants and what he likes to do and if he can’t do what he expects watch out. A lot of the time we have no idea what he expects.”
Dr. Rick: “So it can come out of nowhere.”
Mom: “I’m getting better at noticing when it’s coming. He shows signs and I’m reading his cues better but still when he gets his mind on something, that’s it. He’s obsessed.”
Dr. Rick: “But you wouldn’t call him obsessed in the sense of OCD, would you?”

Mom: “You mean like checking the doors or stove like I do? I’m a little OCD.”

Dr. Rick: “It’s that feeling of ‘having’ to do something or else something bad will happen. Like toilet seats having to be down or having to close all the doors or like his toys having to be in just the right order on his bed a night? I call them ‘just so’ kids they want things perfect.”

Dad: “Not at all. He could care less except for going the right way as I said.”

Dr. Rick: “What about phobias? That goes along with anxiety; like fear of bees, or flying bugs, or storms, or the dark.”

Mom: “He doesn’t want to go down the basement because of ‘monsters’ and he was definitely aware of bugs and bees this summer. But he actually likes them.”

Dad: “I don’t see fears like that either.”

**Medications?**

- Is behavior effecting functioning and happiness? We are not treating a label.
- Does situational stress trigger behaviors?
- DSM Diagnoses
  - Anxiety/OCD/Depression
  - ADHD
  - Oppositional Defiant Disorder
  - Mood
  - Regulatory Disorder

Dr. Rick: “So it doesn’t sound like OCD. It’s not general anxiety. And Jacob is not depressed.”

Dad: “Depressed? You mean sad a lot.”

Dr. Rick: “Depression in children isn’t like depression in adults. They’re not going to come out and say they’re sad. It shows up as not functioning very well, withdrawing from activities, and/or being angry or irritable a lot usually after a long time of being chronically upset and sad. It comes from experiencing a series of losses, from neglect or emotional abuse which is obviously not at issue here.”

Dad: “You think his anger and irritability might be from depression?”

Dr. Rick: “I have to consider everything but I don’t think so.”

Mom: “He’s actually a happy guy most of the time.”

Dr. Rick: “I agree. The anti-anxiety medications probably won’t help Jacob.”

Dad: “What kind of meds are we talking about here?”

**Prozac-like Meds**

Dr. Rick: The Prozac-like Meds (See Glossary under SSRI) increase brain serotonin and make you happy and less anxious and less obsessive. I call them the ‘don’t worry, be happy’ pills. They’re relatively safe at low doses with few side effects and they work great if you have a lot of anxiety. But still I would work with Jacob’s anxiety the way we have been working on everything else.”

Mom: “The transition tricks and that fable on the Right Way Rabbit helped with Jacob’s anxiety. Is that what you mean?”

Dr. Rick: “Right. We want to find the potential within the child to deal with life’s anxiety by being able to put things in perspective.”

Dad: “Sounds like to you need to take these meds every day.”
Dr. Rick: “These are chronic meds. You have to take them for a long time. You can’t start and stop them and they are hard to get off of without the anxiety coming back. But for Jacob I’m not convinced they would help. He’s more reactive than anxious.”

Mom: “And when he reacts, he reacts! He gets mad quick and he escalates fast.”

Dr. Rick: “And he’s getting bigger and stronger.”

Dad: “When he loses it and starts hitting, it’s getting harder to handle him even for me.”

**ADHD?**

Dr. Rick: “Let’s talk about his reactivity, his impulsivity. Let me keep clicking through the diagnostics. I’m screening him here for a number of conditions. Would you say he’s hyperactive and inattentive? How’s his focus?”

Dad: “This guy can focus for hours on his trains. I don’t see him as hyper, do you Julie?”

Mom: “Except when he gets silly.”

Dad: “If anything he gets stuck on things like TV, trains, swinging.”

Mom: “But ask him to do something he doesn’t want to do and he gets silly or runs or throws a fit. Then he’s all over the place. That’s when he looks hyper.”

Dr. Rick: “That’s what makes it hard to diagnose ADHD for kids on the spectrum. When they’re doing preferred activities they’re fine but when they are asked to do non-preferred activities they can really look inattentive and distracted.

“So it’s hard to diagnose and hard to treat. Recently there was an important study where the researchers gave the Ritalin-like stimulant meds to kids with ASD who also had ADHD symptoms and compared them to the neuro-typical kids with ADHD symptoms. The Ritalin-like meds worked for 90% of the neuro-typical kids but only worked in 40% of the kids with ASD!”

Dad: “Wow. That’s a big difference.”

Dr. Rick: “Yep. In other words, kids on the spectrum even when they had true ADHD type symptoms only benefited from meds half the time compared to typical kids.”

Dad: “So how do you know who to treat?”

Dr. Rick: “I hate to say it but it often comes down to trial and error. What I do is give varying doses (including no dose) of the stimulants and have the teacher rate the child every day using a standard rating form.”

Dad: “The teacher doesn’t know what the dose is?”

Dr. Rick: “Right. It’s called a ‘single blind trial’. The teacher is ‘blind,’ i.e., she doesn’t know the dose of meds the child is getting. Which reminds me. What is the preschool saying about Jacob’s behavior in class?”

Mom: “He’s doing fine. No complaints.”

Dad: “It’s like he holds it together at school and then lets it all out at home.”

Dr. Rick: “That tells you something about the philosophy of can’. Jacob can control himself at school at least for a time.”

Dad: “That’s a really good point. He must have some control.”

Mom: “They haven’t called us once. So why does he act out so bad for me?”

Dr. Rick: “Julie, don’t start blaming yourself. It’s not about you. I see this all the time. The kids hold it together at school and then let it all out at home where they feel safe and loved and comfortable. So in fact, school may be contributing to Jacob’s misbehavior at home. I also see kids who go the other way and let it all out at school.”

Mom: “A lot of times he is worse right after school. That’s so interesting.”
“But he can sit still and pay attention great if he wants to. We can read a book together for a long time and he'll stick with it.”

Dr. Rick: “But that’s a preferred activity. What about when he gets to kindergarten and he’s in school all day. There will be more demands and a high value on ‘compliance’ to do non-preferred activities, stay focused without distraction and listen.”

Mom: “He still ignores a lot especially if he doesn’t want to do something. Even when we use your ‘mini time outs’ approach (See Chapter 17, Visit 10: The Good, The Bad, & The Ugly), he still doesn’t listen very well.”

Dad: “Kindergarten isn’t that far away. Jacob does not like to do—what’d you call it—‘non-preferred activities’? Is that what the ADHD meds do, help with listening?”

ADHD Meds.

Dr. Rick: “What The ADHD meds help with is focus and attention. Think of them like a stiff cup of coffee. You guys drink coffee, right?”

Dad: “I’m a coffee-holic.”

Dr. Rick: “When the coffee kicks in you feel good, alert, focused. Stimulant meds are like that. They improve alertness and attention and focus. They reduce hyperactivity, distractibility and impulsivity. There are some newer ADHD meds out now, totally different from the stimulants, that slow you down and reduce impulsivity but they make the children tired.”

Mom: “Jacob can be very impulsive. Like the other day he ran away from me in the store to the toy section without even thinking that he could get lost.”

Dr. Rick: “ADHD impulsivity is more for kids who do things quick, without thinking, a lot, all day long, fast acting kids.”

Mom: “That’s not him.”

Dad: “Are you talking about Ritalin itself?”

Dr. Rick: “There is a whole group of stimulants (See Glossary) including methylphenidate, the generic name for Ritalin. The stimulants are really effective when the symptoms are right—that’s why we’re doling out tons of these meds in this country. They work especially to help children focus and pay attention in school.”

Dad: “Are there side effects?”

Dr. Rick: “Some. Not bad. Loss of appetite. If you give too high of a dose you can have flattening out of the personality. Irritability when the meds are wearing off.”

Mom: “We don’t need more irritability.”

Dr. Rick: “I don’t think Jacob meets the criteria for ADHD but, if you like, I can give you some forms to fill out for both of you and for his preschool teacher that go more into depth about the ADHD symptoms. My opinion is that Jacob is not likely to benefit from ADHD medications. I’d prefer to wait until he’s in kindergarten to even consider the stimulants or ‘slow you down’ meds.”

Dad: “Let’s just wait.”

The DSM-5.

Dr. Rick: “We’re whittling this down. It’s not anxiety, OCD, depression, or ADHD. I’m going through the DSM-5 in my head.”

Dad: “The DSM-5?”

Dr. Rick: “I’m sorry. I thought I mentioned it. It’s the primary document in psychiatry called the ‘Diagnostic and Statistical Manual—DSM’, now in a new edition. In the world of psychiatry, it’s a big deal. The DSM guides psychiatrists and other mental health providers in giving the right diagnosis that leads to the right medication and behavioral treatments. I use the DSM criteria when I’m thinking about giving meds. The DSM diagnoses I’m considering are:
Anxiety
• Obsessive Compulsive Disorder
• Depression
• ADHD
• Oppositional Defiant Disorder
• Conduct Disorder
• Mood Disorder
• Regulatory Disorder

Dad: “Oppositional Defiant Disorder?”
Mom: “That’s him. He opposes us and defies us.”

Dad: “Yet.”
Dad: “I beg to differ. Jacob does a lot of things on purpose. He gives you that look of defiance. He consciously disobeys.”

Mom: “What do you do for those kids? Are there medications?”

Dr. Rick: “Those kids are ‘all kids’. You know what I do for those kids—help them to become more mature and better emotional thinkers. When it comes to medications it’s just a question of how much opposition and how much defiance. If you add aggression to it—biting, hitting, throwing things—then you are into a group of medications that are very strong and have a lot more side effects than the meds we’ve talked about so far.”

Dad: “Worse side effects than the other meds?”

Dr. Rick: “Yes, potentially. They’re called the ‘atypical antipsychotics’ (See Glossary).”

Mom: “You don’t think Jacob is psychotic?”

Dr. Rick: “Of course not, but these meds were first used on adults who had psychosis and it worked to calm them down. The ‘atypicals’ as they are known, reduce abnormal thinking patterns and aggression. So they started using these meds for aggressive, impulsive children with ASD and there is evidence both from my experience and the research that this group of meds work quite well to reduce impulsive aggression.”

Dad: “Impulsive aggression. That fits him!”

Dr. Rick: “They are very powerful and quite sophisticated psychotropic medications.”

Dad: “Do you give them?”

Dr. Rick: “I do. Very carefully. I’m really hesitant to use these meds with any young child because they are strong, chronic medications with serious potential side effects.”

Mom: “Like?”
Dr. Rick: “Some sedation, more than half the children get very hungry and gain a lot of weight.”
Mom: “Jacob already eats too much. He’s picky but he eats a lot of what he likes.”
Dr. Rick: “And there are some potentially very serious side effects including allergic reactions, muscle stiffness, tic like behaviors.”
Dad: “Now you’re starting to sound like one of those TV commercials that show you a beautiful scene while the voice-over tells you all the horrible things that the drugs do.”
Mom: “I don’t want to give Jacob these kind of dangerous medications.”
Dr. Rick: “The dangerous side effects are rare. I’ve never seen them, knock on wood, and hope I never do. (I knock on wood). But I have to tell you about the side effects, which as I said are rare except for the weight gain, which affects maybe 60% of kids. They work like magic for kids with severe behavior problems.”
Dad: “Dr. Solomon, I have to be honest. This is all very discouraging. What you’re telling us is that the meds that fit Jacob the best have the most side effects.”
Dr. Rick: “I don’t mean to scare you at all. But compared to the other meds we’ve talked about—the anti-anxiety and the ADHD meds—these carry the highest risk for side effects.”
Mom: “I was hoping there might be something quick and easy to help Jacob but this is so complicated. Isn’t there anything to help him?”

Mood Stabilizers and Sedatives.

Dr. Rick: “There are two last meds that are options: Mood stabilizers and short-term sedation medications. The mood stabilizers are for seizure treatment but a lower dose is used for mood issues like irritability and kids who wake up on the wrong side of the bed and are miserable for the day.”
Mom: “Jacob is generally happy. He just gets upset easily.”
Dr. Rick: “Once again these mood meds are chronic everyday meds; they have side effects and they may not work for the situations that trigger him. Jacob’s mood is not the problem.”
Dad: “What about the short-term medicine?”
Dr. Rick: “This might be the one that fits Jacob the best given all of our medication considerations. There’s an old medication called clonidine that helps control behavior by calming the child. It’s actually a blood pressure medication that we use for its side effects.”
Dad: “So the side effect becomes the main effect?”
Dr. Rick: “Right. It slows you down, makes you mellow and it is not addicting like the valium-type meds or the other sedatives. It’s very safe and it can help Jacob regulate himself. I really think Jacob’s main problem is impulse control and self-regulation. And we are working hard to help him regulation himself. Go on line and read about clonidine; it can help with self regulation.”
Mom: “Will it affect his blood pressure?”
Dr. Rick: “Not if you use it only when you need it and especially if we keep the dosage low, like half a pill. You could, for instance, use it for a long car ride or if Jacob is having a particularly bad day. Or if he can’t get to sleep. It’s a very good go-to-sleep medication. But it works only for about 4-6 hours at most.”
Mom: “What about going to the store?”
Dr. Rick: “That could work, but if you want to use it all day long there is a longer acting medication that has the same effect.”
Dad: “This sounds pretty safe, the short acting one. You called it clonidine?”
Dr. Rick: “It is safe and effective but if you give too much it will make Jacob sleepy.”
Mom: “Sleepy could be good.”
Dr. Rick: “You don’t want him falling asleep in the car if you have to go to the store. I’d recommend half a pill to start. I’d try it at home to see what it does. Think of it as a rescue remedy. Use it when you really need it.”
Mom: “Sometimes we need rescuing.”
Dad: “This med could help in the short run until Jacob gets himself more under control?”
Dr. Rick: “Yes and no. Clonidine is a very simple, non-addicting sedative and it will help to calm him down for a few hours. Jacob’s big behavioral issues are not going to go away from this med alone. If you want chronic control of impulsive aggressive behavior, the atypical anti-psychotics are best.”
Mom: “Those scare me.”
Dr. Rick: “I agree. I firmly believe that this is a phase, that he’ll get better if we keep expecting him to control his impulses.”
Dad: “A better impulse sandwich.”
Dr. Rick: “That’s what we’re doing by using all of our methods to help him become more mature and a better emotional thinker. But I don’t have to live with him until then. So this med will help some in the mean time.”
Mom: “Thank you so much Dr. Rick. I feel like we have a plan. I feel better.”
Dr. Rick: “We’re going to get there.”
Dad: “We’ll call you and let you know how it goes.”

Summary
• Jacob’s behavior is really affecting the whole family and they are looking for help from medication.
• We discuss Jacob’s behavior to determine which medication might be best for him.
• In the process we review the various medications for anxiety, OCD, depression, ADHD, aggression, and mood disorders and discuss the side effects and possible benefits.
• The family decides that the strongest medications that would address Jacob’s impulsive aggression have too many risks.
• In the end, the family settles for a short-acting, non-addicting sedative that is safe with few side effects.
• I may have convinced the Grants that Jacob is going through a phase (a long, hard phase); and that he will become a more mature and better emotional thinker. . . eventually.

Resources & Websites
• *When Kids Need Meds: Everything a Parent Needs to Know About Psychiatric Medication and Youngsters*, Henry A. Paul (2012)

Coming Up
• We work on toileting and sibling issues, major sources of daily hassles in the Grant family. I think we could get Jacob to go on the toilet—he’s ready! Then we’ll tackle the sibling issues.
Chapter 23
Visit 15
Toilet Training

*Jacob is Almost Five: Time for Toilet Training*

After the last visit I talked to Julie on the phone about toilet training methods for Jacob. He was going to be five in a few months and was still wearing pull-ups. It was time to make a concerted effort to get this boy toilet trained! She wanted to come in and talk about it.

I usher Jacob, Charlie, and mom into the office playroom. After greetings I ask Jacob an open-ended 'wh-type question':

*Dr. Rick:* “So Jacob, where’s daddy? Hey Jacob, where’s daddy?”
*Jacob:* “Work.”
*Dr. Rick:* “Oh, daddy’s working. (To mom: ‘Wow he answered a complex ‘wh question!’) You ready to talk about going pee pee and poop on the toilet?”
*Charlie:* “I go pee pee and poop on the toilet.”
*Mom:* “There’s major competition in everything these days! The sibling rivalry is terrible!”
*Dr. Rick:* “Let’s deal with the toileting today and we’ll get to the sibling issues next time, OK?”
*Mom:* “I’d like Jim to be here for that anyway.”
*Dr. Rick:* “No problem. I’m just going to jump in here... so, give me five, Charlie (we slap). Yay, Charlie’s going pee pee and poop on the toilet. What about you Jacob? Hey Jacob, you going pee pee and poop on the toilet?”
*Jacob:* (ignores me, hangs his head a little).
*Dr. Rick* (to Jacob): “Well, it’s time Jacob. Dr. Rick goes; daddy goes; mommy goes; and Buzz Lightyear goes pee pee and poop on the toilet. (That got his attention.) Pretty soon you’ll go pee pee and poop on the toilet too. (To mom) So, mom, how’s the toilet training going?”
*Mom:* “Not so good. I remember you saying when Jacob started to talk it would be time to get him toilet trained. He’s talking but it hasn’t been easy. Jim told me to tell you that he’s tired of changing dirty pull-ups. Jacob’s almost five years old; Charlie’s already trained at three.”
*Dr. Rick:* “Well, I’m sorry dad couldn’t make it today but I’ll record our discussion so he can hear what we say. (I turn on my audio recorder and speak to dad). OK, dad, today we’re going to make a plan to get Jacob toilet trained. Everybody has to be on the same page so I’m recording this. Jacob is ready developmentally. If we’re persistent, positive, consistent, and strategic Jacob should be successful. (Turning to mom) What have you guys done so far?”

Julie Grant goes into the litany of things they’ve tried including:

- Letting Jacob watch when Charlie and daddy peed in the toilet
- Reading him books about toilet training
- Rewarding him with candy and stickers
- Talking until they were ‘blue in the face’ about how he was getting to be a big boy and how dirty diapers were ‘yucky’
- Letting him run around butt naked. He peed on the carpet and the couch!
- Taking him to the toilet every hour and reading his favorite books to him while he sat for twenty minutes. (He didn’t mind sitting but he peed as soon as they put his pull-up on!)
And threatening to take his trains away if he didn’t go (he was upset at first but then didn’t seem to care. And he didn’t go in the toilet.)

\textit{Jacob’s Elimination Chart: An ‘Empirical’ Study.}

\textbf{Dr. Rick}: “I just read a recent article about the time it takes to toilet train typical children. Guess how long?”

\textbf{Mom}: “One to two months?”

\textbf{Dr. Rick}: “Try, on average, 18 months!”

\textbf{Mom}: “18 months?! That’s discouraging.”

\textbf{Dr. Rick}: “That’s from beginning to end to complete independence in toileting with no reminding, no help with wiping, etc. Some kids get it faster and some slower but it often takes time. The point is, you have to be persistent and positive for months. The children in this study were typically developing and they were ready to be toilet trained, mostly two to three year olds. So you’re on the path and Jacob’s definitely got the idea. That’s the first step.”

\textbf{Mom}: “Oh he’s got the idea. He just doesn’t like the idea.”

\textbf{Dr. Rick}: “Yet. Today we’ll focus on a method I’ve honed over the years. Not only have I learned from families (including my own family) but there’s good research about best toileting practices, and there are some really good books I’ll refer you to. But first, the facts. Do you have that chart for me?” (I had given her an assignment.)

\textbf{Mom (mocking me)}: “I did the \textit{empirical study}.”

Empirical means establishing the facts.

\textbf{Dr. Rick} (joking): “Don’t make fun of my \textit{empirical} study. By regularly checking Jacob’s pull up you have to admit you learned a lot.”

\textbf{Mom}: “It wasn’t easy checking and charting wet and dirty diapers every hour for almost a week but I was pretty consistent” (handing me the chart).”

\textbf{Dr. Rick}: “Nice work! Look at this.”

\textbf{Mom}: “He’s definitely got a pattern.”

\textit{This initial, systematic study of the child’s elimination patterns is highly recommended. It serves as the basis for setting up a successful toileting routine.}

\textbf{Dr. Rick}: “This is good news. He’s holding his urine for hours. He’s even dry through many nights. This is a sign that physically he’s ready. And I know from his functional development that he’s developmentally ready.”

Jacob’s pattern is summarized below:

\textit{Jacob’s Elimination Pattern}

\begin{itemize}
  \item He pees:
    \begin{itemize}
      \item After he wakes up dry from sleep
      \item About every 2-3 hours after that
      \item Sometimes after meals
      \item Just before bedtime
    \end{itemize}
  \item He poops:
    \begin{itemize}
      \item After lunch most of the time
    \end{itemize}
\end{itemize}
– Sometimes after dinner
– Skips a day occasionally

**Developmental Readiness**
In fact, whether they realize it or not, the Grants, by providing Jacob with intensive play-based intervention, have prepared him for successful toileting by getting him *developmentally ready*.

**Note:** For those children who are not developmentally ready, there are ways to *condition* them to go on the toilet using a schedule and behavioral reinforcements. See *Resources & Websites* for books that use this method.

Jacob is *developmentally ready* because he has all of the signs.

*Signs of Readiness*

- Language at two year old level
- Understands routines
- Can follow commands and imitates others
- Wants to please (sometimes). Likes praise.
- Understands consequences (pee=prize)
- Aware of being wet or dirty
- Physically able to pull pants up and down
- Bladder capacity increasing. Can go 1-2 or more hours without wetting. Poops predictably.

**The Three Bad Habits**
Even though he is ‘ready’, Jacob just doesn’t want to change—yet. He has developed three bad habits and *habits in motion stay in motion*. His three bad habits are:

- He goes *wherever* he wants
- He goes *wherever* he wants
- He pees and poops in his *pull-up*

It is our job to systematically help him break these three bad habits by:

- Getting him to associate peeing and pooping with the toilet
- Getting him *into the bathroom at the right times throughout the day*
- *Motivating* him to use the toilet.
- Getting him *out of his pull-ups*

**Potty Chair or Toilet Seat?**
**Dr. Rick:** “Before we get to the habits though we have to deal with one big question. Do you want to use a potty-chair or toilet seat?”
**Mom:** “We used a little potty chair for Charlie but Jacob doesn’t seem to like it much. We have a toilet seat that fits on top of the regular toilet and he seems OK with that.”
**Dr. Rick:** “If we can get him started on the regular toilet that would be easier. Then we wouldn’t have to break another habit to move him from the potty chair to the toilet.”
**Mom:** “He’s bigger than Charlie and he’s a little snug on that potty chair. Maybe that’s why he doesn’t like it.”
**Dr. Rick:** “OK, let’s go with the big toilet with a seat.”
Getting Comfortable with Sitting.

Dr. Rick: “How about sitting on the seat? Does he like it? Can he sit for a while?”

Mom: “We used to sit him on the toilet with his clothes on just to get him used to it.”

Dr. Rick: “Brilliant. That’s a great way to desensitize children and get them used to sitting.”

Mom: “Now, he’ll sit and have a great time if we read him his favorite Thomas the Tank Engine book. Maybe 15 minutes.

