

Q&Autism

Five of today's top experts share their professional perspectives and personal insights about the question of autism in these Q&As

Featuring Q&As with..... and adaptations from their latest books

- Dr. Barry Prizant*..... **What Sets SCERTS Apart**
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Peter is a typical 5-year-old. What a wonderfully mundane statement . . .

Q & A with Dr. Barry Prizant



Q: What is the one thing you would say to a parent who has just found out her child has autism?

A: In my work as a professional over the past 30 or so years, I have often been in the position of discussing diagnosis for a very young child with parents who are overwhelmed and afraid. I always make sure I say these 4 things:

1. There is great potential for positive growth and change for your child, but it will take hard work and a team effort. (This is why we emphasize a team approach in the *SCERTS Model*.)

2. The diagnosis does not change who your child is, and you know your child the best. Trust your “gut” when making important decisions. Beware of professionals who say their approach is the “only” answer, or who make promises about how your child will do if you only follow their approach.

3. Speak to other parents who have young children with ASD [autism spectrum disorder], and whose children are a few years older than yours. They have already spent some time on the journey that you and your family will be on, and they often are a tremendous source for advice and support. Parents who remain isolated often experience the greatest stress.

4. Don’t just focus on addressing your child’s challenges. Understand and use your child’s interests and strengths as a means to get at areas of weakness.

Q: What inspired you to work with kids with autism?

A: I first began working with children with ASD as a summer camp counselor at residential camps in the late 1960s, a few years before I ever heard the word *autism*. My greatest inspiration always has been children and their families.

Q: What do you see as the next breakthrough for autism?

A: This question implies that there have been other “breakthroughs,” which I question. On the contrary, progress for

kids with ASD, sometimes great progress, always is the result of hard work over a number of years, and a team effort with parents collaborating with professionals who understand children with ASD and who support families.

One of the true “breakthroughs” over the past 15–20 years, if you can call it that, has been the insights shared by people with ASD at conferences and in their writings, which we all have benefited from. Who better knows the experience of having autism and how to best support people with ASD than people with ASD themselves?

Q: What is the greatest obstacle you have overcome in your work?

A: I think about challenges rather than obstacles. These occur regularly in my current practice as a consultant to children and schools, when families and schools are not “on the same page,” when there is a lack of trust, and at worst, when potentially collaborative relationships become adversarial.

I see these unfortunate circumstances resulting in a waste of energy, time, and resources. Unfortunately, “outside” professionals may encourage parents to take an adversarial position by telling parents that they must pursue litigation, when many opportunities for positive solutions are not considered.

I work diligently under these circumstances as a “mediator” to support positive relationships and collaborative efforts that form the foundation for a child and family doing well, despite the challenges of ASD. I have worked in such situations, too numerous to mention, when we all kept the child’s best interest in mind and solved differences of opinions in a manner that fostered teamwork and collaboration, rather than eroding the foundation of trust that is necessary.

Q: What is the most rewarding experience you’ve had in working with a child with autism?

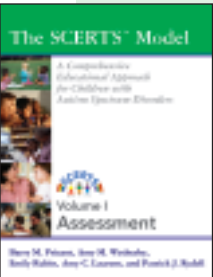
A: Too, too many to make it an easy task to pick one out. However, when I see children I had first diagnosed as toddlers or preschoolers, who are now teenagers and adults, who are doing well, and who enjoy life, it makes me feel very proud of them and their families.

When parents of these children tell me that my work with them made a difference, maybe only a few discussions we had many years earlier, it only confirms that my choice for my life’s work was a good choice.

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What Sets SCERTS Apart

Learn what distinguishes *The SCERTS™ Model* from other autism interventions



Our many years of experience in consulting for and working directly with children with autism spectrum disorder (ASD) have validated the primacy of Social Communication and Emotional Regulation and the need for Transactional Support [the S-C-E-R-T-S of the *SCERTS Model*].

In routine consultations for schools and families focused on supporting children’s development, as well as in crises, the problems that invariably arise are related to a youngster’s difficulties in

- communicating basic needs and
- exerting social control in socially acceptable ways

Such difficulties affect professionals’ and caregivers’ relationships with a child.

We believe that multiple sources of information support the need for an educational model that focuses on social communication and emotional regulation, with the strategic implementation of transactional support.

