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

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."

do it!"

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 <u>at</u>tention is and what his <u>in</u>tention 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 <u>at</u>tention?" **Dad**: "He seems to be looking at the wheels."

Dr. Rick: "Right! Now, what is his <u>in</u>tention?"

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
- Games
- Simple pretend
- One theme pretend

Complex pretend

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 <u>30 hours</u> 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 <u>Jacob</u> 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 <u>at</u>tention and what is his <u>in</u>tention?"

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."

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 <u>our</u> 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 <u>not</u> 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. 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 De'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 <u>your</u> 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 <u>you</u> 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

- Engaging Autism, Stanley Greenspan and Serena Wieder, Da Capo Lifelong Books (2006)
- PLAY Project DVD: Workshop I, Richard Solomon (2007): http://www.playproject.org/parents/play-project-dvd/
- *More Than Words, 2nd edition*, Fern Sussman, Hanen Publications, 2012. 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

- O 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?
- O Are you *paying attention to the child's <u>attention?</u>* Where is he/she looking? What is his/her attention focused on?
- O Are you paying attention to the child's true <u>intention?</u> What is he/she interested in right now?
- O Are you able to *interpret your child's subtle cues* to understand what he/she wants? Are you 'reading' them right?
- O 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?
- o Whose play idea is it? Yours or your child's?
- o Are you using the 'Rabbit Hole Techniques'?
- O Can you define 'circle' of communication? What does it mean to 'open' a circle? Close a circle? Do you know how to *count circles*?
- o Are you having fun together?

FDL II: Engagement

- O Are you playing at the right level? Too high (child not getting it)? Too low (not engaging the child)?
- O Can you engage your child by following his/her lead?
- O Are you enthusiastic, animated, silly, fun? Using voice, gestures, and actions to make it fun?
- O 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.
- O Are you getting 3-4 circles of communication going? Do you know how to count circles?
- o *How long* can you keep the engagement going by being dramatic, silly, fun, sensitive to their interests (are you *sweating* yet?)?
- o Are you having fun together?

FDL III: Two-way Communication

- O Are you slowing down your pace and waiting long enough to get responses from your child?
- o Are you getting 6-10 circles of communication going?
- O 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?
- o Are you using Theme and Variation to be inventive with your play?
- O 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?
- o Are you seeing any imitation yet?
- o Any word-gestures yet? Like signing for 'more', waving bye, pointing?
- o Are you still having fun together?