Dr. Rick: “That’s fantastic.” Five to ten minutes should be plenty. Don’t make him sit too long. When he has to go he’ll go. We’re half way there, mom and dad (I said, speaking into the recorder). I recommend that parents make the bathroom a fun place to go by playing with them or reading to them or having stickers or little fun toys or treats and you’ve already done that. Yay!”

Mom: “But he doesn’t go.”

Dr. Rick: “But from our charting, now we know when he goes.”

Mom: “Ah-h. I get it. We put him on when his bladder is busting and read to him until he practically can’t hold it.”

Dr. Rick: “Get it?”

Mom: “Got it.”

Dr. Rick: “Good.” (We high five)

Sensory Issues. There’s just one more set of issues we need to discuss before we tackle the three bad habits—namely the sensory issues that can derail toilet training before it even begins. There are two types of sensory issues—environmental and physiologic.

Environmental sensory issues. We’ve already discussed the toilet seat being comfortable, not too cold, or unstable. Most kids don’t like their feet dangling from the toilet and like a footstool. Is it too noisy in the bathroom because of the fan? Generally, the room should be reasonably quiet. Is it too bright or does it smell like cleanser. Quite a few children are very afraid of the flushing sound and may need to be reassured that flushing will happen later. It is important to make sure that the bathroom and toilet feel comfortable, sensory neutral, and safe.

Luckily, Jacob’s parents bought a seat that he sits on without problems; they have a footstool for his feet; and he loves flushing the toilet (a built in reward!). The only environmental sensory issue for Jacob is that he doesn’t like the sound of the bathroom fan. So they keep that off.

Note: For children who appear to be sensory defensive, a gradual desensitizing approach works best. Start with whatever the child will tolerate: looking at the toilet with cover closed or sitting on the toilet seat fully clothed, etc. Start there and keep moving by degrees to your final goal of the child sitting on the toilet butt naked for five minutes. Make it fun, have a voice that conveys confidence, keep it positive, and use rewards that are rewarding!

Physiologic sensory issues. Some children with ASD have a hypersensitivity to touch. These children may train early because it bothers them to feel wet or dirty. They notice when their bladder or rectum are full. Not Jacob. Jacob is an under-reactive—physiologically insensitive—type who doesn’t mind being wet or dirty. He’s aware; he just doesn’t care. When his bladder is full he doesn’t say anything but (mom notes on the chart) he ‘gets a little hyper’ just before he has to pee; and he ‘hides behind a chair’ in the living room when he has to poop. So he’s not that insensitive.

Jacob’s Toileting Plan
Dr. Rick: “All right. Let me summarize. We know Jacob’s patterns. We know he’s developmentally ready. We know which type of seat we’re going to use. We know his sensory sensitivities. I think we’re ready to discuss the next steps in Jacob’s toileting plan.”

Mom: “I’m ready.”

Dr. Rick (into the tape recorder): “You ready dad? Two more things before we move on. First, it is very important to keep upbeat and positive about this process—even joyful. The next steps are often the hardest. Old habits are hard to break—and there will be some ‘accidents’, resistance and regression—but this is usually only temporary, best handled by continuing encouragement and a ‘keep trying’ attitude.”

“If Jacob becomes very resistant it is a sign to back off for a while (a few weeks to a couple of months), to avoid a power struggle. It is important not to shame your child or make them feel like a failure.”

Note: In my experience, resistance is usually due to three things: a very, very stubborn child; a resentful/angry child (which requires addressing the cause of anger); or the sibling of a new baby. Since Jacob has none of these factors at work (except for a little stubbornness), I am fairly confident that he will succeed with my usual (tricky) toileting approach.

Dr. Rick: “OK. So here’s a summary of the plan up to this point:"

Jacob’s Toileting Plan 1

- Start training when the child is ‘ready’
- Help the child ‘get the idea of going on the toilet’. Practice sitting on the toilet.
- Study the child’s elimination habits
- Decide on the type of toilet seat & get the child comfortable with sitting for five minutes
- Make the bathroom a fun place to go
- Address sensory issues
- Stay positive. Be patient. Keep it fun!
- Block out time in your busy schedule

Dr. Rick: “This last point is important. You’ll need to block out time to establish the new toileting patterns.”

Mom: “I’ll keep Jacob home from school on Friday to make it a long weekend if I have to. I’ll have Grandma take Charlie so he’s not in the way. I’ll do whatever it takes to be successful.”

Dr. Rick: “That’s the right attitude, mom. In my experience, the second most important factor in success is the parents’ intention to succeed.”

Mom: “OK. I’ll bite. What the first?”

Dr. Rick: “The child’s intention to not succeed and usually, in children with autism, it’s because they don’t want to change. That’s why we have to be positive and patient and keep it fun. So the first steps have to do with attitude and planning. The next steps have to do with action. We’re going to include Jacob in the plan, motivate him and create new habits. I think the two biggest problems have to do with eventually getting rid of the pull-ups, and making sure we motivate Jacob. Let me discuss these first and then we’ll talk about the next steps of the plan.”

The Bane of Diapers and Pull-ups.
If there is one thing that all toileting experts agree on, it’s that the diapers and pull-ups have to go eventually! Super absorbent diapers and pull-ups have undermined the prospects of toileting for millions of children in our fast-paced technological society. For the child, the amazing super absorbent pull-up sucks moisture away from the body like a sponge, allowing the diaper to be soaked and the child to be completely comfortable. For the parents the amazing, convenient, throw away, pull-ups allow for a hectic lifestyle without the inconvenience of having to deal with washing and recycling gross poopy diapers. It’s no wonder the average age of toilet training is going up by years!

The question is: How do we motivate Jacob to give up his pull-ups?

Motivational Issues: The Difference Between Typical Children and Children with ASD. Typical children, like Jacob’s younger brother Charlie, are primarily motivated to please and/or avoid displeasing their parents; to identify with ‘grown ups’ and become ‘big’; and to imitate toilet trained peers. Typical children love the idea of wearing Superman/big boy or Cinderella/big girl underwear. Children with ASD? Not so much.

While motivated to some extent by these appeals to growing up, children with ASD, including Mr. Jacob, are primarily motivated by—you guessed it—‘keeping the world the same’. Having spent four years in diapers and pull-ups, Jacob plans to stay that way, thank you. Unless we can make it easy and/or there are strong motivations for him to change his habits.

Include Jacob: Assume Success.

Dr. Rick: “And that’s what the next steps in the plan are all about. We have to get Jacob on board with toilet training, let him know what’s happening and share the plan with him in his language—fun stories. We’re not going to have any sudden surprises. And (I say into the audio recorder for dad’s consumption) no use of force or fighting about this. (We may use some heavy persuasion though!) We’ll get him used to everything by degrees:

Jacob’s Toileting Plan 2

• Include Jacob. Assume success. No surprises.
• Use a fable, social story & picture schedule
• Use praise, stickers & Big Boy Bag
  – (Siblings get prizes too!)
• Go to the bathroom on ‘his’ schedule
• Read his cues closely; go when indicated
• If necessary, play in the bathroom until he goes (on the floor or toilet)
• Use ‘accidents’ to practice toileting skills
• Change from pull-ups to underwear
• Wean prompts until he’s independent

“On the other hand I want you to have an attitude where not toilet training is not an option. I want you to casually assume that it IS going to happen.”

Mom: “I’m not sure what you mean?”
Dr. Rick: “Don’t ask Jacob IF he wants to be toilet trained. Talk about what he needs to do to get toilet trained. Watch this. Hey Jacob. Can you stop playing with Mack for a second? I need to talk to you.”

Jacob gets up and comes over.

Dr. Rick: “Give me five. (He slaps five.) You see this audio recorder? Listen . . .”

I sing a few la-la-la’s into recorder and push the re-play button to play it back. Jacob loves it. Charlie joins too. I ask Jacob to tell me his name and he does. I ask Charlie to state his name and he does. I play it back. They both think this is very cool. I show them how to push the rewind button and they listen to themselves saying their names over and over a few times.

Dr. Rick: “OK Jacob, listen to this. When you go home today, mommy’s going to get you some new underwear and toys. Yay! (I play it back three times and Jacob hears it.) What kind of underwear do you want? Spiderman, Superman, Toy Story, or Cars underwear.”

Jacob: “Cars”.

Dr. Rick: “Great. Would you like to go with mommy to Toys R Us and pick them out?” (Jacob loves Toys R Us.) Go to Toys R Us?”

Jacob: “Toys R Us?”

Dr. Rick: “Great idea! Then you can put on your new underwear.”

Charlie (not to be excluded, chimes in): “I wear Superman underwear.”

Dr. Rick: “Cause you’re strong like Superman.”

Mom: “I get it. You didn’t ask IF he would wear underwear; you just assumed it and you made it sound like fun.”

Dr. Rick: “Bingo. And now you have it on tape from me, which makes it even more fun. So this is the way you do everything. Talk about it. Make it fun. Assume he’ll go along and he probably will. And include the sibling as an ally. We’ll talk about that later.”

Mom: “But what do we do then if there is resistance?”

Anticipating Resistance: Getting the Underwear On.

Dr. Rick: “Are you sure you’re not dad in mom’s clothing? He’s usually the skeptical one. (Talking into the recorder: ‘No offense dad.’) Of course there’s going to be some resistance. And when there is take a step back, listen to his concerns, negotiate, motivate and help him work it through. Let’s say he doesn’t want to switch to underwear. This is going to be a big change.”

Mom: “He’ll resist that. We tried this last year and he wouldn’t put them on.”

Dr. Rick: “Keep positive.”

Mom: “I’m positive he will resist.”

Dr. Rick: “Very funny. So how do we get him used to the idea and help him to move forward?”

Mom: “Well, I liked the idea of him going shopping and choosing what kind of underwear he wants. I really don’t mean to be negative but what if he doesn’t want to put them on when we get home?”

Dr. Rick: “Take them out of the bag. Have them in his room. Let him get used to seeing them for a day or two. There’s no hurry. How could you make putting them on fun?”

Mom: “Make it a game?”

Dr. Rick: “Sure. Here’s a quick list.”
• You could throw them around the room at each other and have an underwear fight;
• Put them on your head like a hat and dance around;
• Put them on your leg and complain that they don’t fit. Be silly.
• You could tell him to NOT put them on and have him resist you. That’s fun.
• Have a race to see who can get their underwear on faster, Charlie or Jacob and then
• Give them a little treat for putting them on.
• You can tell him how strong he looks in underwear.
• Have him wear underpants just for a count of ten and give him a prize.

Mom: “I get it”.
Dr. Rick: “We’re going to desensitize him to change. We’re going to change in little steps.”
Mom: But he loves his pull-ups. What if he insists?
Dr. Rick: “For a week or two even, we could put the pull-ups over his underwear, pull both the pull-ups and underwear down when he gets on the toilet. The underwear will make him feel it more if he has ‘accidents’ (and I want you to start calling them ‘accidents’).

“And when he has an ‘accident’ I want you to say these words: ‘Jacob, tell mommy when you have to go and we will go to the toilet.’

Then, as he’s becoming more successful with going in the toilet, I would suggest ‘running out of pull-ups’ if you get my meaning, if you catch my drift? Then move to all underpants.”

Mom (skeptical): “Sounds good, I guess.”
Dr. Rick: “And we’re not even close to done yet. The most important methods come next.”
Mom: “You had me worried there.”
Dr. Rick: “Look, mom and dad. If worse comes to worst, we back off and go at it another time. We’re going to make it as easy and as fun as possible for Jacob. But if he absolutely doesn’t want to toilet train, then so be it. It’s important to have a c’est la vie attitude. Jacob will pick up on the tension and he’ll pick up on the fun. Remember, this is the PLAY Project.”

The Steps to Success
Research shows that the following are the key steps to successful toilet training:
• Starting when the child is ready
• Being positive and upbeat and non-critical
• Preparing the child through talk and stories
• Model using dolls and/or people
• Practicing sitting and going
• Make a strong association between the act of elimination and going to the toilet by bringing them to the toilet every time they go
• Using positive reinforcement, e.g., lots of praise (but not too sudden or too loud), incentives, and/or prizes

Ninety eight percent (98%) of typically developing children are capable of being toilet trained by 36 months and Jacob is getting close to that developmental level. While the average length of time to be fully toilet trained is 18 months, as I mentioned earlier, the time it takes to be successful peeing or pooping in the toilet with fewer and fewer accidents without prompting is 3-6 months. Getting the
child on the road to success, i.e., sitting on the toilet, occasionally peeing in the toilet usually happens within days to a week.

**Modeling, Practicing, & Rewards: But First A Fable. . .**

**Dr. Rick:** “All right, you’ve already done the first three steps by starting when Jacob was ready, by being positive (for the most part) and upbeat, and by preparing Jacob through talk and reading him stories. You’ve even done some practice sitting. Now it’s time for modeling, more practice, and rewards. What would be like for a big reward?”

**Mom:** “Ever since he’s seen your Mack the Truck and Lightning McQueen that’s all he’s been talking about.”

**Dr. Rick** (to Jacob): “Hey Jacob. Come here. Charlie. Come here. (They come over.) You like Mack the Truck and Lightning McQueen, don’t you. (they nod.) When you go pee pee and poop on the toilet you know what your mommy and daddy are going to get you?”

**Jacob:** “Mack Truck.”

**Dr. Rick:** “How did you know? When you go pee pee and poop on the toilet you’re going to get Mack the Truck! AND Lightening McQueen! That will be fun. And Charlie? You’re going to get prizes too! Mommy, when Jacob goes on the toilet I want Charlie to get prizes too!”

**Mom:** “Charlie gets prizes too.”

I play back those last lines about getting prizes on my audio recorder three times. Then with a loud dramatic introduction I say: “And now, for a wonderful story about *Puppy Pete*!” (And I start telling my fable into the tape recorder.)

**The Fable of Puppy Pete.**

Once upon a time there was a puppy named Pete whose mommy and daddy said: “Puppy Pete we want you to go pee pee on toilet.” And you know what Puppy Pete barked, Jacob and Charlie? (They loved stories and waited for the answer. . .) Puppy Pete barked ‘NO!’ with a very LOUD bark. ‘NO, NO, NO!! I will NOT go pee pee in the toilet.’ (Jacob loved this.) ‘But Puppy Pete, your Daddy Dog goes pee pee on the toilet. Your Daddy Dog doesn’t wear pull-ups. Your Daddy Dog wears big doggy underwear. Don’t you want to be a big dog like your daddy?’ And you know what Puppy Pete barked? ‘NO, NO, NO! I will not go pee pee in the toilet.’ ‘Well,’ said Puppy Pete’s mommy and daddy, ‘then I guess we will have to give you a special prize—The BIGGEST DOGGY BONE in the WORLD!!’ And Puppy Pete, who loved bones, thought and thought and thought. And then he said, ‘The BIGGEST BONE in the WORLD? ’ And his mommy and daddy said, ‘YES. The BIGGEST BONE in the WORLD.’ So Puppy Pete, who was a very smart puppy said, ’OK. I will go pee pee in the toilet. ‘He knew just what to do. He went to the bathroom; he took off his pull up; he sat on the toilet; and you know what he did?

**Jacob** (totally into it): “Go pee pee.”

**Dr. Rick:** “Yep. He went pee pee! AND . . . you know what he got?”

**Jacob:** “A big bone.”

**Dr. Rick:** “Yep. (Returning to my story voice;) He got the BIGGEST BONE in the WORLD. He was very happy. He was growing up to be just like his daddy. And after that you know what? He got to pick from a BIG DOG BAG that had lots of prizes until finally one day he LIKED going pee pee in the toilet. He got to wear Cars underwear like a big dog. He didn’t have yucky diapers anymore and he liked being a big puppy like his daddy dog. THE END!”

**Modeling with a Big Boy Doll & Using the Big Boy Bag.**

**Dr. Rick** (to mom): “He gets it. Did you see his face light up? So I want you to buy Mack, Lightning, the DVD ‘Cars’, other ‘Cars’ paraphernalia, and put them in a brown grocery bag. In the
beginning, he gets to pick a BIG prize from The Big Boy Bag. I want you to get a boy doll that ppees.”

Mom: “We bought one of those dolls that pee when you squeeze him. Jacob didn’t care.”

Dr. Rick: “Well he’ll care now because of the Big Boy Bag full of fun toys. I want you to do the following in front of Jacob. Try to time it so that it’s been 2-3 hours since Jacob’s last wet pull-up and he’s ready to go. Here are the steps . . .”

• Have the Big Boy Doll say “Mommy, mommy, I have to go pee pee.”
• Be dramatic. Say, “Yay! OK Big Boy Doll let’s go pee pee and YOU will get to pick from the Big Boy Bag.”
• Or you can sing a song to London Bridge: “You get to pick from the Big Boy Bag, Big Boy Bag, Big Boy Bag. You get to pick from the Big Boy Bag when you go pee pee.”
• Then head off to the bathroom bringing Jacob (and Charlie) with you by shaking the bag in front of his eyes saying “I wonder what’s in the bag. I bet there’s a big prize!!”
• Then tell the doll to “Go pee pee big boy. It’s time to go. Go tinkle in the toilet.” Squeeze the doll to pee in the toilet.
• Say “Great job big boy doll you get to pick from the bag.”
• Then have the doll pull out Mack and say “Yay, yay, I went pee pee and I got Mack!”
• Then have the doll dance for joy and hold Mack.
• Then turn to Jacob, who will want to have Mack and say, “When you go pee pee on the toilet, you can have Mack for your very own. Do you want to sit on the toilet now and go pee pee? Then you can have Mack the Truck?”

Dr. Rick: “If you’re lucky he’ll go right then and there. If not, we wait until he goes.”

Mom: “This is going to cost a fortune.”

Dr. Rick: “Not really. After the first big prize then you put less expensive toys in the Big Boy Bag and over time the prizes get smaller and smaller and then the bag disappears. The whole point is to change Jacob’s three bad habits—going whenever, going wherever, and going in his pull-up—into good toileting habits. And as I like to say: ‘A good habit in motion . . .’

Mom: “. . .stays in motion.”

Visual Schedule and Social Story

Dr. Rick: It’s also important to put a visual schedule that is also a social story (See Resources & Websites) on the bathroom wall where Jacob can see it. Have a picture of a boy peeing in the toilet, then a picture of a bag and then prizes and/or stickers and maybe a smiley face. You can draw it or find it easily on the internet these days under ‘pics’ or ‘images’.

Mom: “I’m very crafty that way and Jim knows the technology part. Sounds great.”

Dr. Rick: “You might want to put a sticker chart on the wall so Jacob can document and see his successes. Now we have all the elements of the next step in the plan.”

Putting it All Together.

Dr. Rick: “Jacob’s been prepped. He has his pull-ups over his underwear. You know his pattern of going every 2-3 hours. So wait and check his pull up. When he’s dry after two hours then take him into the bathroom, pull his pull-up and underwear down around his ankles and have him sit. (If you take them off completely he’ll get use to that—a habit in motion.) He can see the toileting plan on the wall. You let him know that when he pees he gets to pick from the big boy bag and put another bigger sticker on the chart. Sit him on the toilet for 5-10 minutes and prompt him regularly to ‘Go
pee pee Jacob. It’s time to go. Go tinkle in the toilet.’ If he’s not successful, give him a little reward for sitting (an M&M, a sticker, a piece of cookie, etc.). When he is successful praise him with high fives and yays! But not too loud or too sudden. Or better yet do a silly jig.”

Mom: “He’d love that but what if he doesn’t go at the two hour mark? What do I do next?”

*The Peing on the Bathroom Floor* Trick.

**Dr. Rick:** “Take him again at 2½ hours and again at 3 hours. Get it?”

**Mom:** “Got it.”

**Dr. Rick:** “Good. This is where you need patience and persistence (and a long dedicated weekend!) Give him extra time in the bathroom. This is a trick I learned from my colleague Debbie Bialer (See References). Take off his pull up and underwear and let him go naked from the waist down in the bathroom. (We’ll only let him go naked for this method.)”

**Mom:** “He loves to be naked.”

**Dr. Rick:** “Just stay in the bathroom until he can’t hold it any longer. Close the bathroom door, play in the bathtub or with toys. Keep him in there. Then, when he has to pee, try to get him on the toilet but, if he won’t or can’t, tell him it’s OK to pee on the bathroom floor.”

**Mom:** “What good will that do?”

**Dr. Rick:** “He will have broken two of the three bad habits. He will have gone *when he has to go, where he has to go, without a pull up on.* This would be a big change for Jacob and set him up to now pee on the toilet.”

**Mom:** “Should I let him pick from the Big Boy Bag?”

**Dr. Rick:** “Not until he pees in the toilet. I would praise him, give him a little treat, let him put a sticker on the wall, and promise him a present from the Big Boy Bag when he goes in the toilet.”

**Mom:** “This is great stuff. Now, I’ve got a very good idea what to do almost no matter what. You’re a very tricky guy. Dr. Rick.”

**The Prompt Less & Less' Trick.**

**Dr. Rick:** “Thank you. And I have one more trick for you. It’s called the ‘prompt less and less’ trick. Once Jacob’s going on his schedule and you ‘run out of’ pull ups, he will be just in underwear. Be vigilant or he’s going to have ‘accidents’ on your couch or chair or carpet.”

**Mom:** “He’s got his own wooden rocking chair.”

**Dr. Rick:** “In the beginning he will wait for you to prompt him. So you’re going to have to read Jacob’s cues like a hawk and get him to the bathroom on time.”

**Mom:** “I’m on it.”

**Dr. Rick:** “At the first sign of peeing or even if he has peed you are going to rush him to the bathroom to make that association between peeing and the toilet. If you have time and he is showing signs of having to go you will say, ‘Jacob, it’s time to go to the bathroom. Come on big boy, let’s go. Time for a prize.’ I want you to get his attention and use a gesture with it, let’s say *pointing to the bathroom with your index finger and raising your eyebrows* as you say the words.”

“Then over time I want you to use fewer words, then just a point, then just raising eyebrows and then he should be going without your having to ask him. Also, of course, make sure you tell him what you want. ‘Jacob, when you have to go, GO! Don’t wait for mommy to tell you.’ That’s the *bottom line*—complete independence.”

**Mom:** “I like that trick of prompting less to get him to go.”

**Accidents: Time to Practice.**
Dr. Rick: “In this whole process which will take a few days to a week or so to complete, Jacob is going to have accidents, either wetting or soiling his pull-ups or underwear or pants.”

Mom: “I’m not looking forward to that.”

Dr. Rick: “When it happens, always say: ‘Jacob, tell mommy when you have to go.’ Then take him directly to the bathroom and have him sit on the toilet and give him a little prize. Afterwards act a bit disappointed.”

Mom: “I thought you said we should be positive and supportive.”

Dr. Rick: “You can be disappointed and positive. You can say: ‘Jacob, next time go pee pee in the toilet not in your pants’ or ‘Pee yew that stinks. Please, next time, go in the toilet. Come on, we have to change you. You’ll do better next time.’ Got it?”

Mom: “I get it. It’s OK to be honest about our reaction.”