We also believe that competence and confidence in communicating is best supported in everyday social activities with caring and responsive partners who are able to enhance capacities for social communication and emotional regulation.

In addition, the very process of enhancing social-communicative abilities is an essential part of connecting with a child, which leads to long-term trusting relationships. Establishing such relationships, in turn, may prevent behavioral difficulties or problem behaviors caused by frustration, a lack of trust in others, and limited success in social interaction.

We have noted a great deal of confusion as to what defines the available educational models or approaches for children with ASD. It may be more helpful to think of the range of educational approaches as falling along a continuum as opposed to being mutually exclusive. Nevertheless, in the interest of clarity, we address what the *SCERTS Model* is and what it is not.

The SCERTS Model is not a prescription. It is systematic and semistructured, but it is also flexible. Some educational approaches for children with ASD are highly prescriptive. That is, they are characterized by teaching practices that follow a specific sequence of teaching steps, with little room for variation, flexibility, or spontaneity on the part of the instructor or the child.

The often-stated justification for highly structured directive approaches is that very young children with ASD or those with less ability cannot learn in less structured settings and without an instructional approach focused on a high degree of repetitive practice.

There is no doubt that the high degree of structure in prescriptive programs provides clear expectations and a highly predictable format. It is our experience, however, that an overreliance on prescriptive teaching practices perpetuates social and cognitive inflexibility, which is a challenge for many children with ASD who are predisposed to interacting, learning, and behaving in inflexible ways due to the very nature of the disability.

In contrast to adult-directed prescriptive approaches, other approaches base their goals and teaching practices primarily on following a child’s preferences and motivations and accepting the child’s behavioral responses through imitation or positive emotional reactions.

For these approaches, which have been referred to as facilitative teaching approaches, the goals tend to be more focused on building social relationships and trust, rather than on providing any direct instruction in specific social-communicative, cognitive, or self-help skills.

We certainly agree that by acknowledging a child’s motivations and focus of attention and interacting with a high degree of emotional responsivity, the parent or teacher is more able to build relationships conducive to the development of trust and a learning partnership.

However, we also believe that most children with ASD benefit from some degree of external structure (i.e., consistency and predictability) provided by partners to entice and motivate communication and social engagement and to support emotional regulation.

Furthermore, by infusing learning opportunities in motivating meaningful activities that are functional in everyday routines, skills can be directly targeted and acquired in a more flexible manner.

Thus, in contrast to either adult-directed prescriptive approaches or facilitative approaches that follow the child’s lead, the *SCERTS Model* attempts to work in the middle ground, in that it is systematic and semistructured but also flexible, with a hierarchy of goals in social communication and emotional regulation informed by research and based on each child’s needs and parental priorities.

Activities are designed to be consistent and predictable, with a priority on social communication, social and emotional reciprocity, and creative problem solving fostered in the context of meaningful activities, shared enjoyable experience, and shared control.

Shared control involves two or more partners having opportunities for turn taking and choice making, with the ultimate goal of each partner developing the capacity to follow the other partner’s agenda, a critical ability that underlies cooperative learning. In this manner, the model is flexible and responsive, allowing partners to capitalize on a child’s motivation, spontaneous communication, and teachable moments.

Furthermore, a basic tenet of the *SCERTS Model* is that to work effectively with children, it is always necessary for the adult to take into account a child’s level of emotional arousal and regulation and therefore the child’s availability to learn and participate in social exchange.

Structure, consistency, and predictability provide the framework and support for learning; however, a child’s self-determination and the ability to adapt and grow emotionally is enhanced by flexibility within structure, opportunities for social control through communication and choice making, and opportunities to solve problems in a variety of social and nonsocial activities.

We believe that children with ASD of all ages and ability levels can benefit from this kind of approach. However, younger children and children who are less able to regulate themselves emotionally and to organize themselves in achieving goals may initially benefit from a greater degree of support through heightened consistency and predictability and through transactional support.

In this manner, the model is designed to be flexible and responsive to individual differences in children and families, providing more or less structure and support, depending on a child’s abilities and needs in different activities and a family’s needs.

