

Prologue

The Origins of the PLAY Project

(for Charles)

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

Pebble Creek. Back in the 70'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, and even vomiting on purpose, etc.

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 were some awkward bird trying to take off. He walked with this 'rocking step walk' *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 DIR (Developmental, Individual differences, and Relationship based) 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 but it wasn't until 1989 when I moved 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.

Pittsburgh. 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 autistic 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 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 Chapter 13: ABA vs PLAY). 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 ARC (Association for Retarded Citizens) for my work with young children with autism and their families.

Back to Michigan. 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 learned in Pennsylvania to 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 that there was *no* Medicaid re-imburement for the intensive treatment of young children with autism! 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 there is so much potential within the child with autism IF he or she get intensive intervention early in life (18

months to 6 years old) when they can make major improvements in their language and social skills. *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 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. So I re-designed The PLAY Project into a Home Consultant Program where *parents* are taught by professionals to provide intensive intervention at home.

Lost to the World. 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 as they were about to leave my office after the 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 Grant 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 Grant 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 Grant 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. 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 cannot 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 the 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 the child into their comfort zone. If you leave these children alone they will further limit their experiences, which in turn further stunts their potential. It's a vicious downward developmental spiral.

Saving Grace. 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 is the saving grace of autism. Engaging interactions with people literally causes the brain to make stronger and better connections until 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 in to the child'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 his 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 chapter 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 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 2 ½ year old son Jacob who was initially quite stuck in his neurologic comfort zone. . . .