

Presentation to the ICDL International Conference

David and Jo Raphael

Thank you for joining us tonight and for being a part of this wonderful community. When Drs. Greenspan and Wieder started this organization, they brought together clinicians from a range of disciplines who worked with neurodivergent individuals to collaborate, share ideas, and learn from one another. Our son and our whole family thrived because of this remarkable multi-disciplinary approach. We are so grateful to all of you for your commitment to this important work and for being here tonight.

There are so many rationalizations we make when our child's difference becomes increasingly pronounced and their behaviors become more and more frightening. "Every baby is different." "Boys are different from girls." "He's still young". But the rationalizations can only mask and suppress our fears and the realities for so long.

Jacob was more than different from his sisters. Not only was his speech not developing, but he lost the few words he had spoken. He did strange things – he sometimes screamed so loudly that his voice pierced our ears. Twice he disappeared into large crowds.

And his unusual behaviors grew. For us, the most frightening part of Jacob's autism was his increasing isolation. That core, basic, joyful element of being a parent – the deep emotional connection to our son – was disappearing.

It was 1993, and Jacob, our third child, had just turned two, and we went to his routine wellness appointment with his pediatrician. We explained to him that we were worried: our son's language wasn't progressing, and he had lost the few words that he had. He seemed to be slipping away from us. Our pediatrician told us that we were used to girls, that "boys develop later", and we shouldn't worry.

When he was two and a half, we knew that something was seriously wrong. Our concerns continued and we went for his next wellness visit. We were alarmed and told the same doctor that neither of us was sleeping, and Jacob seemed even more isolated. When the pediatrician started to downplay our concerns, we cut him off and told him that we needed to do something, to have him evaluated to find out what was going on. After a short pause he agreed to give us a referral to a highly regarded child development center.

In bright fluorescent-lit rooms, a parade of clinicians asked Jacob questions he couldn't respond to and probed his body while Jacob flailed and we restrained him on our laps.

This is what they told us:

THE EVALUATION

Jacob is a handsome 2-year, 7-month-old boy with mild delays in motor development, significant cognitive delays and significantly delayed and abnormal communication development. His behavior is characterized by aloofness, poor eye contact, poor imitation and difficulty in social engagement. These symptoms are consistent with a diagnosis of Pervasive Developmental Disorder.

What is that? What is Pervasive Developmental Disorder? They told us three things:

- 1 They could not confirm Jacob's intelligence.
- 2 He would probably have to be institutionalized.
- 3 We should contact the Autism Society and school system.

Thirty-three years ago, at the end of a long day at a major child development center, we were left with a diagnosis we didn't understand, for a condition we knew nothing about, and a distressing prognosis.

After we got the results and diagnosis, we were in shock. While we knew that something was wrong, we were totally out of our depth. Being told that Jacob was autistic at the child development center didn't resolve anything for us – if anything, it exacerbated our fears. What does that mean? What will his future be like? What do we need to do? How can we fix this? Can this be fixed? How can we help him?

Jo couldn't even say the "A" word. It took ages for her to be able to say Autism. All we knew was that something was seriously wrong and we were thrust into a world we knew nothing about. We researched as much as we could and found lots of conflicting information. It was so striking to her that the term "refrigerator moms" kept popping up and that autism was caused by having "cold mothers".

It's hard not to look back in anger at those who conducted the evaluation. But the truth is that their diagnosis was right. At a time when only one in 10,000 children was diagnosed as autistic, as painful as their pronouncement was, it gave us a starting point and compelled us to act.

We found our way to Dr. Greenspan through sheer luck. After telling friends and family, we reached out to the principal of the girls' elementary school. She was wonderful, listened carefully, and said that she was going out for dinner with a friend, a special ed teacher, and would ask him for recommendations. She called the next day with a stack of articles that were either written by or cited Dr. Greenspan.

We found out that his office was about 30 minutes from our home and called to make an appointment. This was in early fall and we were given an appointment for April. We were also told that Dr. Greenspan had a call back time where he would return calls to parents with questions on Thursday nights. We registered for that as well.

The dire prognosis that Jacob would probably have to be institutionalized didn't account for Stanley Greenspan and Serena Wieder, the Floortime method, our fierce determination, and perhaps of greatest significance, Jacob's innate abilities.