Dr. Rick: “Not mean or punitive. But you should make him stop what he’s doing and take him to the bathroom immediately. Treat changing his clothes as important and urgent. If he pooped, put his poop in the toilet and flush it down. If he wet, have him throw his wet diaper away. Then have him sit on the toilet for practice and say, ‘Next time Jacob go in the toilet and you will get a big prize.’ Let him put a sticker if he wants to on the chart. Don’t make it too much fun. Make changing him take a long time so it’s boring and time consuming.”

Mom: “It’s kind of a disincentive to go in his pants.”

Dr. Rick: “Another one of my tricks.”

Pooping: The Bottom Line.

Mom: “OK. One last question. Do we do anything different with pooping?”

Dr. Rick: “For the most part you will use the same methods as for peeing. He’s a pretty regular guy. It’s pretty easy to read cues because he goes to hide. When he has to go, you will usher him to the bathroom just like peeing.”

Mom: “We tried just having him go butt naked on the advice of a friend for a couple of days and he refused to poop at all.”

Dr. Rick: “This is the one real dangers. As opposed to peeing where eventually you have to go, with pooping a child can hold it back until they develop the dreaded *enuresis*.”

Mom: “The what?”

Dr. Rick: “That’s when the child holds their poop in and the stool backs up and builds up until they lose feeling in the rectum.”

Mom: “Is that dangerous?”

Dr. Rick: “Not medically dangerous but it can become a chronic condition where the child leaves smear-marks in their underwear all day long and leaks poop. You don’t want that.”

Mom: “No thank you.”

Dr. Rick: “If Jacob doesn’t mind going poop on the toilet, we’ll use the same methods as we did with peeing. But if he’s resistant, I’d just get him to go in his pull-up but I’d try to get him in the bathroom instead of behind the chair. That will break two habits, going where and when we want him too. I’d reward him with small prizes in the Big Boy Bag—Matchbox cars or whatever he likes—for doing that.”

Mom: “I notice that he squats in a peculiar way with his hands on his knees.”

Dr. Rick: “To get him pooping in the toilet, he may need help standing on the footstool and squatting over the toilet in his usual position. He’ll be half sitting on the toilet seat. You can try cutting out the back of the pull-up so he still has the feeling of being in a pull up.”

Mom: “That’s tricky.”

Dr. Rick: “And you will have to up the ante with a big prize for going poop.”

Mom: “If we have to.”
Dr. Rick: “Right. I’m hoping we won’t have to.”
Mom: “But I’m definitely going to avoid enco...”
Dr. Rick: “…presis.”
Mom: “Encopresis.”
Dr. Rick: “That’s the bottom line.”
Mom: “Very funny.”
Dr. Rick: “Now that we’re at the end, so to speak...”
Mom (with a wry smile): “Stop, you’re wasting your talent.”
Dr. Rick: “That made me think of one last thing. I should probably mention wiping and hand washing here. Wiping a dirty bottom requires quite a bit of coordination. Ask Jacob to call you for help. Then you can link that with hand washing and get him in the habit of good hygiene.”

**Conclusion**

Dr. Rick: “OK. That’s really the end. This is Tuesday. Let’s give this a go.”
Mom: “There’s a lot to do.”
Dr. Rick: “I’d strike while the iron is hot and get Mack the Truck ASAP like on the way home. Have fun with it. And please call me if you have any problems. I’ve recorded the most important discussion for dad and for the preschool if they are interested.”
Mom: “Really good point. Preschool should know what we’re doing.”
Dr. Rick: “Even if you get most of it accomplished over this one weekend, it’s important to coordinate your plan with them. If dad and/or pre-school has any questions they can call. Here are the handouts for reminders. Let’s cross our fingers and hope Jacob likes our plan.”
Mom: “I’m optimistic. I’m going to set aside this weekend to put the plan in place and I’ll call you next week and let you know how it went.”
Charlie: “Me!”
Jacob: “Me!”
Dr. Rick: “OK. Jacob when you go home I want you to go pee pee and get a Mack the Truck and Lightning McQueen from the Big Boy Bag just like Puppy Pete. OK?”
Jacob: “I go pee and get Mack Truck.”
Dr. Rick: “Right! And Lightning. And Charlie, you’ll be able to play with it too! OK, time for stickers!!”

They both head for the door. I hand mom the handouts, references, and the audiotape. I’m hoping for good news (See Postscript below).

Mom: “I’ll set up a time to talk about the sibling issues. It’s a huge problem, Dr. Rick.”

**Postscript**

The next day (not the next week) Julie Grant called me. Right after the visit, they stopped at Toys R Us, and bought Cars underwear, Mack the Truck and a few of his ‘friends’ including Lightning McQueen. They put the picture schedule on the wall and put Mack in the Big Boy Bag. They tried to get Jacob into underwear. He resisted so they backed off and then they waited until Jacob was near bursting. They modeled using the Big Boy Doll, sat him on the toilet and (drum roll please), Jacob peed on the toilet that night!!
After Jacob got his *Mack the Truck* there was a little backsliding. He didn’t want to go to the bathroom but when Julie threatened to take *Mack the Truck* back to *Toys R Us*, Jacob sat and peed and got more toys. (So did Charlie.) He even started wearing underwear under his pull-ups. She didn’t even have to use all my tricks. Now they were working on pooping and being consistent with his routine. Yay! I was very happy. I knew he could do it.

**Summary**
- Jacob is five. It’s past time for toilet training and he is ready.
- Julie has studied Jacob’s elimination patterns to determine his habits.
- ‘Readiness’ is defined and the plans for toileting are discussed with Julie.
- The first set of plans have to do with getting Jacob used to the toileting process, getting the right toilet seat, having a positive attitude, and making a commitment of time and energy.
- The next set of plans includes using fables and social stories, modeling using a doll (and family members), and developing a reward system.
- A number of Dr. Rick’s toileting tricks are thrown in for good measure.

**Resources & Websites**

**For Parents**
- *3 Day Potty Training* (eBook), Lora Jensen (2014)

**For Kids**

**Coming Up Next**
- Jacob and Charlie have a long history of sibling issues that have evolved over time as the boys change in their developmental capacities. Now the sibling rivalry has matured (and worsened!) to the point where it’s time to talk about the ‘Six Rules for Sharing’.
Chapter 24
Visit 14:
Siblings With Rivalry!

Jacob Grant's behavior is gradually getting better, thanks to months of really hard work by his parents. Their sensitive, responsive, insightful interaction with Jacob has helped him become a better, more mature emotional thinker.

- Bedtime routines are solid and night waking is no more. Check.
- Sleep and morning routines have been... well... routine for a while. Check.
- Jacob is getting himself dressed and 'taking care of himself like a big boy' with one exception: He is still not completely toilet trained. No check. (See Chapter 23, Visit 15: Toilet Training).
- Our strategy of pulling off the road ended dangerous misbehavior in the car. Check.
- There are many fewer tantrums and hassles in public. Check. (Julie only had to give out one of the 'autism cards' (See Chapter 21, Visit 13: Outings and Eating).
- And the Grants are able to go out to restaurants without a lot of anxiety. Check.

Jacob’s Daily Problems
✓ Bedtime routine/night waking
✓ Morning routine/Getting ready for school
✓ Self-help—dressing, brushing teeth
✓ Car misbehavior
✓ Meltdowns in public: grocery shopping
✓ Dinner time and eating problems
☐ Toileting Issues (Still working on it)
☐ Sibling rivalry & sharing

But... there was one last and major vestige of behavioral difficulty, namely worsening sibling rivalry issues including especially continued problems with sharing and almost constant squabbling. It had gotten to a crisis level.

What precipitated the crisis ironically was not Jacob but Charlie! Once cute little Charlie, now nearly three years old, learned how to push Jacob’s buttons, things started really spiraling out of control. We scheduled a visit.

Autism and Sibling Issues
That Charlie and Jacob were just now entering into a new phase together was not surprising. The relationship between a child with ASD and his or her sibling(s) evolves and is guaranteed to not be typical. Let me count the ways:
- There are often role reversals where the younger sibling becomes more functional and acts more like an older sibling to the child with ASD.
- There is often a sense of loss and confusion among the typical sibs when their brother or sister with ASD rejects them and won’t play.
• **Resentment** among (especially older) siblings is common because they see their brother with ASD as getting unfair attention or as not having to follow the rules they have to follow.

• The child with ASD can be loud, intrusive, obsessive, pestering, demanding, and/or unpredictable, which can be very **annoying** to his siblings whose feelings of resentment (and subsequent **guilt**) are often not recognized at all or ignored.

• Older siblings are frequently **embarrassed** when their brother or sister with ASD acts ‘weird’ in public or with their typical friends (though to be fair, some siblings are wonderfully accepting and nurturing of their brother or sister with ASD and teach their friends to be more tolerant.)

• Finally, it is frequently the case that the child with ASD gets aggressive over the slightest intrusion by his cute younger brother.

And when sibling relationships deviate from normal, parents are often at a loss. Parents want ‘normal’ sibling relationships so badly that they miss (or mis-read!) the deep negative feelings (resentment, guilt, jealousy, anger) of the other children in the family. They expect the typical siblings to ‘suck it up’, ‘understand’, ‘be nice’ and ‘share’. When parents deny, suppress, or ignore these feelings it commonly leads to misbehavior from the typical siblings and chaos in the family system. I see it all the time. That’s when I get a call like the one from Julie Grant asking to talk about ‘problems with sharing’. Jacob was getting very aggressive over the slightest intrusion by Charlie. In an earlier visit I recommend that Jim and Julie ‘protect’ Jacob when Charlie was a toddler. Julie and Jim felt strongly that it was time Jacob learned to share and I agreed. He was developmentally ready.

**Jacob and Charlie: The Early Days**

As I waited for the Grants to come in for their appointment I thought back on how Jacob and Charlie's relationship had evolved over the last couple of years. It wasn’t a pretty picture.

*Crying*. When Charlie was born, Jacob was not quite two years old. He was in the throes of autism, locked into his own world and, for the most part, oblivious of his newborn brother. Except, that is, when the new baby Charlie cried. Jacob had auditory sensitivities. He hated loud sudden noises. Charlie’s crying ‘drove Jacob nuts’ causing him to have multiple daily temper tantrums, which in turn caused his mother, Julie, to be on edge whenever Charlie made a peep.

Julie developed a number of resourceful strategies. She was very quick to soothe Charlie; she distracted Jacob by putting him in a gated room with his favorite videos; and she kept as much distance between the crying baby and his brother as the house would allow. When Jim was home he would sometimes have to take baby Charlie for a ride in the car until Charlie fell asleep. Thank goodness Charlie was not a colicky or fussy baby.

*“Not Natural”*. As long as Charlie was quiet, Jacob was oblivious to his brother’s existence. In fact, this lack of relationship with Charlie was one of the prime reasons the Grants sought an evaluation that led to the diagnosis of Jacob’s autism. As Jim Grant said to me at one of our early visits, “It just wasn’t natural for a two year old to take no interest in his baby brother.”

Over the next year, this became a source of sadness for both Jim and Julie who of course wanted the brothers to be close. It was also a constant reminder and a barometer of how affected Jacob was by his autism.
As Jacob began to respond to intervention, he began—slowly—to acknowledge his brother’s existence. He even started to interact with him a little; but, for the most part, until Charlie was 10 months old the brothers led parallel lives. Jacob was so disconnected to the world that he didn’t mind Charlie occasionally coming in to his space or even grabbing a toy. Jacob just moved on to find another toy or just wandered off.

_Crawling._ Then Charlie started to crawl! Jacob, who mostly just wanted to be left alone to line up trains or flip through his books, became at first annoyed, then angry, and finally furious to find his brother constantly in _his_ space. And Charlie only wanted to do whatever his big brother was doing. This was the true beginning of their sibling conflicts.

Jacob’s parents felt that Jacob should learn to share with his brother but Jacob disagreed. At first he pushed little Charlie out of his space, then he slapped at him whenever Charlie even tried to touch his toys. The parents yelled at Jacob: “Jacob, this is your brother Charlie. Let him play with you!” But Jacob had no intention of letting this little, intrusive, annoying stranger in to his private play. As Julie said at the time: “I was so sad that they couldn’t play like regular brothers, I cried.”

Thank goodness Charlie was ‘easy going’. Charlie tolerated the pushing (and even the slapping) pretty well. Of course he’d cry which upset Jacob even more but Charlie was easy enough to distract and happy to play with separate toys, so the conflict was limited.

_Walking._ Until, that is, a couple of months later when Charlie began to walk. And he was quick! Before Julie knew it, he was getting into Jacob’s space and going after Jacob’s toys. Charlie went even faster when his parents said “No!” (The little stinker.) Jacob’s annoyance was growing to the point of neurosis. He was always looking over his shoulder and ready to attack Charlie if he ever came within reach. Eventually, he became unpredictably dangerous, randomly pushing Charlie down or hitting him even if Charlie was _not_ going for his toys. Despite Julie’s efforts to get him to share, Jacob did not understand the concept. All he knew was that his autistic privacy was being invaded.

It was a sad situation. Charlie desperately held on to his toys and, when Jacob ripped the toys away, Charlie protested, then tantrumed. Throughout the day little Charlie, clutching his Matchbox cars or his superhero figures could be seen trying to toddle away from his much faster older brother who would overtake him, wrestle the toy from Charlie’s grip and run away to play.

_Attack!_ Then, one day, without warning Jacob viciously attacked Charlie, biting him badly, pushing him down, and kicking him in the back and the head! Julie was horrified. She ran to Charlie who was hysterically crying, swooped him away from Jacob who, according to an angry Julie, showed no remorse whatsoever. Julie yelled at him and Jacob ‘got a good spanking’. I got an urgent phone call.

The note on Jacob’s chart read: “Julie Grant called. Urgent. Please call back ASAP.” As soon as I had a break, I called back. Julie had calmed herself down but was still very upset. This was the first of a series of conversations that we would have about sibling issues over the next couple of years. She was especially upset with herself for not protecting Charlie and she was furious with Jacob as well as truly worried about him.

Mom: “I don’t know how I could have let this happen. You should have seen him. My poor little Charlie with bites and bruises. You should have seen the _look_ on his face. He was so confused. He adores his big brother.”
Dr. Rick: “Jacob really went after him.”
Mom: “I’ve told him over and over that this is his little brother and he has to share.”
Dr. Rick: “I don’t think he can really understand that.”
Mom: “Nothing is easy with him. How he could do this to his own brother!”
Dr. Rick: “Actually, Julie, this is very common.”
Mom: “It is?”
Dr. Rick: “Please, don’t blame yourself and really at some level it’s not Jacob’s fault either. Blame the autism. What you have, with Charlie beginning to walk and Jacob wanting to ‘keep the world the same’, is a perfect storm. Don’t get me wrong. I think it’s terrible too that Jacob attacked his brother but if you look at it from Jacob’s point of view it makes some sense.”
Mom: “I don’t like feeling this angry with Jacob.”

In fact, this scenario is very common. When a younger sibling is a toddler and an older brother has autism, the irresistible force meets the immovable object and there is a clash. Jacob is the immovable object. He wants his world to be predictable, orderly, to stay put. Now here comes the irresistible force toddling up without asking, without warning, and changes everything all of a sudden.

Typically developing siblings as young as 2-3 years old have a ready-made desire to please their parents, a developing conscience, and a love-hate relationship with their younger siblings. And typically developing siblings will often be (or feel like being) aggressive to their younger siblings (often cloaked in very tight hugs)! They know somehow naturally that they are supposed to love their little brother or sister but they are jealous and angry at the same time for having to share mom with this new intruder.

When I was a general pediatrician and a new mom would tell me how jealous the two year old sibling was I would say to her: “Just imagine your husband bringing a new woman into the house and telling you, ‘Don’t worry darling, you’ll learn to love her just as much as I do.’ That’s what it’s like for the older sibling.” This love/hate ambivalence toward a new baby in the family is universal.

Children with autism, however, may not have the built-in natural controls of typical children and they commonly don’t have an understanding that they are supposed to love their little brother or sister. It’s not even about jealousy.

For the child with autism ‘keeping the world the same’ is their top priority. At some level they may understand that their parents get upset when they get aggressive toward their sib but when the child with autism’s insular world is threatened and falls apart, they get very anxious, they act on impulse, and they can become quite aggressive. I explained all this to Julie and she seemed to understand though she admitted to having residual anger.

Dr. Rick: “Jacob is not going to learn to tolerate Charlie’s intrusions without some help.”
Mom: “When Jim sees those bite marks and bruises he’s going to flip out.”
Dr. Rick: “It won’t do much good to keep punishing Jacob for what he did in the past though we will definitely discipline him for aggression in the future.”
Mom: “Good, because I won’t put up with what he did to Charlie.”
Dr. Rick: “It’s not really his fault, Julie. And it’s not your fault. Within a few weeks he’ll be much better. We have to give him more control at first. Then he’ll come around. You’ll see.”
Mom: “I hope so. Now Charlie is leery of his own brother.”
**Dr. Rick:** “Charlie will be ok. But we have to be vigilant and we have to give the same consistent message. We’re going to use this problem to help Jacob grow emotionally.”

**Mom:** “He better. Or else! I’ll call Amy and set up a time to talk about this.”

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**Promoting Maturity through Sibling Rivalry.** Recent studies in child development reveal that the importance of siblings in shaping a person’s lifelong development has been severely underestimated. Our children’s attitudes toward boundaries, competition, conflict resolution, fairness, sharing, loyalty, and intimacy are profoundly shaped in long lasting ways by sibling relationships.

Families can and should use the sibling relationship to promote the developmental and emotional potential within the child with autism and help him or her become more tolerant, socially appropriate, and more emotionally sophisticated. In short, through sibling conflict, we can help the child with autism become more mature.

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**Sibling Rivalry Office Visit #1: Two Years Ago**

So, when Jacob was about 3 (See Chapter 10, Visit 5: Moving On Up?) and Charlie was around 15 months old we had the first of several conversations about ‘sibling rivalry’. It was about two years ago now but it went so badly, I remember it well. (I’m reconstructing the conversation from memory and from notes taken at the time.)

The Grants rolled in to my playroom and, as I recall, it took about 15 seconds for the rivalry to begin as both boys headed right for the yellow drawer full of little Matchbox cars they had played with the last time, including a set of highly desirable (especially for Jacob) ‘Cars’ characters—Lightning McQueen, Mack the semi-truck, and Mater the tow truck.

First they jockeyed for position, nudging each other, with Charlie, who was still toddling and at a clear physical disadvantage, getting elbowed by Jacob until he fell down crying which only made Jacob more annoyed at which point Jacob started kicking Charlie hard in the side as if to say ‘Stop crying! You’re so loud!’ Charlie screamed in real pain.

It all happened so fast. Julie gave me the ‘I’m so sorry but this is my life’ look. I immediately jumped up from my chair and grabbed Jacob by the arm gently but firmly to stop him from kicking Charlie. Jim picked up Charlie who wanted his mommy. As I firmly guided Jacob over to the chair in the corner, I spoke in my deep, loud, doctor voice:

**Dr. Rick:** “Jacob, you may not hurt Charlie in my office. No kicking! No hurting!”

**Jacob** (without a shred of remorse at what he had done, screamed, cried, and chanted at the top of his lungs): “ka-ka-ka-ka, his word for ‘car.’”

I worried that the whole building complex would hear him. We waited and waited and waited but the boys didn’t settle down. Jacob was totally focused on getting the cars. Charlie was getting over being hurt but now he wanted to get to the cars before Jacob did. Both boys were crying, loudly. I stood up, got right in their faces and spoke loudly and dramatically. My intention was to join their wish and reflect their feelings.

**Dr. Rick** (loudly): “Who wants to play with cars? Jacob, you want to play with the cars! Charlie, you want to play with the cars!”

It was like a miracle, like turning a faucet off. They both stopped crying.
Dad: “Wow. I’m impressed.”

The boys looked hopeful. I repeated myself.

Dr. Rick: “Who wants to play with cars? Jacob, you want to play with the cars! Charlie, you want to play with the cars! OK. You can play with cars but Jacob, no hitting Charlie. If you hit, no cars. If you hit you go in the chair.”

Mom: “He really seemed to understand that.”

Dr. Rick: “There’s a glimmer. We’re going to use the sibling rivalry to help Jacob understand his feelings, your feelings, Charlie’s feelings, the rules about hitting, and the consequences, what happens when you break the rules. We haven’t talked yet about The Good, The Bad & The Ugly but that’s a discussion we should have soon.” (See Chapter 17, Visit 10: The Good, The Bad, & The Ugly).

Then I divvied up the cars quickly and equally. Luckily I had two Lightning McQueens and Charlie didn’t really care if he got the ‘Cars’ characters; he just wanted a seat at the table, so to speak. Jacob played in one area and Charlie in another area of the room. We got through the crisis; we could talk.

Mom: “We’ve been through this so many times. When is he going to learn to share?”

Dad: “I’ve spanked his butt; I did what you did—put him in a chair; I’ve taken his toys away and nothing seems to make a dent. He just doesn’t get it. He keeps hurting Charlie and it’s really pissing me off, excuse the language.”

Dr. Rick: “I understand being fed up with it all but you’re right. Jacob doesn’t get it because he can’t get it.”

At that visit, I explained to Jim and Julie that though Jacob was three years old, his functional developmental level was still at the level of a one year old (See Chapter 10, Visit 5: Moving On Up?). In other words, as much as I hated to say it (I knew it would upset Jim and Julie), he and Charlie were about the same developmental age. And one year olds are not going to understand ‘if-then’ reasoning (i.e., if you push Charlie you won’t be able to play), ‘sharing’, or any other abstract concept. After dozens of repeated experiences Jacob would begin to understand that when he hit Charlie he would have to go to the time out chair. But that could take a long time and Charlie would have a lot of bruises. We had to have a better plan.

Protecting Jacob

Dr. Rick: “So, the first step is to make sure that Jacob is protected from Charlie’s intrusions.”

Both Jim and Julie were incredulous.

Mom: “You want us to protect Jacob from Charlie?”

Dr. Rick: “Yep. For the next week I want you to stop Charlie from getting into Jacob’s play space.”

Mom: “Every time?”

Dr. Rick: “Every time. We’ll get Jacob to accept Charlie but, just in the beginning, I want Jacob to see that he is safe. I also want Jacob to feel understood. I want you to ‘speak for Jacob’.”

Mom: “What do you mean?”

Dr. Rick: “What is Jacob thinking when his brother gets close to his toys?”

Mom: “Probably ‘Keep that kid away from my trains’.”
Dr. Rick: “That’s right. But I want you to use words that Jacob might say if he could talk; something like ‘Mommy, no Charlie.’ Or ‘You want Charlie to go bye-bye?’”

Mom: “I get it now. Speak for Jacob.”

Dr. Rick: “That way he’ll feel understood which will help him calm down (and it will help his language too).”

When all this started, Jacob was just beginning to understand simple concepts. All he understood was: ‘Here comes that intruder, Charlie. He is going to mess up my trains again and I hate it when he does that and I’m going to stop him. If he keeps on coming I’m going to attack him.’ In other words Jacob was not capable of understanding the concept of ‘sharing’.