Adapted from *The SCERTS™ Model: A Comprehensive Educational Approach for Children with Autism Spectrum Disorder*, by Barry Prizant, Amy Wetherby, Emily Rubin, Amy Laurent, and Patrick Rydell

Q & A with Dr. Marion O'Brien



Q: What is the one thing you would say to a parent who has just found out her child has autism?

A: I would say, "I am sure you must feel overwhelmed and confused and even a little bit as if your child, whom you thought you knew well, is somewhat of a stranger to you. I want you to know that these feelings are shared by many other parents of children with autism spectrum disorders, and they are a natural and normal reaction to a very difficult and complicated situation."

I also want you to know that there is hope for your child—there are good, effective intervention services that can make a real difference in your child's life and for your family. And, most of all, you will find that your child is still the person you love so much. As one father told us, 'It doesn't change how you love them. You just love them more and more.'"

Q: What book have you read lately that you are excited about?

A: Recently I got around to reading *The Curious Incident of the Dog in the Night-Time*, a novel by Mark Haddon, that is very entertaining but also gives some helpful insight into living with a child with an autism spectrum disorder. Most interesting to me were the glimpses into the world of the child with ASD and how ordinary, everyday events may be experienced so differently.

Q: What inspired you to work with kids with autism?

A: I grew up with a brother who had Asperger syndrome, but was never diagnosed. When I learned about Asperger syndrome as an adult, much about my family life as I was growing up

became understandable. I realized how much my parents had struggled because of the ambiguity of my brother's condition and the fact that they had no help whatsoever, and I became determined to try to help other parents of children with ASDs.

"You will find that your child is still the person you love so much. As one father told us, 'It doesn't change how you love them. You just love them more and more.'"

Q: What do you see as the next breakthrough for autism?

A: I am optimistic that advances in our knowledge of human genetics will ultimately allow us to have a biological marker for autism and will also bring clarity to what is currently a very confusing set of diagnostic criteria. On the intervention end, I also am hopeful that earlier diagnosis combined with intervention beginning in the second year will be effective in reducing some of the symptoms of ASDs.

Q: What is the greatest obstacle you have overcome in your work?

A: I consider myself one of the luckiest people in the world in that I have always been able to obtain support to do the kind of work with children and families that I felt was important and meaningful. Being able to do work you love and contribute in some small ways to making families' lives better is truly a gift. I really cannot say that I have had to overcome any major obstacles—but that may be partly because I generally consider setbacks as challenges rather than barriers.

Q: What is the most rewarding experience you've had in working with a child with autism?

A: The opportunity to talk with and learn from families of children with ASDs has been a wonderful experience for me, and I am very grateful to all the families who have participated in our research projects for sharing so much of their lives with us.

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VISIT: WWW.UNCG.EDU/FRC/

Partnering with Families

Understand how to help families after the diagnosis



Parents of children on the autism spectrum experience all of the emotions tied to mystery. They fear for their child's survival and for their own hopes and dreams. They become frustrated with the day-to-day demands for patience and persistence in coping with their child's behavior and with the difficulties of negotiating a complex service system that they never before knew existed.

Given the fear and frustration, it is perhaps miraculous that so many parents of children with autism are eventually able to experience its fascination as well and to appreciate their child's unique personality. As one parent of a challenging 11-year-old put it, "Our lives would be boring without him!"

The scientific unraveling of the mystery of autism will help in guiding efforts at prevention and treatment. Yet, for professionals and parents who are involved with children on the autism spectrum, there will always be the need to unlock the mystery presented by each individual child, and this will be accomplished only by working together, dreaming together, and, most important, talking together. Parents know a lot about their children, and well-trained, experienced professionals know a lot about ASDs.

The challenge is to get the two to talk together and work together successfully in order to provide children with the best chance in life.

Autism has been one of the most contentious topics among professionals in the fields of education and early intervention. The diagnosis of autism is often not straightforward; children with ASDs may exhibit many different profiles of strengths and difficulties.

Also, there are differences of opinion among professionals in different fields as to what characteristics describe the individual ASD subtypes and, in fact, as to whether it is a good idea to diagnose any subtype other than full-blown autistic disorder.

Autism makes many people uncomfortable, probably because of the image often portrayed of individuals with autism as isolated and hard to reach. Professionals are not immune from these feelings. Such unresolved ideas and biases about autism interfere with open and honest communication between parents and professionals.