Late one Thursday night in November, when David was out of town our phone rang at 10:45PM and Jo picked it up assuming it was David. On the other end she heard a terse voice she didn't recognize say: "Stanley Greenspan". Jo was dumbfounded, she didn't have her thoughts together and froze. He filled the void by saying: "You called me...". We then began a sharp exchange that only two Brooklyn New Yorkers could have. Jo told him about Jacob's autism diagnosis and explained that the school was asking us to make decisions that we had no idea how to handle. Dr. Greenspan said, "you need to come see me." She told him that we would love to come see him, but he couldn't see us until April. He shot back with "What are you doing Saturday?". Jo said "why"? He said, "because I have a cancelation". Jo said, "What time?". And so, it began.

Dr. Greenspan gave us hope. Thirty-three years later, we still remember the words verbatim: “You should not place any limitations on Jacob’s capabilities. He might not go to MIT, but he just might.” Equally important, he gave us a plan — what therapists we needed to see and how often. What we needed to do at home. Foods we should avoid. During that session we watched our son form a connection with Dr. Greenspan, and through his guidance, with us. As the session ended, Jacob had a major temper tantrum. Jacob didn’t want to leave. Our interpretation was that it was the first time in a long time that he felt understood and he longed for this sense of connection with others.

“He might not go to MIT, but he just might.”

DR. STANLEY GREENSPAN

After our first meeting with Dr. Greenspan, we went home and went to work. Here is the essential tool of that day’s efforts.



The Tootsie Roll bank — purchased for \$5 to support the Kemp Mill Elementary School PTA.

This is a Tootsie Roll bank, purchased for \$5 to support the Kemp Mill Elementary School PTA.

Jacob loved the sound of pennies dropping into the bank.

After returning home from our meeting with Dr. Greenspan, Jacob and David were sitting in our bedroom with the Tootsie Roll bank. He dropped a penny in the bank and went to drop another – but this time, David put his hand over the slot. He pushed it aside. That was a first circle of communication.

Jacob grabbed another penny, went to drop it in, but David put his hand over it again. He pushed it aside again.

Again – this time David put tape over the slot. Jacob pulled the tape off.

Again – David hid it behind his back. Jacob crawled over him to get it.

Again – David hid it under the pillow – said with high affect “Where did it go?” Jacob threw the pillow aside and dropped the penny in.

Six, seven, eight circles of communication in a row – a joyful father connecting with his son, and a giggling child.

In our second session with Dr. Greenspan, we asked him what Jacob’s prognosis was. He looked at us and said that our son had Multi-System Developmental Delay and if we did what he told us he would be fine. Jo pushed back and said, “but they told us he might be retarded, he might need to be institutionalized!” Stanley responded in a manner that was completely “Stanley-esque” – “they were wrong”.

In our third meeting with Dr. Greenspan, we asked him, “When will Jacob begin to speak?”

He responded, “Speech is the icing on the cake.”

Dr. Greenspan was telling us that, because of Jacob’s sensory challenges, he had not yet been able to advance through essential cognitive developmental stages – most notably, the development of symbolic thinking.

This brings us to the next essential tool in our shared journey.



Aladdin's Cave of Wonders — where symbolic play began.

In the months after we began Jacob's Floortime-based treatment program, we gave him Aladdin's Cave of Wonders as a gift.

A day or so after he received this marvel of plastic engineering, we were playing with it and he moved Aladdin into the cave and, pursuing the Floortime mantra of "following his lead," David moved Jafar in the way. He moved Aladdin. David moved Jafar — and we soon realized that the plastic figures of Aladdin and Jafar had become animated. It was the beginning of our symbolic play and his symbolic thinking.

Several months later, we were on our way.

We would like to share some of the things we learned along the way

Autism is Scary

For us, autism was a vast unknown — it was so alien and undefined. We knew it was serious — but we didn't know how serious — and we didn't know if there was anything that could be done about it. For us, autism was the monster under the bed.

A lot has changed since our son Jacob was diagnosed in 1993. Back then, the estimated number of children being diagnosed as autistic was one in 10,000. Now that number is about one in 31. Back then, the only media-based reference point for autism was Rain Man, starring Dustin Hoffman as the profoundly challenged and institutionalized autistic adult. Today, on TV, there are autistic doctors, detectives, and young autistic adults going on dates.