**Protecting Jacob?**

- What is Jacob’s functional developmental profile? Can he really understand ‘sharing’?
- When Charlie goes toward Jacob’s space, go with him. Don’t let him intrude!
- Read Jacob’s cues and ‘speak for him’: “Charlie no! I’m playing. Go bye bye.”
- When Charlie gets sad point this out to Jacob.
- Then ‘tussle’ with Jacob and see if he will let Charlie play ‘just a little’. Promote interacting.
- Discipline Jacob for any aggression.

He didn’t even understand how to use words to say ‘No!’ And he didn’t care if he hurt Charlie or upset mom. Because of his autism, those empathic feelings weren’t natural to Jacob, yet. But I knew that the potential for empathy was hidden within him—if, that is, we approached Jacob the right way.

Mom: “But Charlie is not going to be happy.”

Dr. Rick: “So then you’ll point that out to Jacob. ‘Charlie is sad. Charlie wants to play too. Please Jacob. Can Charlie play a little?’ I want you to ‘tussle’ with Jacob. Show him that Charlie’s not such a bad guy. That it really won’t hurt anything if he plays a little, just a little. Wear him down and show him that Charlie can sit there near the trains, Charlie can hold a train, Charlie can put a train on the track.”

Mom: “And Jacob gets a look on his face that could kill.”

Dr. Rick: “Well, let’s see. Let’s do it right now.”

Mom (getting anxious): “But they’re being so good.”

Dr. Rick: “We’ll start by just talking about it and see what happens. Our goal is to just open up the discussion, so to speak, and see if we can get Jacob to tolerate Charlie first coming closer, then maybe interacting a little, and then maybe playing a little. But you’re going to have to be there. You can’t just expect it to happen.”

Dad: “I see. It’s a step-by-step process. We were going too fast and expecting too much.”

Dr. Rick: “Correct! You must always match your expectations to the child’s developmental level. I call this the ‘philosophy of can’. Can the child do it? If they can’t we have to work at a lower level, which is what we’re doing now.”
The boys were playing nicely by themselves. I asked mom to pick up Charlie and sit on the floor by Jacob, which she did. Charlie was happy when they went over to Jacob’s space. Jacob seemed OK with it too...so far.

Dr. Rick: “Now read Jacob’s gestures and facial cues closely and join him in what he’s doing. What is he doing?”
Mom: “He’s playing cars.”
Dr. Rick: “Simply mirror in words what he’s doing and include Charlie. Don’t ask questions; make statements. What he’s doing is a statement, not a question.”
Mom (holding Charlie in her lap): “Look Charlie, Jacob is putting the cars in a row.”
Dr. Rick: “Perfect, momma! Now point to each car and name the colors in a sing songy voice”.
Mom: “Red, red, blue, yellow, green!

At that moment Jacob looked up and gave mom a great smile. Charlie liked it too.

Dr. Rick: “OK. Dad, hurry. Give Charlie a car to give to Jacob (which he did). OK, now mom, tell Charlie to give the car to Jacob and help him. Just offer it and see if Jacob wants it.”
Mom (holding Charlie’s hand with the car in it): “Charlie, give Jacob the car. Here Jacob, another car for you. From Charlie Charlie, give the car to Jacob.”
Dr. Rick: “When he gives it, give Charlie another car and keep the interaction going.”

Jacob took the car from Charlie! Charlie got another car and leaned forward to put the car in the row that Jacob was forming but Jacob did not like that and frowned.

Dr. Rick: “That’s OK. Stay with it, mom. Jacob is using gestures to communicate. I call that ‘good negative’ behavior. It’s better than hitting, biting and kicking. So tell Jacob’s feelings to Charlie: ‘No no Charlie. Jacob doesn’t want you to line up. No lining up, Charlie’.”
Mom: “And now Charlie will lower his little head and start to cry.”

Which is exactly what Charlie did.

Dr. Rick (to Jacob): “Oh Charlie is sad, Jacob.”
Dad: “He doesn’t care at all. He just went right back to lining up the cars.”
Dr. Rick: “He doesn’t care yet. But look what happened here. We got the boys to interact without aggression. We’re teaching Jacob that his gestural communication matters and we’re putting words on them. We’re tuning him in to Charlie’s feelings. I’d say we accomplished a lot.”
Dad: “And how long is it going to take for them to play like real brothers?”
Dr. Rick: “You can’t push this river, dad. But when Jacob sees that Charlie is not going to ruin his play—because we are protecting Jacob from Charlie—he’ll be more tolerant. The key here is to keep working on Jacob’s development so that he moves up to the higher functional levels. Then he’ll be able to understand more and more and he and Charlie will be great play buddies.”
Mom: “I can’t wait for that.”
Dr. Rick: “It’s going to happen but you have to go slow. It will take weeks to months. Protect Jacob as we did here. Honor his feelings. Go slow. He’ll let Charlie in. You can also play with Charlie near Jacob and see if Jacob wants to join your play.”
Mom: “We do that. But then Jacob just wants to take our toys for himself.”
Dr. Rick: “Do you let him?”
Dad: “She does, I don’t. She let’s Jacob take Charlie’s toys and then when Charlie get’s upset she distracts him to something else.”

Dr. Rick: “Keeping the peace, eh? Well, that might work for a while but it’s not fair to Charlie. We have to have the same rules for both boys. It won’t be long before Charlie gets resentful.”

Mom: “I know but I just don’t want to hear any more of Jacob’s screaming.”

Dr. Rick (to dad): “We’ll let her keep the peace for now since Charlie is OK with it but pretty soon she’ll be calling to say that Charlie’s behavior is getting worse.”

Jim and I have a little laugh together.

Mom: “Hello. I’m sitting here listening to you guys talk about me.”

Postscript

In a follow up phone call, Julie Grant admitted that, at first, both she and Jim (especially Jim) were skeptical—they didn’t think it was right to let Jacob hoard his toys. But after less than a week of ‘protecting Jacob’, Jacob calmed down and was much less vigilant. Jacob’s pushing, hitting, and/or kicking of his little brother declined dramatically. While he wasn’t saying ‘No’ verbally he was frowning and shaking his head to communicate. Julie was getting good at ‘speaking for Jacob’. And, importantly, he was tolerating Charlie more and more but he was still protective of his precious Thomas the Tank Engine trains and he was ‘not really sharing at all’.

Julie laughed to tell me how she ‘tricked’ Jacob into sharing with Charlie. At night when the boys were in bed, she collected all the trains in a box and the next morning when Jacob went to play he couldn’t find them. So he took her hand and pulled her to where his trains were supposed to be and she said, “Hmm, where are those trains Jacob? Let’s go find them.” Charlie tagged along while the three of them went on train hunt. “Are they here? No. Are they here? No. Oh, here they are?” After lots of interaction they found the box. Then Julie said, “I had Charlie give the trains to Jacob one by one. Charlie was so happy to ‘play’ with his brother and Jacob was happy to have ‘found’ his trains. That was the good news. The bad news was, of course, that Jacob wanted all of Charlie’s trains too.

When Jacob was aggressive at all, he learned that it made his parents angry; they made him stop his activity; and they put him in time out.

When Jacob didn’t want to share or play, mom added a little guilt and jealousy by saying ‘Jacob, if you don’t want to play with Charlie then I’ll play with Charlie.’ And she would play in a way that tempted Jacob who was increasingly coming over to join them.

The Evolution of Sharing

All that was a year ago and things got better for a while. But over time, as Jacob made progress with his intensive, home-based, PLAY Project intervention programming (See Visits 5, 6, 7 & 8) and as Charlie moved into the ‘terrible twos’, the brothers’ relationship deteriorated again. I spoke with Julie on the phone.

Mom: “The sharing thing is not going well. As soon as Charlie puts down a toy Jacob goes after it and vice versa. The boys are at each other’s throats.”

Dr. Rick: “The problems with sharing are a good thing, Julie. It’s a sign they’re growing up.”

Mom (with an edge): “Walk a mile in my shoes Dr. Rick, and you won’t think it’s such a good thing. They’re driving Jim and me crazy.”
Dr. Rick: “I don’t mean to be insensitive; I know it’s not easy but the boys have been evolving and, hallelujah I think it’s time to actually have ‘rules for sharing. Remember when Jacob just ignored Charlie?’”

Mom: “Except when Charlie cried!”

Dr. Rick: “Then remember when they both didn’t care?”

Mom: “That didn’t last long.”

Dr. Rick: “Then we had to protect Jacob from Charlie.”

Mom: “But now that doesn’t seem fair to Charlie at all.”

**ASD & the Evolution of Sibling Rivalry**

- Sibling with ASD mostly ignores his/her siblings
- Sibling with ASD is aware but too young to be possessive. ‘Rules for sharing’ unnecessary.
- Possessiveness emerging but sibling with ASD cannot understand ‘rules for sharing’.
- Younger typical sibling becoming intrusive. Child with autism needs ‘protection’.
  - Older typical siblings should be taught about ASD.
- Sibling with ASD can understand ‘rules for sharing’. Competition for toys creates conflict.

Dr. Rick: “I agree. It’s time to have clear rules for sharing or the conflict will get worse because both boys are in a phase of development where conflict is common.”

Mom: “You can say that again.”

Dr. Rick: “Both boys are in a phase of development where conflict is common.”

**Note/Older Sibs**: With older typical siblings there is a different but similar pattern of evolution. At first the child with autism is seen as not capable of sharing, so there is some tolerance. But if the child with ASD is allowed to take the older child’s toys (to avoid angry outbursts by the child with ASD) then resentment often starts and older typical children become annoyed and annoying. They tease, get even behind parents’ backs, can be provocative in many other ways. When older siblings are involved, rules for sharing (see below) are needed sooner rather than later. The children with ASD will get angry over not getting what they want but, over time, they ‘get’ the pattern of not being able to take the older child’s things and they get over it. The older typical child then feels that justice has been done and becomes an ally instead of an instigator. There are of course the wonderful older siblings who tolerate the child with ASD no matter what he or she does but I see these little angels only rarely in my practice.

**Jacob’s Development**: As Jacob turned four years old, he was consistently following one- and two-step commands; his expressive language was kicking in with dozens of single words and some two word phrases; and he was starting to truly understand consequences: if I hit Charlie, mom and dad will be mad; I’ll have to stop what I like doing; and I’ll have to go to time out. In other words Jacob was still significantly ‘behind’ in his language compared to his peers but he was making very good progress in his functioning. He understood, for instance, that he has his toys and Charlie has his toys and that Charlie doesn’t like it when Jacob takes Charlie’s toys. According to the ‘philosophy of can’, Jacob ‘could’ understand key ideas that would lead to truly ‘sharing’ with his younger brother who, at 2½, was becoming a ‘pistol’.
Charlie’s Development. Sweet little Charlie wasn’t always so sweet anymore. He was not easily distracted anymore. He wanted to keep the toy he was playing with but Julie, with her belief that ‘brothers should share’, often made Charlie ‘share’ with Jacob to keep the peace. For a while, Charlie would reluctantly comply to please his mom but he wasn’t happy about it. He knew it wasn’t fair.

As he entered his ‘terrible twos’ phase, Charlie learned how to ‘push his older brother’s buttons’ and make Jacob cry or hit (which Charlie knew would get Jacob into trouble). He was also figuring how to protect himself from Jacob’s aggression by threatening back and/or running away behind his mom for protection.

Though Jacob was less violent, minor battles and squabbles between the brothers were becoming more and more frequent and the issues almost always had to do with sharing. The Grants wanted the boys to share and, over time, they let the boys ‘do their own thing’ which was leading to more and more sibling conflict and outright aggression. This was not working.

Sibling Rivalry Office Visit #2: The Six Rules for Sharing

Julie Grant had mentioned the escalating problems with sharing at our visits about bad mornings, going out in public, and at the last visit on toilet training. So it was time to schedule a visit just to talk about the sibling issues. Jim Grant took off work to be here, a sign that things had gotten serious.

Both boys have made so much progress developmentally! They’ve become more socially sophisticated. I did my ‘Give me five. . .down low. . .on the inside. . .on the outside. . .up high. . .up in space. . .in your face (I put my hand over his face). Jacob got the game and loved it. Charlie wanted to do it too.

Jacob is talking in short connected sentences; he is totally connected and quite able to understand a situation and problem solve to get what he wants. Charlie is easily at the same level if not a bit higher developmentally. The boys are almost twin-like developmentally speaking.

Julie Grant starts off, believe it or not, with complaints about Charlie!

Mom: “Charlie is purposefully ignoring us; he refuses do what we ask him to do like put his toys away and he calls me ‘poopy mommy’. Jim’s a disciplinarian and won’t put up with it. He has spanked Charlie for disobedience and disrespect. Personally I think the spankings only make Charlie worse. He holds a grudge and he has no fear.”

Dr. Rick: “What about you? How are you doing with Charlie?”

Mom: “I feel sorry for him. He has to put up with Jacob’s control issues. Jacob is like a little tyrant. He shouts orders! And this sharing thing is driving Charlie nuts.”

Dr. Rick: “This ‘sharing thing’?”

Dad: “Jacob is claiming all the toys.”

Dr. Rick: “That’s not fair to Charlie.”

Dad: “But I’m not going to put up with Charlie’s screaming and bad behavior.”

Dr. Rick: “But there’s a good reason for Charlie’s screaming.”

Mom: “The fighting is constant.”

Dr. Rick: “So what are you two doing? Are you on the same page?”

Mom: “About sharing? Well yes and no. We both think the boys should share. Charlie seems to get the idea but Jacob doesn’t want to share at all. He thinks all the trains are his, even Charlie’s.”
Dad (digging at me): “We've been ‘protecting’ Jacob.”
Dr. Rick: “Very funny, dad. You didn’t like my idea of ‘protecting Jacob’ when the boys were younger.”
Mom: “It worked. Jacob’s hitting went way down. But I think we created a monster.”
Dr. Rick: “I agree. This has gone beyond ‘protecting’. We are now into true sharing.”
Mom: “Charlie’s no fool. He’s getting the short end of the stick most of the time and then when he gets upset and nasty he gets a spanking or a time out.”
Dr. Rick: “That must make Charlie furious.”

It’s interesting to note that when I am talking about something important to parents, even demanding, disruptive siblings seem to ‘get it’ and miraculously do not interrupt us. That’s the case here. Charlie and Jacob are playing very nicely together. And I think Charlie knows that we’re talking about him.

Mom: “I think Charlie is angry a lot and it’s showing up in other places. He’s not the sweet easy boy he used to be.”
Dad: “But Julie, you back off when Jacob yells and I think that makes it worse.”
Mom (to me): “If Jacob doesn’t get his way, he screams. I hate the screaming.”
Dr. Rick: “Sounds like he’s getting spoiled and now Charlie’s screaming.”
Mom: “And hitting. It’s a mess.”
Dr. Rick: “OK. Let me see if I can summarize what’s going on. Jacob hogs the toys and won’t share. He screams if you make him ‘share’. Then Charlie gets mad and yells or hits and then he gets a time out or a spanking for misbehavior. He’s becoming resentful and having more behavior problems.”
Dad: “That about sums it up.”
Mom: “Jacob’s gets some time outs too. But it’s not getting better; it’s getting worse.”

**Forced Sharing.**

Dr. Rick: “I get the picture. So what are your rules for sharing?”
Dad: “Rules for sharing? They should share.”
Mom: “We don’t have rules.”
Dr. Rick: “You can see what’s happening and it’s pretty universal. Most families in my practice have these sibling rivalry issues around ‘sharing’. So mom, you have a sister, right?”
Mom: “And a brother.”
Dr. Rick: “So your sister or brother can come over to your house, grab your car keys and take your car whenever they want without asking, right?”
Mom: “Of course not.”
Dr. Rick: “Oh, I see. It’s OK to make Jacob and Charlie ‘share’ but you won’t share with your siblings.”
Mom: “That’s not sharing, that’s taking. I get it. When we make Charlie give a toy to Jacob he’s not really sharing.”
Dr. Rick: “Right. You’re forcing him to ‘share’ and forced sharing is not sharing. True sharing is when you want to share.”
Mom: “But we were expected to share and we did.”
Dad: “Same thing in my family. We wouldn’t even think yelling or fighting over things. My dad was scary strict.”
Dr. Rick: “In a previous generation things were different but human nature hasn’t changed and I’ll bet you had your share of resentments when you were forced to share by your parents.”
Mom: “Actually I’m still very possessive of my things.”
Dad: “Yes you are dear.”
Mom (giving him ‘a look’): “I was the oldest. I remember having to hide my favorite things. My sister and I to this day are still very competitive with each other.”
Dr. Rick: “From watching hundreds of families I can tell you that the three most common causes of anger, resentment, and family conflict are:
1. Not getting enough positive attention
2. Unequal treatment/favoritism, and
3. Forced sharing
"By far, forced sharing is the most common source of conflict because the competition over toys and possessions happens every day all day long.”

Mom: “It’s constant.”

Note: I have seen some families where forced sharing or just letting the children ‘work it out among themselves’ seems to work. Sometimes families can get away with it because of the particularly easy going temperaments of the children. But I worry that the seeds of resentment or excessive competition are being planted and will grow into bigger problems in the future (especially when the parents’ back are turned!)

Dad: “When I was a kid, we knew what we could and couldn’t do. Nobody had to say a thing. My dad was a military man.”
Dr. Rick: “Did you like it that way?”
Dad: “It didn’t matter. That was the way it was.”
Dr. Rick: “You didn’t have much of a choice. Is that how you want it to be for your boys?”
Dad (pausing): “Not really. We didn’t have any say. There was resentment with my brother especially. So no, I want my kids to be close.”
Dr. Rick: “You’re not close to your siblings.”
Dad: “Not really. Not at all. . .But I can’t do what my dad did, and what we’re doing is not working.”
Dr. Rick: “So sounds like we have to find a middle ground. Not strict but not so loose that it’s chaos.”
Mom: “It’s getting to be chaos.”
Dr. Rick: “So you ready to talk about the six rules for sharing?”
Mom: “Six rules?”

**The Six Rules for Sharing**
Dr. Rick: “Here they are (I hand them each a list) Rule 1 we’ve already discussed. Forced sharing is not sharing. Rule 1 is that you don’t have to share.”

Rules for Sharing
1. You don’t have to share. No forced sharing.
2. Favorite toys should be put away (otherwise they are public toys).
3. Public toys are shared on a ‘first come’ basis.
4. If both children want the same toys: take turns. A 10 minute rule usually works.
5. If both children get to the toy at the same time: flip a coin.
6. It’s nice to share because:
   • It makes the other person happy.
• When you share with them they’ll share with you.

Dad: “But don’t we want them to share?”
Dr. Rick: “Absolutely. That’s coming up, bear with me. **Rule 2** states that if Jacob or Charlie have their own special toy or set of toys then *they should put their special toys away* (or you can put them away for them) when they’re done playing or, **Rule 3** all other toys (including those not put away) become ‘public toys: first come, first serve.’ If Jacob wants to play with the toy that Charlie’s playing with then **Rule 4** is that you have to wait your turn. I like a 10 minute rule (almost no child will play with a toy for longer than 10 minutes). So **Rule 4** is that you have to take turns with a popular toy after a certain amount of time. That’s not sharing; that’s turn taking.

Mom: “What about when Jacob puts a toy down. It’s like Charlie is just waiting. He runs and grabs it and Jacob chases him.”
Dr. Rick: “**Rule 4** says that it’s your toy for 10 minutes and no one can touch it even if you put it down, unless you are really done with it.”
Dad: “How will we know if he’s really done with it?”
Dr. Rick: “You ask, you talk, you discuss. You work out boundaries, you make the rules clear”.
Dad: “Sounds like a lot of work.”
Dr. Rick: “Actually it is work in the beginning. You have to spend time teaching these rules. But it’s good work. You give positive attention. You acknowledge feelings. You create a level playing field without unfairness or favoritism and you reduce resentment. These are universal rules for sharing, right? These are the rules we all follow.”

Mom: “Sometimes you don’t know how it started. A lot of the hassles happen when we’re not looking.”
Dr. Rick: “That’s true. Sometimes you can’t get all the facts. Oh, look here, it’s happening as we speak.”

After being angels for almost half an hour, Jacob and Charlie, as if on cue, start squabbling over a car. Of course, it’s about Lightning McQueen who has two little tires over the front windshield that look like black-rimmed glasses. Jacob loves that car. It’s pretty clear what’s happening. Jacob has had the car for a while and Charlie wanted it and so he took it first chance he had. The argument is really escalating and Jacob is lying on top of Charlie, loudly yelling ‘my Lighting’ (he can’t pronounce the ‘n’ in Lightning) over and over, trying to get the toy car out of Charlie’s hand while Charlie (who is kind of enjoying keeping the toy away) has extended his arm out of Jacob’s reach.

Dr. Rick: “You gotta love the timing. OK. Let’s deal with this. Dad, what would usually do? Be honest.”
Dad: “I know what I’d do because I do it all the time. Simple, I just take the toy they’re fighting over away. I use to let them fight it out but now they can hurt each other. If I have to, I pick them up and separate them. That pretty much ends it.”
Dr. Rick: “Until the next time. OK. Mom, what would you do?”
Mom (hesitating): “I hate the fighting and the crying. I’d. . .”
Dad (interrupting): “. . .She almost always asks Charlie to give the toy back to Jacob. (Imitating mom in a high voice) ‘Charlie that’s not nice. Give that car back to Jacob. Be nice to your brother.’ And then she buys Charlie off with another toy that he likes.”
Mom (laughing): “That’s actually a good imitation of me. I used to be able to distract Charlie but these days that’s not working. Charlie usually starts it. (Looking stressed) We need to do something. They’re going to hurt each other.”
And indeed they are. The yelling is getting louder and Jacob’s pulling at Charlie’s clothes and pinches Charlie hard. Charlie cries and starts kicking at Jacob. I jump up and get control of the situation.

**Dr. Rick:** “Woah! Woah! OK guys, guys. That’s it. That’s it.”

I pull Jacob up and off of Charlie. Charlie clutches the car to his chest as if he’s won the battle. Jacob, now in my arms, is still reaching for the car and chanting “My, my, my, my!”

**Dr. Rick** (to mom and dad): “I always start with ‘feeling reflections’ or ‘mirroring feelings’. (Then I turn to the boys) **Jacob** you want that Lightning with the glasses. And **Charlie** you want Lightning too. **Jacob** that’s your car. You had the car and Charlie took it.”

Jacob stops chanting and looks at me as if to say ‘You got that right. That’s my car. Charlie took it. No Charlie.’

**Jacob** (echoing me): “No Charlie.”

**Dr. Rick:** “And Charlie, you want Lightning. Jacob played with it a long time and now it’s Charlie’s turn.”

**Charlie:** “Charlie’s turn.”

Charlie acts like he’s won the argument and starts to play with the car.

**Dr. Rick** (I hold him back from playing): “Whoa Charlie. You can’t play yet. If you play I’ll have to take that car from you. We have to work this out. Did you take that car from Jacob without asking? (Charlie lowers his head and has a guilty look.) I see. Jacob had the car a long time and you wanted a turn. (Charlie looks hopeful.) Hmmm. What are we going to do guys? Jacob, can Charlie play with that car?”