Intervention for autism is also controversial. In the absence of a known cause of ASDs, there can be no cure. In the face of parents' clear distress and determination to find a cure, many different kinds of interventions have been proposed. The rumor mill surrounding autism reaches more families (and probably more professionals) than the research literature.

Thus, much of the discussion about intervention for autism is based on hopes, dreams, secondhand stories, and, at best, case studies—not on clear evidence for effective practices.

Building strong relationships and providing effective services for children with ASDs require both professionals and family members to become more knowledgeable about autism in all its guises and to talk together about their hopes and fears for children with ASDs.

Building relationships also requires both parents and professionals to place greater reliance on standards of evidence that are accepted by the scientific community and less faith in hearsay and miracles. To build positive relationships, both parents and professionals must be open to a range of possibilities and not so sure that one way of doing things is the only way or even the best way.

When parents learn that their child has an ASD, they must cope with the difficulties of reorienting their expectations for their child, and at the same time they must face the reality that their own lives will be changed forever.

It is helpful for professionals to recognize the extent of adaptations families must make in their daily lives just to keep things on a relatively even keel. Professionals who are aware of the many difficulties parents face are more likely to respect the knowledge, skills, and endurance of parents of children with ASDs and to interact with parents in a way that shows this respect.

Adapted from Beyond the Autism Diagnosis: A Professional's Guide to Helping Families, by Marion O'Brien and Julie Daggett

Q & A with Dr. Paula Kluth



Q: What is the one thing you would say to a parent who has just found out her child has autism?

A: I would say he is the same great kid you had yesterday and that I hope that this label does not prevent people in his life from seeing his gifts, abilities, strengths, and uniqueness.

Q: What book have you read lately that you are excited about?

A: I loved *Autism and the Myth of the Person Alone* by Doug Biklen and a handful of incredible individuals with autism. I would highly recommend it to everyone interested in autism, communication differences, facilitated communication, or the education of people with significant disabilities.

These authors are gifted storytellers, in a way, and each in their own way, challenge the notion that autism is a collection of deficits and that folks “live in a world apart.” It is poignant and important.

Q: What do you see as the next breakthrough for autism?

A: Well, I don’t know if it is a breakthrough, but the most exciting trend I see is the increased focus on LISTENING to the words of people with autism and honoring their experiences as we make decisions, plan programs, and create supports. I am very encouraged to see all of the autobiographical texts available today to families, teachers, and others with autism labels.

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Q: What is the greatest obstacle you have overcome in your work?

A: Attitudes. In working in inclusive education, I often hear that students with disabilities “can’t” or “won’t” or “never will” and it is always exciting to see situations where teachers reject this language and this way of thinking, teach to student abilities, and create new opportunities for the learner based on hope and possibility.

“The most exciting trend I see is the increased focus on LISTENING to the words of people with autism and honoring their experiences as we make decisions, plan programs, and create supports.”

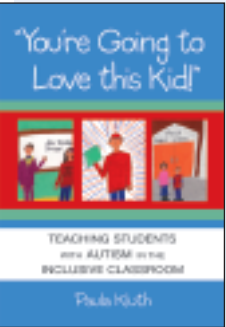
Q: What is the most rewarding experience you’ve had in working with a child with autism?

A: Probably my most rewarding experiences have been in collaborating with students with autism to teach others about their needs and abilities. It is a humbling experience. I

helped one young man draft an “IEP for the teacher,” a document he wrote to help his educators teach him more effectively. Another student asked me to help him lead his transition meeting. I am always interested in helping students demonstrate to others that they are the experts in their own lives.

“You’re Going to Love this Kid!”

Attitude makes all the difference when teaching kids with autism



On the morning of my first day of teaching, I was told I would be working with a 6-year-old student with autism named Jacob. I was given dozens of files to review. I marveled at the stacks of reports, evaluations, observations, clinical assessments, work samples, and standardized test results. I couldn’t believe a child so small could have so many “credentials.”

As I reviewed the files my feelings changed from stunned to overwhelmed to terrified.

Jacob’s paperwork was filled with information about his inability to be a student or a learner. The documents detailed his challenging behaviors, skill deficits, and communication problems. I was dazed—I was scarcely 22 years old, I had only recently graduated from my teacher preparation program, and I remembered little from the one or two lectures I had attended on autism.