1993

1 in 10,000

children diagnosed as autistic

TODAY

About 1 in 31

children diagnosed as autistic

But we imagine that autism is still scary for families. A successful outcome is not only not assured, but it is almost impossible to define what a successful outcome is or should look like. Jacob likes to say that “if you know one autistic person, you know one autistic person.” Every autistic child is different and, we would add, every autistic child’s family is different.

Today, perhaps autism is scary for different reasons. While, chances are, any pediatrician will prescribe the same treatment for an ear infection, parents whose children are diagnosed as autistic these days are faced with what seems like countless treatment options – including “alternative treatment approaches” such as chelation, fecal transplants, and hyperbaric oxygen. Many of these treatment options are backed by scant data and some of them can be extremely dangerous.

In an age when we all look to the web for guidance, parents who look online will be confronted with tens of thousands of autism-related websites.

Roll Up Your Sleeves

For parents and family members, we recognize how frightening an autism diagnosis can be. We were there. But we encourage parents, family members and other members of the child-care team to mobilize all those strong emotions into action. Clearly this is for the benefit of the autistic family member. But additionally, an important way of overcoming the fear and hurt you may be feeling is to put those emotions to work. As Jacob recently said, “fear is a force.” To quote from the Bible “Be strong and of good courage (Joshua 1:9).” For us,

embracing Floortime and committing to Floortime play gave us days of both purpose and delight. Stanley Greenspan, Serena Wieder, Diane Lewis, Valerie DeJong, and Harry Wachs didn't shy away from putting us to work, and we will always be grateful for this.

Along the way, we not only learned new ways to engage with Jacob, but also with family members, and later, as professionals. Jo has always been quiet, shy, more comfortable in the background. Suddenly she found herself front and center and learned to "up her affect" when engaging in play. She can still hear Stanley in her head yelling "come on Mommy, up your affect!" Jo also found that by being the best B actor she could be (over-exaggerating her movements and facial expressions) she was able to engage with Jacob more effectively. He loved the slapstick and humor, and it was a great way to gain his attention and play. Jo often felt anxious going into sessions with Stanley as she felt that she was never going to do Floortime well enough, or right, that she didn't have what it takes to help her son. More often than not Jo left his office in tears. David, on the other hand, became highly energized, eager to try the next recommendation or suggestion. This is a difficult but highly rewarding journey.

Jo also remembers that we were encouraged by both Stanley and Serena to have as many playdates as possible, but we knew no other families with children on the spectrum. Finding playdates was a painful process as parents of typically developing children didn't want to engage. Some of our friends and family didn't understand why we were working so hard with Jacob and our family. After all, the child development center said he wouldn't get better. The world is more accepting today, but Jo knows that setting up these playdates remains a struggle. Whether your child is neurodivergent or neurotypical, engage with all children in their sphere to encourage healthy relationship building.

Autism is a Family Affair

In retrospect, our family's Floortime-based autism journey was filled with discovery, wonder, and joy. But it certainly didn't start out that way or feel that way at the time. We became "master schedulers," making sure everyone got to their activities and sessions and, whenever possible, made time to eat, get some sleep. As gratifying as our experience was, without question, it was a challenging time. As we are sure you have experienced, each family and each family member will react differently and be impacted differently by autism. For David, Jacob's diagnosis and his fear of losing him to the isolation of autism brought up the sadness and pain of his father's death when he was a teen.

Other family members were impacted as well.

In the months after Jacob was diagnosed, one of Jacob's older sisters began struggling academically. Her teacher suggested psychological testing. We put it off – we were just too busy and too emotionally overloaded. But her difficulties led to health-related challenges. Finally, she was diagnosed with ADHD. We placed her on medication and arranged for tutoring. Her grades improved and her medical issues faded. We are not proud of our lack of immediate attention to her needs – but it was our reality at the time.

This reality points to something important that we learned along the way. You make the best decisions you can at the time – because you never make decisions for your family with malicious intent. If, in an hour, or a day, or a year it is no longer the best decision, you make another best decision. That flexibility is crucial for our own emotional wellbeing as well as being a model for our children.