**Jacob:** “My Lightning.”

**Dr. Rick:** “Jacob you had that car a long time.”

**Jacob:** “My Lightning.”

**Dr. Rick:** “Charlie, Jacob does not want to share. You have to give the car back to Jacob and then you can have the car in five minutes.”

**Charlie:** “No, no, no. My car.” (He clutches it tight with both hands.)

**Dr. Rick:** “Charlie, give me the car and you can have it in five minutes. Here is another car. Look it’s Mater. He’s cool.”

**Charlie** (hitting Mater out of my hand): “No.”

**Mom:** “Charlie that is not nice to do to Dr. Solomon.”

**Dr. Rick** (holding my hand out): “You can’t take Jacob’s car without asking. You have to ask. And Jacob does not want to share. If you don’t give me the car I will have to take it.”

Charlie, giving me the car—he understood the whole conversation!—starts to cry pathetically.

**Dr. Rick:** “I know, Charlie, you really want that car and you will get it, I promise, but you have to wait five minutes. (Charlie seemed to understand). (To Jacob) And Jacob you get to play with Lightning for five minutes then you have to give it to Charlie. You understand? Five minutes. You’ve had that car a long time. You could share with Charlie, he likes that car too.”

**Dad:** “So you are forcing them to share.”
Dr. Rick: “This is not sharing. This is taking turns, Rule 4. If Jacob would have given it to Charlie willingly, that would have been sharing.”

Dad: “I get it. There’s like an invisible boundary.”

Dr. Rick: “Right, a psychological boundary that says ‘You can’t take something from someone without asking.’ But we allow our children to do it all the time in the name of ‘sharing.’”

Mom: “That’s so true.”

Dad: “But what if you can’t tell who took what?”

Dr. Rick: “You try to find out what the truth is so you can be fair. With my kids when they were a little older than the boys—when the squabbling reached a certain decibel level or it’d gone on too long—I used to ‘hold court’. I’d get a towel and put it over my shoulders like a judge’s gown and I’d get a hammer like a gavel. I’d sit them down, pound the table with my hammer and say ‘Court is in session. Present your case.’ Then my kids would tell their stories. I’d listen carefully, reflecting everything they’d say like ‘I see. You were watching TV and your brother wanted to watch another show and you wouldn’t let him so he teased you.’ and I’d make it take a long time and very boring. And then invariably I’d determine that they both did something wrong—my son teased and my daughter hit him for teasing—and I’d give them time outs, four minutes for teasing, five minutes for hitting. They’d both be mad. They had to stop what they were doing; they had to listen to a boring court session; and they got short annoying time outs. It didn’t take long. I’d hear them saying to each other, ‘Stop, you’re too loud. Dad will hold court.’”

“So, that’s a long way of saying that you should try to find out what happened in order to be fair but if you can’t then what I do if they were fighting over a toy, for instance, is put the object in question in time out—take it away for five minutes—and then flip a coin to see who gets it after that (Rule 5) and then take turns (Rule 4).”

Mom: “This all makes so much sense. Why didn’t we do this earlier?”

Dr. Rick: “The boys weren’t developmentally ready. It’s been about five minutes so let’s do Rule 4—Turn taking. (To Jacob). OK Jacob, five minutes are up. It’s time for Charlie to have the Glasses Lightning (Charlie’s little face brightens). Of course Jacob clutches the car to his chest with both hands and scowls.

Dad: “I gotta see this.”

Dr. Rick (to dad): “I’m going to use my transition tricks here dad. (To Jacob) Jacob you still want to play with the car. (Jacob brightens.) But look at Charlie. He wants to play. It’s his turn. Come on Jacob, give it to Charlie. (No deal, Jacob holds on tightly.) OK. Jacob. You can have it for one more minute then you give it to Charlie or I take it away. (To Charlie) One more minute Charlie, then you can have it.”

Dad: “You’re giving in to Jacob.”

Dr. Rick: “Right, for one minute. But I accomplished a lot. We ‘tussled’ over something important with lots of circles of interaction. I tuned Jacob in to Charlie’s feelings. I talked about time, rules, and consequences. And now the time is up and we’ll see if Jacob will give the car to Charlie willingly.”

Mom: “That would be a first.”

Dr. Rick (after one minute I turn to Jacob): “OK Jacob, time is up. Give the Glasses Lightning to Charlie. (Jacob ignores.) Jacob, look at me. (He looks) If you don’t give the car to Charlie, I’m going to take it and if you hit you are going to time out. I’m going to count to three Jacob. Give the car to Charlie. You have had it a long time. (Charlie has his hand out) 1-2-3.”
I start to get up from my chair and Jacob throws the car down angrily toward Charlie who grabs it greedily.

**Mom:** "Jacob don’t throw.”
**Dr. Rick:** “Ignore that ugly behavior mom. He’s taking turns.”
**Mom:** “That’s amazing.”
**Dr. Rick:** “Not really. Jacob knew I meant business.”
**Dad:** “And if he didn’t give it to you then you would have taken it away.”
**Dr. Rick:** “Absolutely. And if he got aggressive, I would stop him and put him in a time out or hold him if necessary until he calmed down.”
**Dad:** “I can live with this. These rules are fair.”
**Dr. Rick:** “These are the universal rules of sharing. They’re complicated but they’re real. This is what I want for all the children, a real understanding including the final rule.”

**Mom** (reading the list): “It’s nice to share.”
**Dr. Rick:** “Right. (To Jacob). Hey Jacob, look at Charlie. He's happy that you let him have Lightning. (To Jim and Julie). I’m going to point out Charlie’s feelings. This Rule 6, promoting sharing.”
**Dad:** “Jacob looked but he doesn’t care.”
**Dr. Rick:** “Not yet. It takes many exposures but eventually he will understand that his taking turns and his sharing makes Charlie happy. This is Greenspan’s Functional Developmental Level VI.”
**Mom:** “I feel much better.”
**Dad:** “This puts us on the same page. (To his wife) I really didn’t like it when you gave in to Jacob.”
**Mom:** “It wasn’t fair but I can see that I’m going to have to put up with some of Jacob’s yelling. But he’ll get it.”
**Dr. Rick:** “And when he does, it will be a permanent understanding. The brothers will get along a lot better. The way you were going you were sowing the seeds of resentment in Charlie and that was coming back to haunt you.”
**Dad:** “Thanks so much Dr. Rick.”
**Dr. Rick:** “I see from your list that Jacob is still working on toilet training.”
**Mom:** “Any tricks for that?”

**Summary**
- As Charlie, Jacob’s younger brother, gets older, he is quickly becoming aware that Jacob is getting more than his fair share of the toys and he’s getting resentful—and getting even—by pushing Jacob’s buttons and making sharing a big issue in the Grant household.
- Sibling rivalry is a complex developmental process that must take the whole family system into consideration.
- I summarize for the Grants the six universal rules for sharing and demonstrate how to implement the rules when Jacob and Charlie have a knock down, drag out fight right in my office.

**Resources & Websites**
- *Siblings Without Rivalry*, Adele Faber and Elaine Mazlish (2012)

**Coming Up Next**
In the Epilogue we peer into Jacob's future. He is facing a big transition—full day school and leaving the PLAY Project intervention program. He's made amazing progress but Jim and Julie Grant understand now that progress never stops, and that Jacob has the potential within to grow emotionally, social, and academically and have a happy, meaningful life. I look forward to supporting Jim and Julie as Jacob heads off to kindergarten...
Epilogue: What is the Potential Within?

What is the potential within a child who has an autism spectrum disorder? As I mentioned in Chapter 1, a follow-up study of 34 children diagnosed with ASD before the age of five were reassessed later in life (ages 8-21 years of age) and were found to not meet criteria, i.e., they no longer had autism. These children did not simply ‘outgrow’ autism; they had had good early intervention. The researchers estimated that this is possible for up to 10% of the children. So the potential within a child who has ASD is to become non-autistic.

But what about the other 90%? As I hope I have shown with Jacob Grant, the real potential within all children is to progress along a developmental path that has clear functional developmental milestones. According to Greenspan and Weider, these milestones cannot be skipped without causing poor social functioning. People with ASD will move along this path at their own pace. Some will move slowly, some at a medium pace, and some are fast movers.

Jacob Grant was a medium to fast mover who came a long way from the time of his diagnosis when he wasn’t talking, wasn’t interacting, and wanted to stay in his Comfort Zone ‘doing his own thing’ all the time. When his story in this book ended, he was talking in connected sentences, wanted to engage with others, liked pretend play, and became a robust emotional thinker. Jacob was heading for a regular kindergarten class with some in-class support from a paraprofessional aide as part of his special education programming. Did he possess all of The Seven Habits of Highly Effective Kindergarteners (See Chapter 16)? Not quite, but by age six when he enters school he should be close.

The future challenges for a child like Jacob will be many. He will need a lot of support to become better able to socialize with his peers. This will require promoting social sophistication and emotional maturity. He will be challenged intellectually in school to learn math concepts, phonics, and reading comprehension skills. His parents will need to help a child like Jacob grapple with the increasing demands of getting older. The demons of anxiety, anger, obsessiveness, rigidity, withdrawal and even depression will threaten to derail development. But with skilled help and a supportive family, a child like Jacob Grant will have the potential to make it in this world.

What does it mean to ‘make it’ in this world, to be successful? Parents, of course, want their children to go to college, get married, get a good paying job, and be happy. Many of my patients will ‘make it’ on these terms. But some won’t. So I offer a redefinition of success for the majority of children with an autism spectrum disorder. My wish for them is to be warmly connected with others, to continue to grow and be curious and creative, to cope well with inevitable stresses, and to have a life that is meaningful, built around what they love and what they are good at. This is what it means to be happy. This is the true potential within.

Appendices

A. Jacob Grant’s Initial Evaluation by Dr. Solomon
B. Evidence for PLAY: References, Link to Article, and Abstract
C. List of articles on Developmental, Relationship-based, Interventions
D. Functional Developmental Level Summaries
E. Functional Developmental Level Details
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Appendix A
Jacob Grant's Initial Evaluation

May 4, 2012

GRANT, JACOB
DOB: 10.5.09

Dear Doctors:

I had the pleasure of consulting on your patient, Jacob Grant, a now 2-1/2-year-old boy whose parents have brought him to the Ann Arbor Center for Developmental and Behavioral Pediatrics for evaluation of possible autism spectrum disorder.

Currently, Jacob has been enrolled in an Early Intervention (EI) program through the county’s Intermediate School District (ISD) where he is getting special education services under his IFSP (Individual Family Service Plan) that include once a week home based services from a developmental specialist, along with some speech and language therapy as part of the home visiting program. Jacob participates in a playgroup once a week, also provided by the ISD EI program. The family has obtained private speech and language therapy for half an hour once a week.

To Jacob’s parents main concerns have to do with delays in language, problems with social engagability, dominating interests, as well as some sensory issues.

In terms of his language, Jacob has only a small handful of words which is uses inconsistently. His parents must prompt him to use his words. He had what sounds like a mild regression at around a year to 15 months of age when he had more single words and then seemed to lose them. More recently, he has begun to add a few words to his repertoire including ‘cookie, car, choo-choo, etc.’, and he has begun to sign for ‘more’ when he wants something to eat or desires more of whatever he wants. He is not consistently turning to his name, though this has improved recently. In fact, his parents worried about his hearing and had his hearing tested, which was within normal limits (see Past Medical History below). In terms of routines, he appears to understand when it is time to eat if preparation are being made in the kitchen. He will go to the bathroom upstairs when the water is running for bath time, but he does not seem to understand routines by name alone. He is definitely not following one-step spontaneous commands to ‘give or get’ things. When reading books Jacob does not appear to be interested as much in the book as in flipping the pages. He cannot point to pictures on command nor answer the simple WH-questions like ‘what, who, or where’. Jacob seems to know his colors and has a special fascination with letters. He is learning the ABC song and enjoys putting letters in a row in what appears to be alphabetical order. Today I administered the REEL-3, a parent-report measure, of Jacob’s receptive and expressive language capacities upon which Jacob achieved an age equivalent of 14 months for both receptive and expressive language.

In terms of his social interaction, Jacob is very happy to be on his own doing his own thing. When his parents attempt to engage him, he often moves away. As mentioned he turns to his
name only inconsistently especially when he is absorbed in his interests. He can entertain himself for long periods of time and is described as “very independent.” His parents note no ‘triangular pointing’ where Jacob shares his interests with his parents by pointing and looking at them. With other children, for example in his recent playgroup, the parents note that Jacob tends to be a ‘parallel player’ at best and often ignores other children’s overtures. It bothers the parents that often times when Mr. Grant comes home from work Jacob does not notice that he has arrived until his father approaches him and begins to play with him; then Jacob seems to enjoy the fact that his father is home. He appears to have a strong attachment to his mother as Jacob will ‘cuddle’ with her and will go to her when he is frightened, but more often is happy to play on his own with his trains and cars. Jacob loves to roughhouse especially with his dad and enjoys games of chase (‘I’m gonna get you’) and some musical games like ‘Ring Around the Rosie’. With his mom he likes water play (‘bubbles in the sink’), stacking blocks/Legos, and putting simple puzzle pieces (like animals or car puzzles) in the right place. He will sometimes allow his parents to join his car play.

Jacob has very strong interests in anything with wheels, especially cars and trains, and especially Thomas the Tank Engine trains. He also enjoys spinning the wheels by turning the cars over. He has a history of being fascinated with doors and drawers, and anything with hinges. He seems to have a special interest in the way things work. He would turn the light switches on and off repeatedly if his parents let him. Recently, Jacob has begun to line up his cars and trains in a row, and seems to know the order. When his parents change the order, Jacob will get upset and put them back into exactly the same place as he had them before. Jacob ‘loves’ TV, iPad, the computer, and his mother’s iPhone. He gets so absorbed in these that his parents have had to limit them almost completely. Interestingly he is quite skilled at navigating through the iPad to find his favorite You Tube videos of alphabet songs, showing an ‘amazing memory and that he seems really smart’. His favorite TV show is Super Y, which is a cartoon about letters. Recently he had become interested in letters, numbers, and puzzles. He has not yet gotten the idea of color.

Jacob has significant sensory issues. Loud noises bother him as do loud noisy, chaotic environments like malls and big box stores (though he loves going to Lowes). He is fascinated with water and flushing the toilets, though he dislikes the loud noises of public toilets that are automatic flushes. He seeks deep pressure and loves to cuddle. He loves to run, climb, jump and spin, and he throws himself onto the couch. There is some toe walking though this is improving and some hand flapping especially when he sees something exciting on TV or other screens.

PAST MEDICAL HISTORY: Past medical history reveals that Jacob has been healthy without any major recent illnesses, injuries, hospitalizations or surgeries. He has had a couple of ear infections and his parents worried about his hearing. A full ENT evaluation was negative including hearing evaluation. His mother’s pregnancy with him was essentially unremarkable, though his mother had to take Zofran for frequent vomiting. She stopped taking anti-anxiety medication before she became pregnant with Jacob. There is no history of fertility problems. This was her first pregnancy. The birth went well without significant complications. Jacob was born at 42 weeks, weighed 6 pounds 9 ounces and had good Apgar scores of 7 and 9. Jacob went home with his mother from the hospital. He did have some mild jaundice, which resolved without intervention.
**REVIEW OF SYSTEMS:** Review of systems reveals that Jacob has difficulty falling asleep and some frequent night waking. His eating has grown progressively more limited over time, and he seems to be quite resistant to trying new foods. He has no problems with urination or defecation per se in terms of constipation or diarrhea, but he is not showing any interest at all in toilet training. There appear to be no problems with hearing or vision.

**MEDICATIONS:** None.

**ALLERGIES:** No known drug allergies.

**IMMUNIZATIONS:** Immunizations are up-to-date without adverse reactions though the parents noted the regression in Jacob's language following the MMR at one year of age. They are worried that immunizations may have caused Jacob's delays.

**ALTERNATIVE THERAPIES:** The patient is on no special diet or alternative therapies though the parents are considering a gluten-free, casein free diet.

**FAMILY HISTORY:** Family history is significant for obsessive-compulsive disorder on the mother's side of the family. The mother acknowledges some OCD tendencies. She was shy and socially awkward as a young girl. There is a cousin on the father's side of the family with autism spectrum disorder. The maternal grandfather was 'a drinker' and the maternal grandmother suffered from depression. The father's sister was 'moody' but not diagnosed with a mood disorder. The rest of the family history is negative for serious neurologic, psychiatric, developmental or genetic disorders.

**SOCIAL HISTORY:** Social history reveals a stable nuclear family with good social support. Mr. Grant works as an independent information technology (IT) consultant and has various contracts with large firms that need his services. He describes himself as detail oriented and perfectionistic. The family recently bought a home and are financially strapped but stable. The mother is a stay-at-home mom with a background in education. She admits to having some 'OCD' type tendencies. The mother is 5 months pregnant with their second child and due in October. Jacob is described temperamentally as 'intense'. He is quick to get upset and tends to remain upset for a while until he gets over it. On the other hand he seems happy most of the time to do what he likes as long as he is not bothered too much. There are no major stressors on the family system outside of the current pregnancy and the concerns that the family has for Jacob's development.

**OBSERVATIONS IN THE OFFICE SETTING:** Height: 34 inches (50-75th percentile), Weight: 28 pounds (25th percentile), Head Circumference: 52 cm (90th percentile). Observations in the office setting revealed Jacob to be an alert, well-developed, well-nourished appearing young boy who was in no apparent distress and has no dysmorphic features though he does have a large appearing head confirmed by head circumference measurement. Physical exam was completely within normal. Skin was clear without hyper or hypo pigmented areas or birthmarks. Hands, feet, face and genitalia were unremarkable.

Further observations revealed Jacob to be quite independent and self-absorbed throughout the two hours of the visit. I did not really hear any words. He showed brief ability to be engaged and was able to sustain a few back and forth reciprocal exchanges. However, he quickly returned to playing with the trains and cars in my office setting lining them up, putting them on the train tracks, and
pushing them along the tracks. He was fascinated by the jack-in-the-box and wanted to do that repeatedly, which showed some persistence and ability to be engaged in new activities. He went to his mother especially in the beginning for security purposes, but otherwise was not even particularly engaging with his parents.

**ASSESSMENT:** My assessment is that Jacob Grant is a 2 year, 8 month old boy with a history of delays in language, problems with social engagement, and self isolating interests that are dominating and stereotyped. He also has sensory issues (both avoidant and seeking behaviors). It is my opinion that he as a mild autism spectrum disorder with a good prognosis given some early language development, recent signs of progress, signs of good intelligence, and a highly motivated and stable family.

Today I made an audiotape that described the following plan:

1. Jacob should continue with his current Early Intervention program with the expectation that he will transition to special education pre-school in the fall with an IEP (Individualized Education Plan) through the public schools.
2. Jacob should also continue with Speech and Language therapy once per week though I do recommend that the parents attend the sessions, videotape selected activities, and use the SLP methods at home to promote speech and language acquisition at home.
3. I summarized the science of early intervention for autism spectrum disorders (National Research Council Report by Lord, et al, 2001) that emphasizes the importance of 'intensity' i.e., 20-25 hours per week (2-3 hours/day) of one-on-one, engaging intervention (to start) that has a strategic direction to address the comprehensive needs of children with ASD (namely, social/interactive, language, educational, and sensory/motor needs.)
4. The two most evidence-based intervention types are the behavioral and/or developmental types or some combination of the two. The most readily available behavioral type of ASD intervention is called ABA (Applied Behavioral Analysis) or VB (Verbal Behavioral) that uses a 'drills for skills' approach with rewards for success and has been shown to be very effective in teaching especially academic and discrete language skills. ABA services may be covered by insurance in Michigan (see handout). The most readily available developmental type is called the PLAY Project, a parent-implemented program that teaches the parents how to engage their child in a way that fun and helps with social development. ABA and PLAY are complementary and can be used very effectively together.
5. I am also recommending Occupational Therapy 1x/week to help Jacob with his sensory and motor integration.
6. I am recommending Autism Speaks Website (www.autismspeaks.org) and the first 100 days kit which will summarize a general plan of approach for intervention.
7. I have two 'don’ts’. First, don’t let Jacob spend hours playing alone or in isolating play. Screens of any type are not good for him at this time. Limit screen time to 1-2 hours per day at most. Second, don’t seek cures for autism as described on the Internet. Dietary (e.g., gluten-free/casein free diets), vitamin (e.g., B12 shots, etc.) and alternative therapies (e.g., hyperbaric oxygen, chelation, etc.) do not work (based on my long clinical experience) and there is no scientific evidence to support these practices. Intensive behavioral and developmental interventions are best.
Specifically, I am recommending that the family begin the PLAY Project intervention as soon as possible, continue with speech and language therapy, and add occupational therapy. They should check with their insurance company to see if it covers ABA services.

I would like to see the family back within the next six months to help them address their IEP goals for the coming special education preschool program. I remain available to them by phone in the meantime and will follow them through the PLAY Project if they choose to do that intervention. I thank you very much for allowing me to consult on Jacob.

Sincerely,

[Signature]

Richard Solomon, M.D.
Medical Director
Appendix B

PLAY Project References, Article, and Abstract


This article is available online at: http://journals.lww.com/jrnldbp/Fulltext/2014/10000/PLAY_Project_Home_Consultation_Intervention.1.aspx


Abstract

Project Home Consultation Intervention Program for Young Children with Autism Spectrum Disorders: A Randomized Controlled Trial

**Objective:** Evaluate the effectiveness of the PLAY Project Home Consultation (PLAY) model, in combination with usual community services (CS), to improve parent-child interaction and autism symptomatology in young children with autism spectrum disorders (ASD) compared to CS only.

**Methods:** Children (N=128) with ASD, 2 years-8 months to 5 years-11 months, recruited from five disability (Easter Seals) agencies in four U.S. states, were randomized in two one-year cohorts. Using videotape and written feedback within a developmental framework, PLAY consultants coached caregivers monthly for 12 months to improve caregiver-child interaction. CS included speech/language and occupational therapy and public education services. Primary outcomes included change in: parent and child interactions; language and development; and autism-related diagnostic category/symptoms. Secondary outcomes included parent stress and depression; and home consultant fidelity. Data were collected pre and post intervention.

**Results:** Using intent-to-treat (ITT) analysis, large treatment effects were evident for parent and child interactional behaviors on the Maternal and Child Behavior Rating Scales. Child language and developmental quotient did not differ over time by group. PLAY children improved in diagnostic categories on the Autism Diagnostic Observation Schedule (ADOS). PLAY caregivers’ stress did not increase; depressive symptomatology decreased. Home Consultants administered the intervention with fidelity.