Before I could complain to my colleagues or sneak out the back door of the building, I heard my name on the loudspeaker and was beckoned to the school office. I grudgingly made my way down the hallway only to be met halfway by a grinning and extremely animated school administrator. Dr. Patrick Schwarz seized me by the shoulders and said, “So, you’re going to be Jacob’s teacher. That’s fantastic. You’re going to LOVE this kid!”

This inspirational leader could not have been more accurate in his assessment of Jacob or the future I would have with this young student. In the next few years, Dr. Schwarz, the school principal, my general education colleagues, Jacob, and the other students in the school all collaborated to create an inclusive environment and experience in the first-grade classroom.

The first few weeks of school were a challenge, but the school community worked together to create success for this young man. Administrators shifted classroom schedules to accommodate Jacob’s need for a recess break early in the day; students worked to learn Jacob’s communication system; teachers created materials and invented lessons that intrigued and engaged their new student; Jacob’s family shared their expertise and gave suggestions for making him comfortable in

his new school, and Jacob worked daily to meet new friends, learn classroom routines, and participate in lessons.

Though Jacob did not speak, occasionally struggled with challenging behaviors, and needed a wide range of adaptations to engage in curriculum and instruction, he was soon participating and succeeding in all aspects of school life.

Through this energetic, precocious, and unique 6-year-old, I learned how to be a teacher—not just of students with autism—but of all learners with and without disabilities in the inclusive classroom.

An important piece of this story is obviously the role of my former administrator, Dr. Patrick Schwarz. His positive attitude and encouraging behaviors influenced my impression of Jacob; inspired me to learn about students in holistic ways; and prompted me to study more about autism, behavior supports, skill instruction, communication needs, and curriculum development.

Unfortunately, the perspective and attitude offered by Dr. Schwarz seems to be rare. The dominant paradigm in educating students with autism has been and continues to be based on deficits, labels, and a positivist tradition. This paradigm was verified by the information in Jacob’s files and is exemplified in much of the educational literature, college textbooks, and popular media sources that introduce pre-service teachers to autism.

I believe Jacob’s story is an appropriate way to illustrate an alternative approach to educating students with autism. Dr. Schwarz’s approach to educating Jacob was based on a positive, individualized, and inclusive ideology instead of based only on student needs, failures, and struggles.

This anecdote portrays the possibilities that exist when educators see students as part of the school community, view inclusive schooling as a possibility for all learners, and understand “inclusion” as something that can be pursued every day for every student instead of something that is appropriate for some and not others.

Adapted from “You’re Going to Love this Kid!” Teaching Students with Autism in the Inclusive Classroom, by Paula Kluth

Q & A with Dr. Robert Naseef



Q: What is the one thing you would say to a parent who has just found out her child has autism?

A: Finding out that your child has autism can be an extremely dark day for parents. This is tough news to swallow. You don't have to kid yourself or those who love you about how hard this can be. It will take time to regain your balance.

The diagnosis is the beginning of your journey. As your child gets the appropriate therapies, you will see progress and you will feel relief because now you know what to do to help. While it can be painful to say goodbye to the child of your dreams, you can say hello now to the child who needs you just as much if not more. You will find great joy and great love in each and every achievement that you would have taken for granted had your child had a "typical" developmental course.

Q: What book have you read lately that you are excited about?

A: Actually there are two books. For the general readership, I am very proud of the book I have just co-edited with Cindy Ariel, *Voices from the Spectrum: Parents, Grandparents, Siblings, People with Autism, and Professionals Share Their Wisdom*.

The broad scope of this book presents insights into the autism spectrum from many different perspectives—from firsthand accounts of people who grew up with autism to parents' and grandparents' reactions to a diagnosis.

The other book geared toward a professional audience is *Beyond the Autism Diagnosis: A Professional's Guide to Helping Families*, by Marion O'Brien, Ph.D., and Julie Daggert, Ph.D. Written with keen insight and sensitivity, this book is an essential guide for professionals who work with families who have a child with autism.

Q: What inspired you to work with kids with autism?

A: My son. There are times, even now that Tariq is in his 20s, when I still wonder who my son might have been, without the autism, and who might I have been as well.