Autism and other developmental and physical differences are family affairs, and each family and each family member will respond differently. An autism diagnosis can bring a family together or it can tear a family apart. We have seen family members roll up their sleeves and we've seen families, for whatever reasons, choose not to fully engage. As parents, we don't get to judge the actions of other families. We recognize the complexities clinicians might face in working with families. We have lived the experience of all members of our family facing the challenge of autism.

We would respectfully propose that when clinicians are working with a child who has developmental or physical challenges, the entire family is the client. We would also suggest that, whenever possible, family members should be engaged as members of the treatment team. Give us home assignments. Each of Jacob's clinicians gave us home assignments. And that work, that role we played in addressing Jacob's challenges, was nourishing and empowering for us.

In the months after we initiated a Floortime approach, he began to speak –nonstop. He engaged with others and found joy in the world around him. Over the years he blossomed.

Thoughts for Clinicians and

Educators Based on Our Experience

Based on our family's experience and conversations with other neurodiverse families, here are some messages we would ask clinicians and educators to consider sharing with families of children and young adults who have recently been diagnosed as autistic. (Parents, let us know what you think).

1 Your child is not broken. Increasingly, autistic children and adults are succeeding in the world – not in spite of their autism, but often because of it. Autistic individuals have the capacity to perceive and engage in the world differently. We will be your partner in helping your child reach their highest potential.

2 Your child's autism is not your fault. The best current scientific evidence does not show that vaccinations or taking Tylenol during pregnancy cause autism. And no, you're not a refrigerator mother.

3 We are with you. You are not alone. This is a journey that will take some time – we will be there with you all the way. Let us know what your concerns are and when there are things you don't understand.

4 This is a collaborative effort. A comprehensive treatment program for autistic individuals may involve multiple clinicians such as psychologists, developmental pediatricians, and play, speech, and occupational therapists. But among the most important members of the treatment team are you – the parents, family members, and caregivers. Floortime calls for hours of play-based therapy. If the autistic child has siblings, other family members, or caregivers, they can help.

5 We will always be honest with you. When we say that your child is making great progress or has a bright future, you can believe us. We will also be honest with you when we have concerns. There is a wonderful saying David learned from Irving Miller, a social work professor of his: "Always tell the truth, know how to tell it."

Where Things Stand Now for Us

Jacob is a college graduate with a major in Creative Writing and a minor in Philosophy. He is committed to being an author, has written a number of short stories, and is working on a book. He is an active participant in two writing groups. To provide some income while he pursues his writing, he is a substitute teacher and tutors autistic teens.

Perhaps the most significant emotional development is that Jacob has embraced his autism identity and has become an autism advocate. With remarkable thoughtfulness and insight, he speaks openly about his autism experience, recognizing both the challenges it presents and the unique capacities and strengths it provides him.

We love this excerpt from a recent speech he gave:

IN JACOB'S WORDS

It's one thing to know that you're autistic. It's another to understand what autism is and what it means to be autistic. Even if I could get a straight answer about autism from my parents, my teachers, the TV, or the internet, none of them could have answered the real questions I had. Questions like: what did it mean for me to be autistic?

So, I'd have to find those answers through my own lived experience. And based on my lived experience, I understood that being autistic was why sounds were either inaudible or so loud that it hurt my ears. It was why tags on shirts constantly itched and nagged. It was why it felt like everyone else had a basic understanding of what to say in any given social situation, but I didn't. It was why I went to this or that specialist for everything from hand-eye coordination to allergies.

In other words, it was why life was just a little harder.

And without any guiding voices or genuine sources for answers, autism became a source of shame for me. Something to be hidden and only revealed to those who needed to know, or those I absolutely trusted. Something to be medicated, treated, and willed out of existence, hence the endless procession of specialists and therapists.

It's taken me three decades to become more comfortable in my own skin and with my own unique qualities. I'd like to think that I've learned a thing or two along the way. For one, going to occupational therapy and other such things will only help in navigating the world. If you truly want someone who's autistic to be happy and feel like they're a part of the world, you have to find people who they can connect with, whether they be neurodivergent or neurotypical. More than that, find people who are okay with who you are, autism and all.

Because I've learned that there are two major things that help you feel a part of something: having a history and having a community.