**Conclusions:** PLAY intervention demonstrated substantial changes in parent-child interaction without increasing parent stress or depression, although child developmental and language outcomes were not affected. ADOS findings must be interpreted cautiously as results do not align with clinical experience. PLAY offers communities a relatively inexpensive, effective intervention for children with ASD and their parents.
Appendix C
Developmental, Relationship-based Interventions

References


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Kasari, C; Gulsrud, A; Wong, C; Kwon, S; & Locke, J; (2010) Randomized controlled caregiver mediated joint engagement intervention for toddlers with autism. Journal of Autism and Developmental disorders, 40(9), 1045-1056


Appendix D
PLAY Project FDL Summaries

Functional Developmental Level I
*Shared Attention (Starts birth to 4 months)*
- Can remain calm and regulated enough to share attention with people:
  - Can sustain brief episodes of interaction
- Regulation derailed by *Comfort Zone (CZ)* activities:
  - Stimming (e.g., hand flapping), scripting, lining up, etc.
- When you see CZ, child has holes in FDL I
- Key Question: How much is the child *with us*?
- Where is the child’s attention? What is the child’s intention?
- Use ‘The Rabbit Hole Techniques’ to join the child at FDL I

Functional Developmental Level II
*Engagement (Starts 4 months to 8 months)*
- More sustained attention leads to engagement
- You call to them and they look. Circles begin!!
- Peek a boo is the classic FDL II game
- Key Question: How easy is it to engage the child?
- This is the ‘sweat’ level. The parent/professional has to do the work (i.e., sweat) to keep the child engaged
- Hard to follow lead but you can! (See Rabbit Hole Techniques)
- Watch out for visual activities
- Use ‘Comfort Zone’ techniques

Functional Developmental Level III
*Two Way Communication (Starts 8 months to 14 months)*
- Opening and closing of 6-10 circles in a row with a balance of turn taking
- Key activities: Simple cause and effect games
- Key Question: Is the child initiating (i.e., opening the first circle)?
- We want to ‘create a monster’ (i.e., child won’t leave you alone!)
- This is the ‘wait’ level. The parent/professional has to wait to see if the child will initiate (i.e., open circles)
- Beginning of understanding *routines*
- Beginning of first single words

Functional Developmental Level IV
**Complex Two-Way Communication (Starts 14 months to 20 months)**

- Problem solver! Has his/her own ideas
- Gestural communication primarily with dozens of words
- Opening and closing of 10-30 circles in a row. There is a continuous flow of interaction.
- Simple pretend: Phone to ear or Cow says ‘Moo’.
- Much more ‘with us’ continuously
- Imitation
- Follows spontaneous one step commands: Go, get, give to, bring it here . . .
- ‘Little stories’: ‘Gets’ meaningful sequences
- Parallel play with peers/sibs
- Feelings more and more organized

**Functional Developmental Level V**

*Shared Meanings (Starts 18 months to 24 months)*

- Major increase in receptive language and understanding
- One thematic pretend play with adults
- Mostly 1-2 word phrases
- What, Where, Who, Actions, Yes/No
  - Not Why, When, or Pronouns
- Continued parallel play with peers with some interaction
- Follows 1-3 step commands
- Simple greetings and manners emerging
- Sense of humor emerging
- Compliance: Starting to do what other want them to

**Functional Developmental Level VI**

*Emotional Thinking/Building Bridges between Ideas (Starts 24 months to 48 months)*

- Talking in sentences
- Asks and answers ‘Why’ questions
- Can recall the immediate past
- Builds bridges between ideas
- Identifies own and others’ feelings
- Recognizes relationship between feeling, behavior and consequences
- Two thematic play
- Carries on simple conversations
- Peer play established
- Misbehavior as a developmental accomplishment
Appendix E

Complete Descriptions of the Functional Developmental Levels

(Developed by the Astra Foundation)

FDL I: Self-Regulation and Shared Attention (Interest in the World)

The child’s ability to enter and sustain a state of shared attention with another person and stay focused, organized and calm (first learned at 0-3 months).

- Harness all available senses, as well as motor capacities, to help child stay calm and regulated in order to draw child into shared attention.
- Involve child in enjoyable interactions that involve looking (look and examine faces), hearing (focus on voices), touch (pleasurable tickles, stroking or sharing an object or toy) and movement.
- Increase the interactive circles of communication and sustain shared attention as child develops.
- Use constructive and playfully obstructive strategies with affect cues to stretch the child's capacity for shared attention.

When shared attention is not developed child's attention may be fleeting, easily distracted, preoccupied and/or lethargic and passive.

Self-Regulation and Shared Attention: Additional Information

The infant:
- Is calmed by being held, talked to, touched, looked at, and interacted with. Is starting to be able to calm himself down. Remains calm for two or more minutes at a time.
- Shows more interest in the world. Focuses on sights and sounds for three or more seconds. Holds head upright; follows objects with eyes; and responds to sounds.
- Makes eye contact.

An older child:
- Will be able to stay connected with people while playing a game that she enjoys.
- Will be able to calm himself down after getting overly excited (such as during rough housing)
- Who tends to be passive will be able to motivate herself to pay attention and join in with others and sustain interest.
- Will begin to be able to tolerate transition to a new activity, which may not have been his choice.
- Has sleeping and eating patterns that are becoming more regular.

Goals Related to FDL 1: Self-Regulating & Shared Attention

Child will sustain shared attention with a special adult in sensorimotor interactive play using the child’s preferred and pleasurable sensory and motor modalities, such as movement, looking, touching, or listening.

1. Child will regulate his sensory system in order to sustain shared attention with support.
2. Child will regulate his sensory system in order to sustain shared attention independently.
3. Child will increase shared attention by increasing interactive circles of gestural communication, resulting in a continuous flow of interactions between child and adult rather than trying to focus on a particular object or toy.
4. Child will sustain shared attention with a peer in interaction.
5. Child will sustain shared attention in a group.
6. Child will sustain shared attention independently across contexts.

### FDL II: Engagement and Relating

The ability to form relationships and attachment and to engage another person with warmth and pleasure (first learned at 2 to 7 months)

- Woo the baby into engaging you with pleasure and delight. This can be seen when baby brightens with a smile, focuses on faces, moves arms or legs to the rhythm of caregiver's voice, vocalizes in response to caregiver's cadences, turns or reaches toward care giver.
- Encourage growth of intimacy and caring – notice the gleam in the child's eye when child interacts with you along with a sense of falling in love.
- As child develops, deepen the relationship to include the full range of feelings such as assertiveness, anger or sadness. Notice that these feelings can be incorporated into the quality and stability of the child's engagement (e.g., does he/she withdraw or become aimless when under stress, does she stay connected when angry or scared?)
- Emphasize the importance of relationships constantly in order to help the child develop a sense of security, intimacy, caring and empathy for other. Relationships also provide the foundation to encourage progress in related areas where child must work really hard to develop motor planning, language acquisition, and a positive attitude toward all learning.

When relationships and engagement are weak (e.g., the absence of trusting, positive expectations), avoidance, distrust, or apathy may take their place.

### Engagement and Relating: Additional Information:

Other Examples…

**The infant:** responds to simple rhythmic movements and sounds (like boom, boom, ba-boom)

**The older child:** will stay engaged with peers and adults.

### Goals related to FDL II: Engagement and Relating

1. Child will form relationships with special adults through pleasurable and enjoyable interactions.
2. Child will sustain engagement in reciprocal social interactions with special adults that bring pleasure and joy.
3. Child will sustain engagement in reciprocal social interactions when annoyed and protesting.
4. Child will increase sustained engagement by increasing the circles of communication.
5. Child will increase sustained engagement through a wider range of emotions, such as jealousy or fear.
6. Child will sustain engagement with a peer with adult mediation.
7. Child will sustain engagement with a peer “expert player”.
8. Child will sustain engagement within group interactions.
FDL III: Two-Way Intentional Communication
Back and forth affective signaling and communication to convey intentions, interests and needs (first learned at 3-10 months).

- Follow baby's lead and challenge him to communicate with you through the exchange of gestures and emotional signals about his affects (interests, needs, or intentions) and also respond to your affective signals in a back and forth reciprocal pattern.
- Elicit communication. Use affect cues (signals) to woo and wait for child's purposeful social gestures (facial expressions, making sounds, reaching, pointing, throwing, movement, etc.) to express his desires, objections or other feelings.
- Encourage the flow of continuous communication by opening and closing circles. A circle is opened when the child evidences some interest or initiates a behavior, e.g., the child looks at a toy, and the parent or caregiver follows the child's lead by picking up the toy and showing it to the child. The child closes the circle by reaching for the toy, while acknowledging (looking at) the parent, nodding with a smile, etc.
- Encourage communication by building on child's interests, initiative, and purposeful behavior. Challenge him to do things to you, help him achieve his goal, and later build obstacles to add steps and increase the number of circles.

Two-way communication is the basis for all relationships, as well as language and learning where conversations and exchanging information are necessary.

Two-Way Intentional Communication: Additional Information
Other Examples
- Child is beginning to have his own ideas. You begin to have a sense of the child's Personality
- Child shows desires by pointing, reaching, making sounds to get something or to be picked up.
- Child purposefully creeps or crawls; comprehends and initiates different sounds; and discriminates between people.
- Child engages in back and forth interaction, gestures (Ping-pong).
- Child acts with purpose and intention (Reaches up to be picked up).
- Older children will be able to open and close circles with adults and peers even when they are feeling a variety of different strong emotions.

Goals related to FDL III: Two-Way Intentional Communication
1. Child will interact in a back-and-forth rhythm in animated exchanges using facial expressions, sounds, and other gestures.
2. Child will initiate purposeful interactions around desires (open circles) and will close circles following adult’s response to her initiative.
3. Child will increase number of purposeful interactions around desires for sensorimotor activities, to go somewhere, to obtain objects, or in response to adult strategies to expand the number of circles; for example, when the adult poses obstacles, plays “dumb,” or creates extra steps to reach desired goal.
4. Child will increase number of purposeful interactions using imitation.
5. Child will increase number of purposeful interactions using simple gestures, such as reaching, taking, pulling, or pointing.
6. Child will increase number of purposeful interactions across widening range of emotions, such as dependency, assertiveness, and jealousy.
7. Child will increase purposeful interactions in various processing areas, including visual-spatial, motor planning, perceptual motor, auditory processing, and language.
8. Child will sustain purposeful interactions with a peer with adult mediation.
9. Child will sustain purposeful interactions with a peer “expert player.”
10. Child will initiate purposeful interaction with a peer spontaneously.
11. Child will sustain purposeful interactions within group interactions.
FDL IV: Purposeful Problem-Solving Communication
The ability to use complex circles of communication by stringing together a series of gestures, actions and words into an elaborate problem solving sequence of interactions which helps child develop a sense of self (first learned at 9 to 18 months).

- Become an interactive partner with a toddler as she learns to use a continuous flow of gestures with you to pursue her interests and wishes and to meet her needs.
- Combine affect cues with action (be animated and show affect through tone of voice and facial expressions) while creating interactions. Your goal is to help your child learn to open and close multiple circles of communication. This begins by using a dialogue without words through subtle facial expressions, a gleam in the eye, and other emotional signals or gestures, to a dialogue with problem solving words.
- Work up to a continuous flow of 20 to 30+ back and forth circles of communication, e.g., child can take a parent by the hand, walk her to the door, point that she wants to go out, and perhaps vocalize a sound or word to further the caregiver’s understanding of his intentions.
- Expand the conversation by asking where child wants to go, what they need, who else will come, what they will get, what else and where else, etc. These conversations are necessary for negotiating the most important emotional needs of life, e.g., being close to others, exploring and being assertive, limiting aggression, negotiating safety, etc.
- Increase interactive range of affects and emotions when solving problems (e.g., feed hungry baby, bandage hurt knee, fix broken truck, chase away hungry wolf, etc.).
- Encourage different emotional patterns, e.g., dependency, assertiveness, pleasure, etc., organized into integrated, problem solving affective interactions. Look out for child polarizing and being dominated by one or another feeling state (organized aggression and impulsivity, organized clinging, needy or dependent behavior, organized fearful patterns).

Purposeful Problem-Solving Communication: Additional Information
Other Examples…
- Child imitates motor actions (throws ball to mom, pop beads). Can imitate pretend play (feeds the baby, but imitates only the motor action without the symbolic act of pretending to be parent).
- Child follows a few one-step directions, uses objects functionally, delayed searching (looks persistently for bottle)
- Child begins to understand others' emotions (happy, sad, fearful) by reading words/intonation (Yuck), facial expressions, gestures
- When feeling different emotions, child can remain engaged, and interactive (when the child gets upset because his brother has his toy, he stays connected and communicating, instead of becoming self-absorbed or having a tantrum.)

Goals related to FDL IV: Purposeful Problem-Solving Communication
1. Child will express communicative intent through gestures or words to get what he wants.
2. Child will sequence (motor plan) in order to execute an idea, such as a desire for a cookie, to pull a chair over to a cabinet, climb up, open cabinet, open container, get cookies and smile at mom.
3. Child will sequence (motor plan) in order to execute a desire; for example, in order to play with Dad, who is reading the paper on the couch, the child will climb up, bounce on Dad, and pull him onto the floor to play.

FDL V: Creating and Elaborating Ideas (Symbols)
The child's ability to create ideas (symbols) observed in pretend play and words (phrases and sentences) to convey some emotional intention (begins between 24 to 30 months).

- Encourage child to relate sensations, gestures and behaviors to the world of ideas that have meanings which can be shared with others in pretend play and drama. Whether the animals are fighting, the dolls are hugging, or there is a tea party, ideas (symbols) are guiding this play.
- Enter the child's ideas through his make believe world as a character in his drama using words and actions together. Let child initiate the play idea and through interaction (dramatization in roles), elaborate with expanding themes and range of emotions (closeness, assertiveness, fear, anger, jealousy, aggression, etc.) which child can explore and express safely.
- Encourage action words instead of acting out to convey intent and feelings. When feelings and impulses are elevated to the level of ideas they can be expressed through words and play instead of acting out (e.g., child doesn't have to hit his friend, but can say, “I’m mad.”).
- Engage in long conversations to communicate interests, feelings, desires and objections throughout the day.
- Promote symbolic play in order to provide the distance from real life and immediacy of needs to differentiating self from others through different roles, feelings, and actions (child pretends to be a mommy comforting the frustrated baby who broke his toy).

Elaborating Ideas: Additional Information
Other Examples
- Child gains the ability to use ideas (words) to convey feelings and intentions. (“More juice?” “No open!” “Kiss baby.”)
- The child imitates familiar pretend actions, such as hugging or feeding a doll. But now the child views herself as the doll's mommy. Increasingly the child develops symbolic play skills as a way to understand complex feelings (Dolls go to bed, hug, or fight).
- Symbolic play begins to have emotional themes, closeness, assertiveness, fear, anger, (Feeding the doll: doll tells you it doesn't like pink ice cream; Pretends to go to the park: doll is afraid of slide.)
- Child involves you in his play, i.e., he is not exclusively playing by himself.
- Child jumps, runs, scribbles, comprehends simple designs.
- Child throws ball, draws a line, reproduces simple design.

Goals related to FDL V: Elaborating Ideas
All the goals at Levels V and VI assume that the child is creating ideas while playing interactively and spontaneously with another adult, child, or group. Some children may create ideas but prefer to play alone or act out all the roles themselves. These levels are not fully reached until the child is fully interactive based on previous levels of established shared attention, engagement, and two-way communication.
1. Child will initiate the use of realistic ideas in interactive imaginative play, such as by hugging the dolls.
2. Child will initiate the use of ideas using realistic verbal interactions.
3. Child will express ideas derived from her affect or intent, such as saying “Play outside!” when she wants to go outside.
4. Child will express ideas derived from her affect by combining words and reality-based actions, such as sequence of pretending to be hurt and going to the doctor to get better.
5. Child will engage in conversations to express ideas.
6. Child will elaborate on ideas through increasing verbal and symbolic play sequences, such as getting hurt in a crash, going to the doctor, being examined, and going home.
7. Child will create imaginary (not reality-based) ideas using magical thinking/powers.
8. Child will assume different roles and act as the character in role-play.
9. Child will predict how others will feel or act in certain situations.
10. Child will respond to other's feelings appropriately.
11. Child will demonstrate confidence to resolve conflicts that come up in social situations, such as waiting, trading toys, taking turns, playing together, asserting self to retrieve his toy, joining in, or defending others.
12. Child will assume multiple roles and use figures to represent characters.
13. Child will expand ideas to include a wide range of themes and feelings.
FDL VI: Building Bridges between Ideas (Logical Thinking)

The ability to build logical bridges or make connections between different emotional ideas (emotional thinking) begins between 36-48 months.

- Challenge child to connect her ideas together by seeking her opinion, enjoying her debates, and negotiating for things she wants using logical reasons. Begins with logical conversation involving at least two give and takes: “Time for school.” “I don’t want to.” “Why?” “I feel sick now.”
- Encourage child to engage in pretend play with both peers and adults where the story or drama "makes sense", with a beginning, middle and end where elements in the drama logically fit together.
- Promote the use of pretend play, words, and/or visual symbols to elaborate a partially planned pretend drama (theme or idea is identified in advance), or engage in logical conversation dealing with causal, spatial, and/or temporal relationships between themes.
- Challenge child to create connections between differentiated feeling states, e.g., “I feel happy when you are proud of me!” Identify relationship (contingency) between feelings, thoughts and actions.
- Expand identification and differentiation of more and more subtle feeling states, e.g., lonely, sad, disappointed, annoyed, frustrated, etc.

This capacity is a foundation for higher level thinking, problem solving and such capacities as separating reality from fantasy, modulating impulses and mood, and learning how to concentrate and plan.

Building Bridges between Ideas: Additional Information

Other Examples…

1. Creates logical bridges between ideas (Can hold a simple, logical conversation involving at least two exchanges: “Time for school.” “I don’t want to.” “Why?” “I feel sick.” Or, alternatively “because there is a fierce dinosaur at school.”
2. Is able to engage in pretend play with another person where the story or drama makes sense (the bears are going to visit the grandmother and then have a big lunch).
3. Pretend play, words, and/or visual symbols convey two or more logically connected, emotional ideas (“Hit bad guy because he did bad thing.” “Hug nice dolly.”)
4. Interactive pretend play with both peers and adults where there are a number of elements or elements in the drama that logically fit together. (Whereas in FDL V a child might dress up a doll, then seeing a crayon, scribble, then, seeing a drum, pretend to be a drummer, a child at FDL VI connects the pieces. (She might have the drummer play for the dressed-up little girl and use the crayon to make invitations for the performance. Or, the doll might have a tea party, call friends to invite them, prepare refreshments, set the table, and determine the seating pattern.)
5. Child skips, hops, copies cross, can recall four or more numbers or words, asks and answers “why” questions, classifies and quantifies objects, recalls recent past.
6. Child takes turns with a toy, copies circle, uses full sentences and answers “what, where, who and doing?” type questions, has a sense of quantity (big/little) emerging.

Goals related to Stage VI: Building Bridges between Ideas

1. Child will close all symbolic circles in both pretend play and reality-based dialogues.
2. Child will respond to ‘wh-questions’, including who, what, where, when, and why.
3. Child will debate, negotiate, and make choices when deciding what to play, what to do, where to go, and who goes first.
4. Child will connect ideas in logical ways that make sense (not fragment, change topic, or become tangential).
5. Child will integrate concepts of time in ideas.
6. Child will integrate concepts of space in ideas.
7. Child will integrate concepts of quantity in ideas and problem solving.
8. Child will explain reasons for feelings and actions.
9. Child will compare and contrast ideas, preferences, and other people’s views.
10. Child will give opinions, selecting appropriate dimensions for views.
11. Child will create dramas with a beginning, middle, and end.
12. Child will identify motives of other people or characters’ actions and understand different points of view and feelings.
13. Child will predict feelings and actions of other characters.
14. Child will recognize complex intents, such as deception, sarcasm, and conflict.
15. Child will reflect on feelings in both pretend dramas and conversations taking place in reality.
16. Child will expand play to full range of emotional themes, including conflict, aggression, and morality.
17. Child will reach higher levels of abstraction and will be able to see details as well as the big picture (trees and the forest).
18. Child will recognize strengths and weaknesses in self and others.
## Appendix F
### PLAY Project Techniques

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PLAY Techniques with Examples
For Functional Developmental Levels I-IV
Shared Attention/Engagement & Two-Way Communication

1. ‘Being with’
   - Sit near the child as he plays in his comfort zone
   - Keep engagement going. Follow cues gently
   - Make comments/describe what the child is doing: “You are jumping high!”
   - Repeat words/sound if they say anything
   - Gently open or close one or two circles: offer a toy
   - Give the child what he wants. Use natural motivations.
     - Turning on and off the water together
     - Hand him Lego’s, train, cars, books to line up
   - Do not command, direct, teach

2. Sensory-motor play
   - (Touch) Rubbing the back, tickling, wrestling, rough housing
   - (Vision) Watching/blowing bubbles
   - (Sounds) Humming, drumming
   - (Rhythm) Clapping on the back with rhythm
   - (Movement) Wind-up toys
   - (Kinesthetic) Shaking the arms in rhythm
   - Putting the child on a spinning chair saying “go” and stopping her while saying “stop”
   - Jumping on the bed

3. Theme & Variation
   - Open and close door.
   - Open and close door with a song
   - Put your hand in the door and close it (gently) and say ‘ouch’
   - Hold the door closed until child complains
   - Play peek-a-boo on the other side of the door.
   - Use a puppet to play peek-a-boo
   - Have the puppets head get caught in door and cry
   - Bonk you head into the door & fall down dead
   - Build anticipation with each variation
4. **Taffy Pulling**—stretch the interaction. Open and close 2 or 3 circles instead of one. Keep interaction going.
- Play dumb for a couple of circles. Ask the child what they would like to do?
- Give the train and ask for it back.
- Then try to take it back and let them resist you.
- Say “mine” i.e., gently tease the child.
- Give the train but fly it around their head first.
- After they have the train spin each wheel
- Make a different funny sound for each wheel

5. **Salient Language**
- Label each activity like “SPIN” for a spinning game, “DOOR” for a door game, etc.
- Then consistently use the word: “Would you like to play “SPIN”? Or “Let’s open and close the DOOR!”
- Say the word/words loudly and clearly.
- Use salient words across different settings/care takers
- Use sequences of language like 1-2-3, Ready-Set-Go
- Wait to see if child will finish the sequence: 1-2-...
- Repeat key words: Do you want MORE?
- Use opposites: OFF/ON, UP/DOWN, OPEN/CLOSE

6. **Rhythm & Music**
- Use rhythm in your speech patterns frequently
- Sing Children’s Songs like Ring-Around-the-Rosy & Row, Row, Row Your Boat, etc.
- ‘Capture’ child in your lap and move their arms up and down while counting 1-2-3.
- Pound gently on their backs and sing old MacDonald with each pounding motion.

7. **Sense of Humor, Suspense, Surprise**
- Find ways to make them laugh
- Have them push your nose and make a sound
- Fly them on your feet
- Pretend you’re asleep. Wake up suddenly when the child comes near.
- Play chase/I’m going to get you
- Capture them in your prison and let them get away
- Try slapstick (Bumping your head, falling down)
- Use mock anger (“Hey you give me that back. You took my toy.”)
8. One and Two Step Commands
   - Ask them to give you something (and then . . .)
   - Ask them to put it someplace else
   - Ask them to get their shoes and ask for different feet. (“No not that foot, the other foot!”)
   - Have them make choices (“Do you want this car or this car.”)
   - Have them get the ball and give it to daddy.

9. Playful obstruction
   - Get in their way so they have to move you
   - Play dumb when they want something and make them open another circle.
   - Close the door when they want it open
   - Move the trains out of line ‘by accident’

10. Making them work
    - When you think they can do something expect them (using your voice, facial gestures and pregnant pauses) to do it
    - Play dumb and make them show you or tell you what they want
    - Expect them to use their words (“Do you want more? Tell me you want MORE.”) (Use salient language.)