Everything changed when the "autism bomb" hit and he stopped talking and began an endless sequence of repetitive activities. Tariq stopped relating by sharing his joy and interest in life. A few years later he was diagnosed with autism and mental retardation. The impact sent his development and family life veering sharply from the course we were on.

I thought I could change Tariq and make him the boy I wanted him to be, frantically and persistently following various treatment approaches: behavioral, educational, dietary, and developmental. Despite intensive treatment, he did not make dramatic progress. Instead he has been a catalyst to transform me.

He taught me the meaning of unconditional love—to honor his sacred right to be loved for who he is, not what he has achieved lately, how he looks, or how much money he will earn. Without words, he continues to teach me a priceless lesson and continues to inform and inspire my work with families and children.

Q: What do you see as the next breakthrough for autism?

A: So many children have been affected, and so many families have had their lives disrupted. The money being spent on research is a tiny fraction of what is needed.

The most urgent need is for state-of-the-art services for children and their families who have been struck by autism. Alarming, a 2-year-old child just diagnosed with autism in the United States gets only a few hours of home-based services per week, while experts recommend 30 to 40 hours of programming.

In many parts of the world services are just beginning to be developed. Parents shouldn't have to beg and scream for services when their child enters school. Many of these schools are poorly funded, especially in the inner cities, and have inadequately trained staff and few or no opportunities for developing social skills by including children with autism with their same-aged peers.

It is heartening to have the issues finally begin to be recognized more widely. We need to do our best to find solutions.

Q: What is the greatest obstacle you have overcome in your work?

A: My greatest obstacle is accepting my own limitations. I try to help people accept themselves just as they are. This is the key to accepting our children with an open, kind, and loving heart.

What Tariq has taught me besides accepting him is to accept myself. I think the challenges in our children radiate inwardly to our own imperfections. I had to begin accepting my own flaws. Finally accepting our pain and ourselves leads to accepting and enjoying our child and our family life. That awareness is the gateway to love and wholeness.

Q: What is the most rewarding experience you've had in working with a child with autism?

A: I take great joy in seeing parents fall in love with their child all over again. First, I try to help people look at their grief. It doesn't help to pretend to be positive when underneath you may be lonely, afraid, or sad.

I learned we don't have to lie to ourselves. You can grieve. You can complain. You can mourn. This helps you to go on, make the best of the situation, and enjoy life.

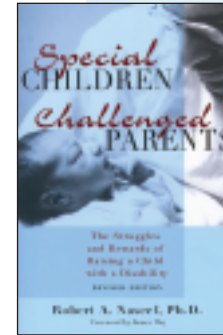
A perfectly lovely child or adult on the spectrum can be very hard to be with because of their behavioral, social, or communication issues. When you love someone, you expect yourself to love to *be* with them. When you don't feel that and think you should, the guilt can be unbearable, and your heart aches.

This is an inner conflict that any parent can relate to, but when a child has autism, this can happen much more frequently. Learning to join your child where she is on the developmental ladder and rejoicing in each little step is the antidote.

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A Father Is Born: My Story

No one can understand having a child with autism quite like a fellow parent



More than 20 years ago, my only son and my oldest child, Tariq, was a seemingly typical happy toddler. There was something new in our life every day. When he was 4 months old, for example, he began to lift his head and look around. I took a picture of him that I still prize. There was an amazing resemblance to an old picture of me that my mother had taken at the same age.

A month or so later he began to crawl. There was a gleam in his eye as he motored himself at will around the house, pulling himself along with the help of furniture and walls to get where he wanted.

By his 8th month, he could pull himself up to a standing position, beaming with pride. A few weeks later, he began to "cruise," holding onto furniture and getting around whenever he could. Frequently, I would hold his hands above his head and walk behind him, full of anticipation for his next achievement.

Before long it was his 1st birthday; Tariq also took his first baby steps on that big day. I recall his look of apprehension and then the thrill of achievement expressed with a smile as he took his first awkward, wobbly steps. I was so proud of him. What an amazing accomplishment!

By 18 months, he was just beginning to speak and had a small but useful vocabulary. He had been reaching all of the usual developmental milestones, and I imagined that before long he would play little league baseball. I would be there watching as my father had watched me.

At this time, however, Tariq was treated for an ear infection, and our whole life changed. Tariq became frustrated and withdrawn. He cried a lot and didn't sleep well at night. I worried, especially at night, when I was awake with him.