Among the great joys of this period of David's life are the annual trips he and Jacob take to national parks. The time together and the shared discovery of places of wonder are so meaningful. They've traveled together to the Grand Canyon, Bryce Canyon, Zion, Yellowstone, and the Blue Ridge Parkway.

David and Jacob have several traditions when they take these trips. But the most important one is downloading science fiction books to listen to as they drive. On their first trip to the Grand Canyon, Jacob selected *Project Hail Mary* by Andy Weir. Earlier this year, for his birthday, Jacob and David went to see the movie together.

In retrospect, listening to the book on the way to the Grand Canyon and seeing the movie on Jacob's birthday, was a third tool for us: Tootsie Roll bank, Aladdin's Cave of Wonders, Project Hail Mary.

TOOL ONE

Tootsie Roll bank

TOOL TWO

Aladdin's Cave of Wonders

TOOL THREE

Project Hail Mary

Essentially, the story is about solving difficult challenges by learning to communicate with someone who is alien to you – learning to connect with the other and to enter each other's worlds.

Until we learn to communicate with the other, we are all aliens to someone else – another culture, another generation, another political perspective. Someone who perceives and

processes the world differently than we do.

We believe this is true of the way many people perceive individuals with developmental and physical differences. It is easy to view autistic individuals as being different and alien. They may have no spoken language, run in circles, flap their arms, and cover their ears and scream. From the outside, these actions may seem bewildering and frightening. But while they may seem alien to us, the actions of autistic individuals have a meaning and a purpose.

In his wonderful book “Uniquely Human: A Different Way of Seeing Autism,” Barry Prizant writes that we fail when we *“treat the person as a problem to be solved and to be fixed rather than an individual to be understood.”*

Our family learned to follow Jacob’s lead rather than trying to stop behaviors that we didn’t understand. If dropping pennies in a Tootsie Roll bank was meaningful for him – we made it meaningful for us. If Jacob was running in circles, we got in his way, forcing him to change his path – and to close another circle. We began to see these behaviors not as obstacles to forming a relationship but as invitations to nurture one.

We met Jacob in the middle and learned to respect and care about each other. Thus, here is what we would like to propose: rather than insisting that neurodivergent individuals enter our world, let’s honor them for who they are and find ways for our worlds to meet. And here is the other thing we learned: when we open ourselves up to the other, just like Grace the astronaut and Rocky the alien did in “Project Hail Mary,” not only can we find that person, but we can find ourselves. In our case, Jacob and his parents found themselves in the middle and saved each other.

“The best way to help autistic and neurodivergent individuals progress toward fulfilling, meaningful lives is to find ways to engage them with deep respect, to help them build a sense of self, and to foster connection and joyful experiences.”¹

BARRY PRIZANT, *Uniquely Human*

We would like to think that we have embraced Jacob’s autism identity. Not as something

defective, or something to eradicate with more and more treatments and therapists. And not something to hide or be ashamed of, but something to be proud of. Something that makes him unique and remarkable. Something else to love about him.

And something worth writing a book about. So David and Jacob did: *A Miracle of the Heart: A Father and Son's Autism Journey*

Among the essays in the book is one entitled “Zeno’s Paradox.” The essay is based on an enigma proposed by Zeno of Elea, a Greek philosopher who lived in the 5th century BCE, that states if you keep covering half the remaining distance to your goal, you will never get there.

Twenty-two years ago, when David wrote that essay, the focus was on the half-distances Jacob was traveling to enter our world. We now realize that there is another part of that equation: What half-distance are we prepared to travel? The “we” here is the rest of us – families and friends, clinicians, educational institutions, places of work – society as a whole. Jacob and so many others have embraced their autism identities. Are we prepared to do the same? We want our children to have the tools they need to navigate the world. That is real and necessary. But what is our collective responsibility to fulfill our part of the bargain – to meet our autistic children and adults halfway – to recognize not only the legitimacy of their identity, but its unique beauty and brilliance?

Zeno was right: if only one of us does the traveling, we never arrive. But when we each move toward the other, we meet in the middle. That halfway space can be the stuff of miracles – and it is a very beautiful place to be.

We thank all the clinicians, educators, and paraprofessionals who are engaged in such magnificent work on behalf of our families. And we thank all the parents and family members who share our passion and our love for our children.