11. Rewarding/Reinforcing
    - Applaud their accomplishments (if they like applause).
    - When they initiate a response (open a circle), reward them with a rub or tickle or rough housing
    - Give immediate rewards for accomplishments (like sensory motor play when they use their words.)

12. Making Random Behaviors Purposeful
    - When they open and close doors get on the other side and say “Hello” when they open the door and goodbye when they close it.
    - When they build blocks call it a “tower”
    - When they pour water turn it into a “pouring game” by offering them different containers.
    - When they line up trains make a “choo-choo” sound
13. **Expectant waiting**
- Waiting is a primary technique but it must be *expectant* waiting i.e., waiting for a return response.
- This helps children initiate (which is the essence of Greenspan Functional Level III).
- The key here is to make an overture and then see what the child wants to do.
- Waiting allows you to observe the child more accurately and increase circles of interaction.

14. **Going for Fun**
- Ask yourself: “What would the child love to do with me?”
- Then wait for an answer. This is an intuitive way to play.
- You can use this technique both in the moment as you play but also as a way of generating activities.
- Then list the activities and try them out. You’ll probably be right!

15. **Big, Little & Micro Circles**
- This is a variation on ‘Taffy Pulling’
- A **big circle** happens when you say, “I’m gonna get you” and the child runs . . .
- **Little circles** happen when you chase and capture the child in your arms and say: You want a tickle? And child indicates: Yes, by looking or saying ‘more’ or ‘yes’. . . .
- **Micro circles** happen when you raise your hand to tickle and say slowly (as your hand starts coming down) so that the child connects with each word: I’m….gonna….tickle…you….Here….it….comes….now (then tickle with a sudden final movement). (See also ‘Suspense/surprise’)

16. **Add a word**
- This helps children expand their language.
- When the child gives you one word, you give them two back. If they give you two, give three, etc.
- You have to imagine what the child *would* say if he or she could talk in longer sentences.
- For example, when the child says: “Up!” You might say: “Up, momma.” or “Go up.”
- Eventually you will add several words: “Momma, go up please. More cookie.”

17. **Asked and Answered**
- This helps children expand their language and is a form of *Salient Language*. 
• You say the word in the form of a question and then say the word in the form of an answer.
  For example, if the child wants a cookie, you would say: “Oh, you want a cookie?” Then as you are handing the cookie over you say: “A cookie” (You should stretch out/emphasize the sound of the ‘answer’ word.)

18. Sequences/Little Stories
- Create little sequences that have 1, 2, or 3 steps.
- A good example would be “door play”.
  - First, open the door and play simple peek-a-boo.
  - Then knock on the door and wait. Then pop your head in and say ‘peek-a-boo’.
  - Then say “Where’s ____ (child’s name)?”, then knock on the door, wait, and then play peek-a-boo. Use rhythm to keep the child’s interest.
- I call these ‘little stories’. The idea is to help the child understand cause and effect (more than just pushing a button and making a noise).
- Use with skills of daily living (e.g., getting shoes on, going out, taking a bath, eating) as well as playing.

19. Problem Solving (PS)
- This is fundamental technique begins at FDL IV.
- The child wants something. You play dumb. They have to take your hand to the cupboard and point to what they want. That’s problem solving. (See “Playful obstruction”)
- You say, “Time to go bye-bye.” They get up, get their shoes and bring them to you. That’s PS.
- You ask: What do we do next? They hook their train to yours. That’s a higher level of PS.
- Problem solving never ends!! Greenspan says: “Throw them curveballs, mix it up, make ‘em work.”

20. Onomatopoeia
- Onomatopoeia means that the word sounds like what it means. The word ‘buzz’ sounds like a bee. ‘Boink’ sounds like hitting something.
- Onomatopoeia is often used by parents to imitate what the child is doing like going ‘zoom’ when the child is racing a car.
• Use it to emphasize an activity. Make your voice go up when you life the child up as you say ‘U-u-u-p’.

21. **“Rabbit Hole” Techniques**

The Rabbit Hole is our metaphor for the self isolation of CZ activities. ‘Joining’ a child in their CZ allows for engagement (FDL II), and as engagement increases, the perseverative and repetitive behaviors naturally decrease. This is the goal of the “Rabbit Hole” Techniques!

- **Being With**: Simply be with (i.e., quietly observe) and wait for the child to re-engage.

- **Narrate**: Label and provide a running commentary. Focus on paying attention to what the child is doing. This means to watch and describe **out loud** what it is that he/she is doing. You may sound just like a sportscaster – that’s good! As an example, let’s say he is coloring. You might follow what he’s doing by saying, “... and now you’re coloring the hat red.” **Don’t tell the child what to do.** You should just describe their actions. Also, stop paying attention if he/she starts demonstrating naughty/unwanted behaviors. If for instance, he/she starts whining, **don’t** say, “... and now you’re whining.” In cases like this, ignore the bad behavior.

- **Help him do it better**: For example, if the child is lining up cars you would begin to hand him or her additional cars to add to the line of cars or show the child new ways of using the cars.

- **Imitate/Parallel Play**: Do something similar to what the child is doing (and see if he/she will imitate you). If the child is lining up his or her toy cars, you can begin to line up a set of cars next to them but add a slight variation (e.g., line them up facing in the opposite direction).

- **Theme and Variation**: Do something different with the same activity, e.g., open and close a door. Sing a song while you open and close the door, hold the door closed until the child complains.

- **Change the Sensory Mode**: If the child is “in his or own world,” you can try to engage their attention with a really fun activity (e.g., bubbles or offer other sensory activities). *Keep in mind the child’s primary/preferred sensory modality (i.e., visual, tactile, auditory, etc.)*
PLAY Techniques with Examples
for Functional Developmental Levels IV-VI
Complex 2-way, Shared Meanings & Emotional Thinking

1. Simple pretend play
   - Give dolls and cars feelings or personalities (“I’m a car and I want to go fast up and
     down your arm.”)
   - Use slapstick with the dolls (Have them fall/say ouch)
   - As the child begins to be able to open simple circles (FDL III) challenge him to do
     one more circle. (“Your turn” or “What does your car want to do?”)
   - Build simple repetitive sequences if the child can follow. (“Hi. I’m a car. I want to say
     hello to the animals. Hi cow. Hi Horse. Etc.”)
   - Use books to look at pictures and have child show you the animals, etc.

2. More complex pretend play
   - Note the difference between ‘pretend’ and ‘real’
   - Add more circles to increase complexity.
   - Make themes become more complex.
   - Play “Army”. Work with aggression/helping out
   - Play doll “Hide & Seek” or ‘Chase’ - pretend fear).
   - Play “Halloween” Get candy from play animals.
   - Play “Tea Party” Work with hunger/wanting more
   - Play night-night (bedtime rituals) with a doll

3. Multiple Circles of Communication
   - You can increase circles easily if you think of doing so
   - At first child may only close circles (i.e., respond to you). Get them to do one more
     thing.
   - Use natural motivations like getting ready for a bath. Make them do every single thing
     to take a bath. Turn on the light to the bathroom. Turn on the water, etc.
   - Have them make choices about which toys they want.
   - Challenge yourself to create five more circles. Write them down.

4. Feelings, Empathy
   - Identify feelings early on (“You’re mad about that!” or “Boy, that was FUN!”
   - ID your feelings. Use clear facial expressions
• Draw feeling faces
• Incorporate feelings into simple and complex pretend play (see above) or when reading stories
• Pretend to be “sad” or “mad” or “happy” or “scared” when playing with dolls

5. Outings
• Outings are a three step process that involves:
  o A. Reading about going somewhere (e.g., the Zoo, the Farm, to a construction site, etc.)
  o B. Going on the outing and
  o C. Talking about it afterwards.
• Outings help the child learn about time, events, language, the difference between real and pretend.

6. Using motivation
• Using natural motivations increases the numbers of circles of interaction with the child
• Natural motivators are: Leaving, Going outside, Getting dressed to go, Going for a bath, Going Swimming, Bedtime, Meals, Going for a ride. Anything sequence the child wants to do.
• Get child to open/close as many circles as possible as they go through the highly motivating activity.

7. Appropriate/Real Language
• Make requests using a natural tone of voice instead of ‘baby talk’ or shortened sentences.
• Instead of saying “Want more?” say “What do you want?”
• This is a way to generalize ‘salient language’ and increase the quality of interactions.
• Appropriate language avoids ‘prompts’

8. Essays
• More verbal children and can string sentences together. Expect them to use simple essays.
• When you are reading a book don’t just ask ‘yes and no’ type questions.
• Ask “What is going on this page?” “Tell me 3 things you see going on.”
• Eventually expect the child to tell you about their day or a recent experience (see ‘Outings’ below)
9. Answering ‘Wh-Questions’

- “What” comes first. As in “What is this animal?”
- “Where” is a close second. “Where are your shoes?”
- Then comes open-ended “what” questions. “What are you doing?” “What do you think?”
- “When” comes next. Set up sequences of activities. (See OUTINGS below) It helps to have sequences of pictures or schedules. First we do this. Then we do that.
- “Why” is a FDL V-VI skill - children begin to understand why in FDL V, but will not ask “why” questions until FDL VI. Begin by explaining simple cause and effect relationships (e.g., The doggy is sad BECAUSE he bumped his head.)
- These may seem like ‘teaching’ but can be incorporated into PLAY activities when the child is ready.

10. Time Concepts

- Children at Level V can understand simple time concepts. “Wait. OK now it’s your turn.” Gives rudimentary sense of time.
- –Work with calendars, schedules, clocks, seasons in the context of everyday life.
- Use the words “Yesterday, today, tomorrow, later, etc.” connected to real life events (“Later we are going to go to McDonald’s”)
- Stories are a great introduction to time because “What happens next? Oh, then he did X, Y, Z.”

11. Practicing Pronouns

- Pronouns are hard for children with autism
- Start with receptive language: ‘Give it to me/her/him.’ Or ‘You take it.’
- Using pronouns clearly & repeatedly in pretend play and in daily life can be helpful.
- Puppet play with pronoun concepts can be helpful.

12. Model, Rehearse, Expect (for advanced workshop)

This is the process of demonstrating complex social skills that are almost on the verge of being learned (i.e., just outside the child’s zone of proximal development).

- Model dramatic situation with toy characters
- Rehearse with people playing out the situation
- Expect means expecting the child to do the skill in question in a real life situation
- Example: Learning ‘Hi and Goodbye’. The doll would use the greetings, the parents would use it and then the child would be expected to use it.

13. Theory of Mind: Puppet Play (for advanced workshop)
• Puppet play can teach children at Level V that people are thinking about things.
• Puppets can be the ‘thinking’ part of the brain
• The puppet can say, “I sure would like some ice cream” and the person playing can look like they are thinking and then say, “I sure would like some ice cream.”

14. Social Stories (for advanced workshop)
• Based on the work of Carol Gray
• Social stories address children’s fears, needs, desires, behaviors, feelings
• Stories are simple and descriptive
• Can help children learn to cope more quickly with difficulties (e.g., fears) than other methods
• See the PLAY Project Blog for an example.

15. Meta-cognitive strategies (for advanced workshop)
• MCSs can help the child avoid stresses by talking about the stressful situation before it becomes problems.
• For instance: “It’s too noisy in here. I want to get out.” is a meta-cognitive strategy.
• Use the “Model, Rehearse, Expect” technique to help children learn MCS.

16. Everything comes alive
• This teaches children imagination skills
• Make any object act like a puppet
• Use a high silly voice or a deep silly voice
• Salt shakers can say “Here I come. Shake me. I make snow!”
• Make a (half a) glass of milk waddle along the table like a person and say: “Hi. Would you drink me?” or “No, no, no! Don’t drink me!”
• Any object can ‘come alive’

17. Mirroring/Reflecting: Feelings
• This important technique helps children understand their own feelings and put words to their feelings.
• First, be alert to all the feelings the child exhibits through his/her gestures.
• Then label the feeling with words and gestures that express the feelings for the child. Match the intensity with your voice.
• This is called ‘mirroring’ the child’s feelings because you act like a mirror only reflecting back what you see.
• A mirror would not ask questions (i.e., ‘Are you mad?’) Instead use statements. ‘You’re mad!’
• Imagine what the child would say if he or she could tell you how he/she feels.
• For example: The child is very angry that his brother took his toy. You say: “That’s my toy! Leave my toy alone!!!!”
• Other examples: “Weeee, that was fun!” or “You didn’t like that!” or “Stop it, Mommy, please!”
• It may seem that we are encouraging children to be disrespectful but we are not. . .
• . . .It’s very important that the child be allowed to ‘talk back’ appropriately even if angrily. (see the technique ‘Negotiating Relationships’)

18. Three-way modeling
• Once the child is tuned in to the world and imitating fairly well, try three-way modeling.
• Have dad and mom ‘model’ for the child.
• Let’s say we want the child to answer ‘wh-questions’.
  o For example, at the dinner table mom could say: ‘Daddy what are you eating?’
    Dad: “I’m eating peas.” Then Dad says: “Mommy, what are you eating?”
    Mom say: “I’m eating some delicious chicken.”
  o Then the parents ask the child.

19. Speaking ‘to’ and Speaking ‘for’ the Child
• These are two related techniques that help children expand their language once they are talking with meaning. Age equivalent 18 mo. to 2 years old. Greenspan Level IV-V.
• Speaking to the child is easy. It means not baby talking but using appropriate language.
• Parents whose child has evolved to Level IV often continue to use salient language. This is not good for this stage.
• Talk to the child in normal tones and rhythms and usage. Let them hear the music of the language.
• Speaking ‘for’ the child is trickier. It is related to ‘Add a word’ and ‘Three way modeling’ techniques, only more sophisticated.
• This involves modeling language for the child from the child’s perspective, i.e., what would the child say if he could say what he means. You will speak ‘for’ him.
• For example, the child says, “Up!” You say, “Pick me up, daddy.”
• Or the child says “Go out.” and you say, “Go outside, momma.” Get it?
20. Finishing up/completing a task
- Once a child is understanding most of what you say then it is time to make them finish up tasks.
- Don’t let them ignore you!
- This doesn’t sound like ‘following their lead’ but, in fact, it is because it is within their capacity (their ‘lead’ so to speak).
  - When you call their name, make sure they respond. (See “Negotiating the relationship”)
  - Make them say things the ‘right way’.

21. Negotiating the relationship
- Important for children solid at FDL V or higher.
- Be aware of the boundaries of your relationship and help the children be aware of them too.
- Don’t let them break off the relationship without at least acknowledging it. “Hey, where you going?”
  - If I walked away from you suddenly without saying anything, you would think it was weird!
- Expect the child to say, “All done” or “No more play” (or you say it for them). (See ‘Finishing up’)
- Previewing and reviewing what you going to do and what you have just done is a wonderful way to help the child understand relationships.
  - “First, let’s play trains, then we can play chase and THEN we can sword fight!”
  - “We played with trains; we chased; we played sword fight. That was fun to do together!”
- I also call this ‘huddling’ to make plans.
  - “OK. You be the good guy and I’ll be the bad guy and you can put me in jail.”
    or “How should play good guys and bad guys?”

22. Overdramatizing
- This technique is important to help children empathize. Children with ASD have poor abilities to ‘read’ others emotions.
- Overdramatize your feelings:
  - When the child will not do something, cry and whine: “Please, please, I NEED it!!”
  - Make your face show the feelings you have.
- Use big gestures or a more dramatic voice to make your point.
### Appendix G
Jacob’s PLAY Project Video Review Form

<table>
<thead>
<tr>
<th>Activity</th>
<th>Time</th>
<th>Parent feedback</th>
</tr>
</thead>
</table>
| Sleep play/Play on the floor with Dad | 0:00-2:55 | • Dad great job pretending to sleep. I think Jacob was enjoying cuddling with Dad and getting some proprioceptive input.  
• **Suggestion:** Jacob might need some modeling or a little push about what to do next. That’s why I said, “Jacob, are you going to wake up dad?” Jacob responded quickly and continued the game. We want to encourage him to wake dad up.  
• Dad you then continued the play by giving Jacob some good proprioceptive input. You rolled back and forth on him and Jacob loved it. This was great!  
• **Remember to take your time doing this.** Keep the pace slow so that Jacob has time to respond and request for more.  
• At around 1:50 you stopped and Jacob gave some eye contact and he pulled you to continue rolling. This was perfect!!! You were aware of circles and kept the flow going! **Always think circles!!**  
• Jacob kept asking “Roll on you?” I liked the way you mirrored back his intent, “Oh, you want to roll on dad.”  
• He’s having problems with pronouns so you can model “Roll on ME, dad.”  
• You can also model statements for him so that he is making statements rather than questions. We want to stop Jacob always ‘talking in questions’. |
| Play with mom                | 2:55-7:50 | • I love the way he’s talking in short phrases.  
• **Let’s expand on his language.** Add a word to his phrase or summarize his ideas in 2-II word phrases. Try to avoid asking him too many questions. So when he says ‘Bean bag.’ You can say “More bean bag.” |

**Child's Name:** Jacob  
**Child's Age:** 4 ½ (DOB 10.5.2009)  
**Visit Date:** April 2, 2015  
**Visit #:** 10  
**PLAY Consultant:** Amber M.  
**Next Appointment Date:** May 8
<table>
<thead>
<tr>
<th>Activity</th>
<th>Time</th>
<th>Notes</th>
</tr>
</thead>
</table>
| Hide and seek with mom and dad | 8:20-9:10 | 9:00. Mom, great job pretending not to find him.  
Hide and seek is a game that can go all the way to FDL VI. Kids at FDL IV don’t ‘get’ some aspects of the game (like being quiet or waiting until you’re found.)  
So Jacob came out of hiding too soon (before you found him). I really liked that you just ‘followed his lead’ and got lots of hugs and kisses.  
Continue to work on your pacing and making sure you are going for circles!  
This is a good way to expand this sort of play. You can have him hide, pretend not to see him, then have him find you. This brings in Levels I-V  
Jacob is very responsive to others when play is at his level. He responds very well to cause and effect as well as sensory motor activation. |

• At 4:12 Jacob has some great (and persistent!) ideas. He wanted both of you to sit near him and play the game. He is opening so many circles.  
• I summarized what he wanted. “You want Daddy and Mama to come sit near you.”  
• He is a seeking so much deep pressure and you are giving it to him. Great!  
• Mom, nice narrating what was going on and following Jacob.  
• At 5:45 you started a ‘Don’t wake me up.’ game and he ‘got it’ right away. Go Jacob! He’s really getting more solid in FDL IV and even FDL V.  
• You even recognized when you went a little too high trying to expand the conversation. Great job really focusing on being aware of his intent here: ‘Everyone falls asleep.’ This takes practice!  
• Don’t be afraid to act mad (Don’t you wake us up!!) and add some feeling (one theme pretend technique) to the game.  
• Mom, I also notice that you are trying to slow down your pace. You are really sound sleepers and waited until Jacob woke you up. Great job. Once again this takes practice, but there is a noticeable difference in this visit.  
• I loved the turn taking and his idea to include dad in putting the bean bag on daddy’s head. |
### PLAY Plan

#### Main Points
- This was a great visit. Jacob is making excellent progress and was so engaged!
- Jacob is very responsive to others when play is at his level. Continue to **label his intentions and ideas**. We are seeing lots of circles during this video. You will also notice how long he stays engaged with you. Jacob is much more regulated. He is not as fragmented as our first couple of visits. He is also saying with one activity for longer. This shows strength in his Levels I through IV.
- We want to avoid asking him too many questions because that is too high for him right now. We can expand the activity and conversation with him by summarizing his statements, and following his lead.
- Keep up the good work! Jacob has some great potential. We are already seeing some great progress and expect him to continue to climb up the developmental ladder.

#### Comfort Zone (CZ)
**Definition of Comfort Zone**: When Jacob “tunes you out” and appears to be in his “own world” this is when he is going into his Comfort Zone. When he is in his Comfort Zone he is dysregulated and not engaged in the interaction.

Jacob had some brief moments of Comfort Zone activities. His main Comfort Zone today was lining up letters on the refrigerator. Mom, you did a great job joining him. Continue to use Rabbit Hole techniques when he gets stuck in Comfort Zone. We’re seeing less and less CZ activity over time.

#### Sensory Motor Profile (SMP)
**Sensory Motor Profile (SMP)** The Sensory Motor Profile (SMP) refers to the unique way that a child experiences the world through the 7 primary senses and through movement.

Regulatory Profile: It was amazing how well regulated Jacob was. He was able to stay calm and attentive and organized in his play.
**PLAY Plan**

throughout much of today's visit even though it was exciting. Deep pressure and vestibular activities give him needed input to keep him regulated.

1. Visual—still a source of absorption for Jacob as he loves TV, iPad. Good job of limiting this today.
2. Auditory—He loves singing but doesn't like sudden loud noises.
   Song games would be great for him.
3. Tactile – He was crashing into the bean bags and enjoyed being rolled over and loved cuddling with dad.
4. Proprioceptive – Jacob really enjoys proprioceptive input like playing tug of war with the bean bags. He might like you and dad having a tug of war with Jacob “He's mine” “No, He's mine”
5. Vestibular—He loves rolling and moving in space.
6. Olfactory—No issues here.
7. Gustatory—No problems here.
8. Oral/Motor—Still a little picky as an eater because of texture issues.
9. Motor Planning—Jacob still has trouble with fine and gross motor modulation. Don’t be afraid to challenge him here and make him more precise and graded (softer/harder, slower/faster) in his actions.

**Functional Developmental Level (FDL)**

<table>
<thead>
<tr>
<th>Level</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level I: Regulation and attention</td>
<td>75%</td>
</tr>
<tr>
<td>Level II: Engaging in relationships</td>
<td>100%</td>
</tr>
<tr>
<td>Level III: Intentionality &amp; Two-Way Communication</td>
<td>75-100%</td>
</tr>
<tr>
<td>Level IV: Social Problem Solving, Complex interaction</td>
<td>50-75%</td>
</tr>
<tr>
<td>Level V: Uses ideas, words and symbols</td>
<td>25%</td>
</tr>
<tr>
<td>Level VI: Emotional Thinking &amp; Logic</td>
<td>Not yet</td>
</tr>
</tbody>
</table>

**Here is a quick glance at the levels**

**Level I-Shared attention and self-regulation- 75%**
Jacob is displaying a lot of growth at this level. Although he still fragments, he sustained interaction for a long time at this visit. He was also much more regulated at this level. Great job giving him lots of sensory input.

**Level II- Engagement and relating- 100%**
Jacob is very engagable. We are seeing longer and longer spans of sustained attention. He turns to his name every time (unless he doesn't want to!)