My daughter Antoinette had recently arrived on the scene, and at first, the pediatrician thought it could be an emotional response to no longer being an only child. I hoped that the doctor was right, but I was scared of what it would mean if he was wrong.

Soon, Tariq stopped talking and stopped playing with the toys that he had received for his birthday—like the little workbench with its nuts and bolts and tools that my parents had given him, just like the one that I had when I was a little boy.

Tariq began playing with a transparent rattle with brightly colored beads inside. He seemed fascinated by this toy and played with it for days and weeks on end while ignoring virtually everything else around him, including his baby sister. He became very agitated and upset if the rattle was taken away. My sweet toddler was gone.

The awakening was rude. That exciting time when every day brought a new accomplishment was gone. His life, which had been a great joy to me, became a worry that preoccupied what seemed like my every moment.

When Tariq was 2 years old, I spent the summer with him while on vacation from my teaching position. The pediatrician had said that he might just need time. I worked hard to get his attention—to establish eye contact and a connection.

I would put him on the swing in the backyard and stand in front as I pushed him. At the same time, I tried to catch his gaze for a fraction of a second. He would turn his eyes to the side on purpose; he was a master at avoiding contact. It felt like a personal rejection.

It wasn't until he was diagnosed with autism a few years later that I learned he was easily overwhelmed by stimuli and that I had to back off.

Tariq was in an early intervention program by his 3rd birthday, and he was the most difficult child in the school to manage. He required one-to-one attention at all times. He couldn't or wouldn't stay in his seat for more than a few seconds when he was left unattended. Whenever I wasn't teaching, I spent the day with him in school, helping the teachers.

Eventually, my son was diagnosed with a "pervasive developmental delay," a broad diagnostic category that includes autism. The condition is found in 1 of every 500 children according to current estimates. The team of professionals that evaluated Tariq used the words *autistic-like* and *retarded* in their diagnosis. I went numb and then became livid with them.

Although the anger subsided long ago, the tears are never far. The professionals seemed to have no hope for my son. "Has anyone told you that your son is retarded?" With these words, the social worker broke the news. What a way to tell a parent something of this nature! How could they make such a diagnosis? Their words sliced through me like a knife. How could I give up on Tariq?

As I remember it now, I withdrew inside myself as I learned about the disorder. It was painful to read that autism is a severely incapacitating and lifelong disability. It was hard to comprehend that my child's brain cannot process what he hears, sees, or touches. The information that he takes in is distorted or fragmented, making it incomplete or confusing. I was told that communication with others would be extremely difficult for him.

Like many parents in similar situations, I spared no expense in the quest to find a cure for Tariq. We tried to help him with speech and movement therapies and even vitamins and a special diet. For many years, the burden of the debts from these treatments was in itself a constant reminder of my hope for a cure. My dreams died a slow death as I ran out of treatments to try. As I became strong enough to face it, the reality that Tariq's condition was lifelong slowly came into focus.

* * *

At that point, more than 15 years ago, a colleague showed me an article in the *Journal of Counseling and Development* that talked about the grief experienced by the parents of children with disabilities. As I read sentence after sentence, I came to a deeper awareness of myself. Suddenly, many disconnected feelings and thoughts began to make sense. I leaned back in my desk chair, took a few slow deep breaths, and thought, "So, that is what Tariq's life is all about to me; I am a bereaved parent."

From that day onward, my life began to change for the better.

Adapted from Special Children, Challenged Parents: The Struggles of and Rewards of Raising a Child with a Disability, Revised Edition, by Robert A. Naseef, Ph.D.

Q & A with Dr. Robert Koegel



Q: What is the one thing you would say to a parent who has just found out her child has autism?

A: I would like to say 2 things.

1.) Children with autism have many strengths and desirable qualities that need to be recognized

2.) There have been many treatment research advances in recent years that greatly improve the prognosis for children with autism

The bottom line is that there is a lot of hope. The future should be happy.

Q: What book have you read lately that you are excited about?

A: *Freakonomics*. [I would recommend it to anyone who is interested in looking at creative solutions for difficult problems.

Q: What inspired you to work with kids with autism?

A: I was interested in applying the scientific method to solving difficult problems affecting human beings. Autism seemed like an area where there was great potential for science to come to the rescue.