**Level III- Two way intentional communication- 75-100%**
Strength at this level. With lots of initiation and long back and forth
## PLAY Plan

<table>
<thead>
<tr>
<th>Level IV</th>
<th>Purposeful problem solving communication 75%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>This is where Jacob is at right now and getting very solid here 😊 He is having longer interaction with others. He shows some good problem solving capabilities. He is very determined and expressive about what he wants. We want to continue to work on expanding this level by adding more circles. We want him to have more complex play.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level V</th>
<th>Creating and Elaborating Ideas (symbols) 25%</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>He is showing some early FDL V. He's showing that he understands more and more of what you are saying and the early 'wh-type questions' (like 'where' is your nose?) is just beginning. He might like some silly or dramatic puppet play.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Level VI</th>
<th>Emotional Thinking</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Jacob is not here yet</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>Here are the core Methods of PLAY:</td>
</tr>
<tr>
<td>1. Read the child's cues and intent</td>
</tr>
<tr>
<td>2. <strong>Slow the pace of play, observing and waiting for the child's idea</strong></td>
</tr>
<tr>
<td>3. Follow the child's lead, responding to what the child wants</td>
</tr>
<tr>
<td>4. Open and close circles of communication (back and forth interactions)</td>
</tr>
<tr>
<td>5. Build on the child's interests</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Techniques</th>
</tr>
</thead>
<tbody>
<tr>
<td>- ‘<strong>Speak for</strong>’ Jacob and <strong>use statements</strong> that summarize his ideas, sentences, and gestural intentions.</td>
</tr>
<tr>
<td>- <strong>Mirror</strong> feelings, behavior, and language back to Jacob.</td>
</tr>
<tr>
<td>- Use ‘<strong>theme and variation</strong>’ when play becomes repetitive. What are 10 ways to play ‘roll on me’.</td>
</tr>
<tr>
<td>- ‘<strong>Add a step</strong>’ to any activity. Make it a longer sequence.</td>
</tr>
<tr>
<td>- <strong>Playful obstruction</strong> is one way to add a step.</td>
</tr>
<tr>
<td>- <strong>Taffy Pulling</strong> - stretch out the interaction. Mom you did this when you got into the tug a war activity with him.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Activities</th>
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</thead>
<tbody>
<tr>
<td>- Do more <strong>pretend play</strong> at the one theme level. Try some puppet play or making silly sandwiches where you say ‘yuck!’</td>
</tr>
<tr>
<td>- Keep up the gross motor play - Tug a war, chase, hide and seek.</td>
</tr>
<tr>
<td>- Music games like RAR</td>
</tr>
<tr>
<td>- Hide and Seek - Continue to play this trying to really expand with pretend. When you look for Jacob, look for him in silly places where he can’t fit (in the refrigerator, under the couch…Etc.)</td>
</tr>
<tr>
<td>- “He’s mine, no He’s mine…” this is a fun tug a war game that Mom and Dad can play together to gently “fight” over Jacob. You each will pull him back and forth saying, “he’s my Jacob…”</td>
</tr>
<tr>
<td>PLAY Plan</td>
</tr>
<tr>
<td>-----------</td>
</tr>
<tr>
<td>Additional Comments</td>
</tr>
<tr>
<td>• I am so pleased with Jacob’s progress!!</td>
</tr>
<tr>
<td>• Please contact Amber with any questions. Your next visit is scheduled for: May 8th at 2pm.</td>
</tr>
</tbody>
</table>
Appendix H
Functional IEP Goals for Children with Autism
("See Appendix E & Chapter 16 for more IEP Goals")

FDL I-III: Shared Attention, Engagement, & Two Way Communication
- Increase the length of time the child stays engaged with others (parents, teachers, peers).
- Increase the number and length of times he/she responds (e.g., smiles, frowns, reaches, vocalizes, gestures intentionally, or speaks) to others.
- Increase the number of times he/she initiates social overtures to others.
- Increase the number and reciprocal exchanges within a given encounter.
- Decrease self isolation by promoting interaction and engagement.
- Participate in X number of reciprocal social interactions.
- Respond consistently to his/her name.
- Stop action in response to strong commands (No, Stop, Don’t).
- Stay calm and attentive in challenging sensory/social situations (too loud, too chaotic, too much change).
- Consistently respond to gestures with intentional gestures of child’s own (e.g., reaches out in response to outstretched arms).

FDL III-IV: Two way and Complex Two Way Communication
- Use increasing numbers of word sounds (e.g., Uh-oh) and first words to communicate.
- Increase the number of longer interactions with others.
- Respond consistently to one step spontaneous commands to ‘get’, ‘give’, ‘bring’.
- Play imitation games daily to promote imitation abilities including imitating hand movements, body movements, sounds, words, use of objects, songs, finger-plays and rhymes.
- Sustain attention on a directed activity for _______ minutes.
- Increase the number of times child express wishes, intentions and feelings through gestures.
- Problem solve frequently throughout the day. The child’s dyadic partner should avoid prompting and adult solutions.
- Increasingly understand the name for his/her feelings. Note: School personnel should recognize and verbally label important feelings of the child.
- Consistently look for others when asked “Where is [person]?”
- Sustain simple pretend play with others.
- Consistently follow someone’s point when object is in close proximity and can be touched.
- Consistently follow someone’s point when object is distant.
- Consistently point to desired object when object can be touched/over distance.
- Consistently engage in functional action with a toy.

FDL V: Shared Meanings
- Regularly use two-word combinations to communicate with others.
- Sustain long interactions with an emphasis on balanced reciprocal exchanges with others.
- Child will increase ability to label his/her own feelings. Note: This is a dyadic IEP goal because the child’s learns about their feelings from caring adults who acknowledge the feeling and mirror the feelings back to them with words and gestures.
• Consistently demonstrate one thematic pretend play (i.e. feed dolls, use doctor kit, sword fight, race like a car. Note: School could promote this goal by providing pretend play sessions throughout the day.
• Frequently participate in turn taking activities with others.
• Consistently follow simple rules to games (e.g., duck duck goose, catch, etc.).
• Consistently follow two-step directions involving two different actions.
• Consistently respond to simple ‘Where, Who, & What’ questions with searching movements.
• Consistently indicate ‘yes’ or ‘no’ verbally when asked a “Do you want” question.
• Point to pictures, body parts, objects upon request.
• Follow a series of 2-3 simple related commands with the same object.
• Respond to open ended 'wh-type questions' (e.g., “What do you want to do?”).
• Consistently seek help when needed.

**FDL VI: Building Bridges between Ideas/Emotional Thinking**
• Refer to self by name.
• Consistently be able to recall recent familiar events using sentences.
• Talk about an event that has just happened.
• Summarize the main idea of a book or story.
• Consistently respond to ‘Why & When’ questions.
• Consistently connect two ideas together logically (e.g., It’s cold. I need a coat.).
• Play two thematic pretend with a simple story line or role playing with others (e.g., Playing ‘Doctor’, or ‘Cook’, or ‘Bus Driver’).
• Use pretend play scenarios to explore negative affect and practice appropriate responses.
• Assume the role of another person (e.g., dress-up).
• Consistently say first and last name when asked without prompting.
• Consistently use basic greetings and manners.
• Regularly use pronouns ‘I & You’ appropriately.
• Regularly use pronouns ‘He, She, & They’ appropriately.
• Accurately answer questions that connect actions to adjectives (e.g., “What do you do when you are hungry?”)
• Consistently ask for help when needed.
• Accurately identify the feelings she/he has in a variety of settings and be able to explain the relationship of events to her/his feelings.
• Increasingly identify emotions in others as an act of empathy.
• Increasingly respond appropriately to the emotions of others.
• Be increasingly tolerant of own mistakes and performances that were not perfect.
• Honor personal space during social interactions and explain why it is important.
Appendix I
Breathing, Relaxation, & Imagination (BRI)
Techniques for Children with ASD

Introduction
For children with autism who are fairly solid at Functional Developmental Level V or above, the use of simple breathing, relaxation, and imagination (BRI), when used with other coping techniques (See Dr. Rick's 20 Transition Tricks and The Good, The Bad, & The Ugly) can be very effective in helping reduce anger, sadness, worry, and upsets.

For several years when I was working at Michigan State University in the Department of Pediatrics, I worked in the oncology unit as a developmental and behavioral pediatrician with children who had cancer and had to undergo painful procedures (spinal taps and bone marrow aspirations). I taught them how to use BRI as a form of pain control and, in the process, learned a few ‘tricks of the trade’.

Procedure for BRI

1. The child must be a willing partner. Always tell your child what you want to do, namely, teach them how to calm down when they get upset. Telling them sets the ‘suggestion process’ in motion. “When you get mad or sad or worried, it’s not fun is it? I have a fun way to help you stay calm and be happy (positive suggestion). It’s easy. Tonight when you get ready for bed, I’ll teach it to you.” Don’t ask for permission; assume that they will do it and can do it. Use positive suggestions. Don’t use “don’t,” i.e., ‘We don’t want you to worry.’ Instead make positive suggestions to stay calm and be happy.

2. It is best to teach your children these techniques when they are going to bed. They are already relaxed, in a comfortable place, and laying down all of which make it easy.

3. During bedtime say again: “I’m going to teach you how to stay calm and be happy when you start to get mad or sad or worried. I have a really fun trick to teach you called the ‘Loose, loose, loose trick’. First you will breathe three times and then you will tighten your arms and then you will make them loose loose loose. It’s fun!”

4. Then ask (never force) the child to take 3 slow deep breaths and you count them. Deep breathing uncouples breathing from its normal unconscious pattern and can help the child gain more control over the relaxation process. This technique alone can be helpful in stressful situations. If you want to go for even more relaxation read on. . .

5. As the child breathes and you count to 3 then time your talk exactly to the outbreath. This is very relaxing for the child. “Just enjoy. . .relaxing. . .your whole body. . .as you breathe. . .in and (this is on the in breath). . .out. Relax. . .relax. . .more. . .more. And now. . .I want to teach you. . .the loose, loose, loose trick.”

6. Loose, loose, loose trick. As the child is laying on the bed, ask him/her to tighten his/her arms on the in-breath while you say “Tight, tight, tight” and then, on the out breath, you say, “When you breathe out, let your arms go loose, loose, loose.” Do this with the legs too. Suggest, on the out breath, that it “feels good to be relaxed”. You can repeat this if the child is enjoying it.

7. Then give a suggestion (on the out breath) for the future. “When you feel mad. . .or sad. . .or worried. . .you can use your new tricks. . .to stay calm and happy.”

8. Lastly, suggest that the child will ‘return to normal’ and feel good and calm and happy. The whole process should take no more than 15 minutes.
Autism: The Potential Within

Glossary

ABA - Applied Behavior Analysis (ABA) is a method of behavioral intervention developed by Ivar Lovaas PhD and Tristam Smith PhD that focuses on skills, based on drills involving a Skinnerian (rewards for success) approach. Research evidence supports ABA as an effective intervention for young children with autism.

AD/HD - Attention Deficit/Hyperactivity Disorder (See Stimulants). A brain condition characterized by inattention, distractibility, over-activity, and impulsivity that interfere with functioning in home and school environments.

ADI - Autism Diagnostic Inventory (ADI) is a questionnaire developed by Cathy Lord, PhD, that can accurately diagnose autism.

ADOS - Autism Diagnostic Observation Scale (ADOS) is a research-based observation instrument developed by Cathy Lord, PhD, that can accurately diagnose autism.

Affect – The feeling life of the child; what the child likes, wants or intends.

ASD - Autistic Spectrum Disorder includes the range of autism from mild to severe characterized by problems with social interaction/communication and repetitive, stereotyped and dominating interests. Sensory processing difficulties are common as are language delays.

Asperger Syndrome (AS) - A high functioning form of autism characterized by normal language and IQ, eccentric social style and dominating intellectual interests. No longer considered an official diagnosis (See DSM 5)

Atypical Anti-psychotics - Medications, like Risperdone and others that control aggression. They are approved for children with ASD.

Auditory Processing - the way a child processes information that is heard; the process of decoding sounds and the meaning of words is often difficult for children with ASD i.e., they have trouble making sense of what they hear or need more time to process auditory information.

CARS-2 - Childhood Autism Rating Scale-Second Edition. A measure designed to diagnose autism developed by Eric Schopler PhD.

CHAT - CHeccklist for Autism in Toddlers. A commonly used screening tool for identifying young children who might have autism. Developed by Simon Baron-Cohen PhD.

Circles of Communication - The back and forth process of communication. Opening a circle means initiating an interaction. Closing a circle means responding to a social overture (see reciprocal interaction). The 'ping-pong' of relationship.

Cognitive Delays - Lower than normal mental IQ which includes problems in thinking and understanding. This is a more recent term for mental retardation.
**Comfort Zone** - The neuro-psychological sense of comfort that a child with autism has when they are doing what they want and like to do, especially when they are repeating activities. The Comfort Zone is based on the child's abnormal neurologic system that makes the child want to keep the world the same.

**Content vs. Process** - The content of an interaction is the “what” of the interaction; the process of the interaction is the “how”. For example, imagine a child and parent playing catch. The content would be ‘A game of catch’; the process would be ‘tossing the ball back and forth’.

**Contingent Interaction** - When my interaction depends on your interaction, it is considered contingent. See circles of communication.

**Cues** - A cue is an observed behavior of the child that tells you whether the child is enjoying an interaction, feeling neutral about the interaction, or not enjoying the interaction.

**DTT** - Discrete Trial Therapy. This is the method of ABA/EIBI whereby the children are taught in simplified and structured steps. Instead of teaching an entire skill in one go, the skill is broken down and ‘built-up’ using discrete trials that teach each step one at a time.

**DIR** - Developmental, Individualized, and Relationship-based approach developed by the child psychiatrist, Stanley Greenspan MD and child psychologist Serena Weider PhD. The theoretical foundation of the PLAY Project is based on the DIR framework.

**DSM 5** - Diagnostic and Statistical Manual 5th edition. The official diagnostic manual of the American Psychiatric Association for categorizing and defining mental illnesses. In regard to autism spectrum disorders (ASD) the DSM IV included 3 diagnostic categories: Autistic Disorder, Pervasive Developmental Disorder (PDD) and Asperger Syndrome (AS). The DSM 5 eliminated PDD and AS and now only refers to ASD characterizing ASD as mild to severe. The emphasis in the DSM 5 in on autism as a disorder primarily of social communication.

**Dyspraxia** - difficulty expressing thoughts. Children are dyspraxia: a.) when they have trouble pronouncing words, i.e., have speech delays, or b.) when they know what they want to say but have trouble saying it.

**Echolalia** - automatically repeating words or phrases heard without fully understanding the meaning.

**EIBI** - Early Intensive Behavioral Intervention is a form of ABA (see above) designed for young children with autism spectrum disorders. In this ABA method young children perform clear's tasks usually at a table and are rewarded/reinforced for success with external rewards like food or ‘yays’ or fun activities.

**Functional Emotional Assessment Scale (FEAS)** - A video-based measure of social interaction. Both the caregiver's sensitivity to the child's cues and the child's functional developmental level are measured with this tool.
Functional Developmental Level (FDL) - The stages of development according to the DIR theory of Stanley Greenspan MD. There are six functional developmental levels before age five: FDL I: Shared Attention and Regulation, FDL II: Engagement, FDL III: Two-way Communication, FDL IV: Complex Two-way Communication, FDL V: Shared Meanings, FDL VI: Emotional Thinking.

Fragile X - a genetic condition primarily affecting males involving some degree of cognitive delays/mental retardation and associated with autism in 10-15% of affected children.

Generalization - The ability to apply what is learned in one situation to another separate situation at another time.

Genetic etiology - caused by genes. Genes are made up of DNA and are responsible for the inheritance of physical and some personality characteristics. Some cases of autism has been shown scientifically to have a genetic etiology.

Hypersensitivity - being overactive or oversensitive to the environment.

Hyposensitivity - being underactive or under-sensitive to the environment.

IDEA Laws – Individuals with Disabilities Education Act - These federal laws establish guidelines for the early intervention and special education services provided in all states in the United States. A few of the most important components of this law include the following: a.) Free and appropriate education i.e. your child’s appropriate education must be free. b.) Least restrictive environment i.e. your child has the right to be with other typical children in an educational setting. c.) Individualized education plan (IEP). Your child must have an educational plan that is your agreement with the school for their individualized education. d.) Advocacy. You have the right to a free advocate, someone hired by the state to advise you on your legal rights related to your child’s disabilities.

IEP - Individualized Education Plan. This is the legal document that describes the special educational plan for children ages 3 years to 5 years-11 months of age.

IFSP - Individual Family Service Plan. This is the legal document that describes the special educational services for children ages Birth to 2 years-11 months of age.

ISD - Intermediate School District. The official entity responsible for administering special education services. ISDs are separate from regular school services but are most often located in regular school buildings. The ISD has it own ‘director’ of special education services along with other administrative personnel like ‘autism consultants’. The ISD oversees all special education services including speech and language and occupational therapy services; special education classrooms; resource rooms, etc.

Intent - What the child wants to do as judged by the caregiver by reading the child’s nonverbal gestures as well as verbal cues
**Lead** - The direction the child wants to go. Similar to intent. By following the child’s ‘lead’, the adult engages the child in pleasurable back and forth interaction which enhances the child’s developmental functional level.

**LD** - Learning Disability. A specific learning difficulty within the context of normal IQ, i.e., the child has a normal IQ but trouble with reading or math or writing, etc.

**Motor Planning** - Motor means movement using muscles. Motor planning is the ability of the child to move from one activity to another or to sequence a given motor activity. Children with autism frequently have trouble with motor planning.

**Mental Retardation (MR)** - Scoring less than 70 on a standardized test of intelligence. Children with autism frequently score poorly on IQ tests and so may be referred to as mentally retarded or cognitively impaired. Mental retardation is an older term. Cognitively impaired is preferred.

**Natural Settings** - Settings not specifically designed for therapeutic interventions. Typical natural settings include the home, the park, grocery store, etc.

**Neurologic Comfort Zone (NZC)** - (see Comfort Zone)

**Over-reactive** - (see Hypersensitivity and Sensory Motor Profile) A sensory-motor profile characterized by being overly responsive to the environment. Children who are over-reactive are too sensitive to the environment (e.g., loud noises bother them) and need lower levels of stimulation to help them be calm and attentive to people.

**Operant Conditioning** - a type of learning where behavior is controlled by consequences. Key concepts in operant conditioning are positive reinforcement (i.e., positive consequences), negative reinforcement (i.e., negative consequences), positive punishment and negative punishment.

**Oral Motor Problems** - Difficulties using the mouth and tongue to pronounce words or to chew and swallow food effectively.

**Plasticity** - The capacity of the brain to develop new neuronal (brain nerve) connections based on exposure to a stimulating and sensitive environment.

**PLAY Project** - PLAY Project is an evidence-based, parent implemental intervention model for young children with autism spectrum disorders (ASD). PLAY stands for Play and Language for Autistic Youngsters. The PLAY Project helps parents engage their hard to engage children using a developmental, relationship-based approach usually in the home setting. PLAY Consultants coach and model for parents and give video tape feedback to help parents learns PLAY principles, methods, techniques, and activities. In this way parents help their child move up the functional developmental levels as described by Stanley Greenspan MD and Serena Weider PhD in their DIR model. PLAY-based methods follow the lead and cues of the child without drilling or predetermined outcomes as opposed to ABA or other behavioral interventions.

**PLAY Principles** - There are four PLAY Principles: 1.) Fun with people, 2.) Put in the time (about 2 hours per day broken up into 10-20 minute play sessions), 3.) Profile the child accurately according
to their *Comfort Zone* (what they love that isolates them), their *Sensory Motor Profile*, and their *Functional Developmental Levels*, and 4.) Play at the right level so interaction is fun and promotes development.

**Play strategies** - The basic strategies used for engaging the child in PLAY-based activities including a.) Comfort Zone, b.) sensory-motor and c.) functional developmental strategies. These are fully described in the PLAY Project CD Workshop.

**PRT**- Pivotal Response Therapy. A behavioral intervention therapy for autism based on ABA theory developed by Robert Koegel PhD and Lynn Koegel PhD. It is more playful than traditional ABA/EIBI/DTT and uses play and the child’s interests as a positive reinforcer. (See Glossary definitions).

**Process vs. Content** - (see content vs. process)

**Proprioception** - Feedback from the joint structures of the body to the brain and vice versa.

**Reciprocal Interaction** - Interaction that depends on the behavior on the other person. Mutual interactional processes depend on one another so that when you do something the child reacts or vice versa.

**Sensory Motor Play** - The use of play that involves the senses or movement. Examples include a rough and tumble play, spinning, rocking, jumping, turning on and off lights, etc.

**Sensory Motor Profile (SMP)** - The unique way that a child experiences the world through the various sensory modalities and movement. Some sensory modalities are preferred and sought; some are disliked and avoided. There are nine primary modalities: proprioception (the experience of joints in motion i.e. jumping, shaking of arms/leg, etc.), spatial (the child’s experience of closeness and distance), tactile (light touch/tickles and deep pressure/squeezing-pushing), vestibular (turning in space/spinning), visual, auditory (hearing/music), oral (tasting and eating), motor planning (coordination of small and large muscles and the ability to do what you intend to do), and olfactory (smell). In addition the SMP includes the way the child reacts to the world. *Over-reactive children* are highly sensitive to the environment and can easily be overloaded when there is too much sensory or emotional input; *under-reactive children* tend to be self-absorbed and unresponsive to input and/or overtures; and some children have a *mixed reactive profile* over-reacting sometimes and being self-absorbed sometimes.

**Sensory Integration (SI)** - The process of using sensory experiences to help children understand their world. SI therapy is usually provided by occupational therapists and involves specific therapeutic techniques.

**Seven Circles of PLAY** - The 7-step process by which parents and professionals can implement a skillful approach to helping young children learn the PLAY Project approach.

**Social Pragmatic Interventions** - Play and language based interventions that focus on social language and social interactions between two people, as opposed to drilling types of approaches typical of ABA. Examples of social pragmatic interventions include the work of Greenspan, Prizant, Hanen, and the PLAY Project.
**SSRI** - Selective Serotonin Re-uptake Inhibitors. The Prozac (Fluoxetine) like drugs that help with anxiety, obsessive/compulsive disorder (OCD) and depression. Generally very well tolerated and very effective. Must be taken daily.

**Stimulants** - Amphetamine-based medications (e.g., Ritalin/Methylphenidate) that are used to treat Attention Deficit/Hyperactivity Disorder (ADD/ADHD)

**Under-reactive** - (see also hyposensitivity) A sensory-motor profile characterized by being unresponsive to the environment. Children who are under-reactive are hard to arouse and need a lot of stimulation to help them be calm and attentive to people.

**VB or VBT** - Verbal Behavioral Therapy is an ABA intervention based on Skinnerian conditioning that teaches verbal skills using a behavioral approach. Vincent Carbone, Carl Sundberg and James Partington developed the clinical model that is now used in many states in the U.S.

**Vestibular** - having to do with the neuro feedback to establish one’s place in space

**Zone of Potential Development** - a term developed by Vygotsky characterizing the outer limits of the child’s development. When the parents expect more than the child can understand they are in the child’s zone of potential development when they need to be in the child’s zone of proximal development.

**Zone of Proximal Development** - a term developed by Vygotsky characterized by interest, excitement and engagement typical of interactions occurring within the child’s understanding. This zone is where the child learns best. They are neither bored because the interactions are too simple or repetitive nor are they confused because the interactions are too advanced (See Zone of Potential Development).
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