Rapidly, I became attached to the children and their families, and as I saw improvements taking place, I became very excited about the potential for a bright future for these families.

Q: What do you see as the next breakthrough for autism?

A: I think we are on the verge of a cure. Behavioral interventions such as Pivotal Response Treatment are producing dramatic improvements in symptoms and in the overall condition of autism. The likely improvement in neural functioning and brain pathways suggests that, with further systematic research, we have the potential to soon be able to cure autism by building alternate neural pathways.

Obviously additional intensive research is necessary in order to accomplish this, but it should be possible given what we have already accomplished. I anticipate a cure for autism within our lifetimes.

Q: What is the greatest obstacle you have overcome in your work?

A: The biggest obstacle has been system change. Many advances in the field of education and health for children with autism suggest major systems changes are needed in these service delivery areas.

The educational system, especially the development of classroom models requires considerable and continuous change. Similarly the health care system, involving the delivery of intensive treatment for such a severe disorder as autism, requires change in order to allow for financially and fiscally responsible treatment delivery.

Changing systems is extremely difficult and frustrating. But, it can be done.

Q: What is the most rewarding experience you've had in working with a child with autism?

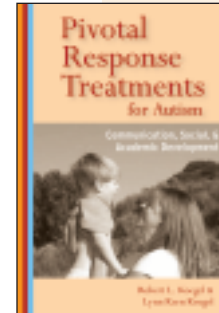
A: The look of happiness on the children's faces, and the current expression of joy and hope on their parents' faces.

"I think we are on the verge of a cure. Behavioral interventions such as Pivotal Response Treatment are producing dramatic improvements in symptoms and in the overall condition of autism."

DR. KOEGEL IS DIRECTOR, UCSB KOEGEL AUTISM CENTER; PROFESSOR OF CLINICAL PSYCHOLOGY AND SPECIAL EDUCATION, GEVIRTZ GRADUATE SCHOOL OF EDUCATION, UNIVERSITY OF CALIFORNIA SANTA BARBARA; CO-AUTHOR, **PIVOTAL RESPONSE TREATMENTS FOR AUTISM: COMMUNICATION, SOCIAL, & ACADEMIC DEVELOPMENT**.
VISIT: [HTTP://EDUCATION.UCSB.EDU/AUTISM/](http://education.ucsb.edu/autism/)

How One Boy Lost His Autism Diagnosis

Peter is a typical 5-year-old. What a wonderfully mundane statement ...



Peter was diagnosed with autism by a developmental pediatrician at the age of 2. His parents reported that they had heard him say seven words, however these words were not used functionally or consistently.

In addition to communication delays, Peter engaged in a number of inappropriate behaviors

- He regularly engaged in tantrums and aggression to request desired items, to terminate interactions, and when he was denied access to a desired item or activity.
- He generally used nonverbal communication, such as leading parents to desired objects.
- Transitions were often accompanied by crying and disruptive behavior.

Socially, Peter did not demonstrate any joint attention behaviors, did not show an interest in his peers, or engage in simple interactive games or pretend play. Rather, he preferred to engage in repetitive and restricted interactions with items—such as spending unusual amounts of time playing with public payphones—that were followed by tantrums when his mother tried to leave the phone or engage him in appropriate activities.

Consistent with the features of a comprehensive model of service delivery, intervention began early (2 years 2 months), and focused on reducing the core symptom areas of autism to address Peter's behavioral excesses and deficits.

Specifically, initial goals of the program were directed toward

- increasing Peter's motivation to respond
- increasing his production of functional verbalizations, and
- replacing his challenging and inappropriate behaviors with functionally equivalent behaviors.

In order to maintain a high level of intensity, procedures were coordinated with all of Peter's care providers across all of his daily environments. Since Peter spent the most time with his mother, she began participating in a parent education program that could be implemented across the family's daily activities and routines.

Lisa was introduced to the motivational procedures of Pivotal Response Treatment (PRT), highlighted in *How to Teach Pivotal Behaviors to Children with Autism: A Training Manual* (R.L. Koegel, et. al., 1989), and taught how to incorporate their use into daily interactions with Peter throughout the day and in natural environments (i.e. home, park, restaurants, grocery store).

At first, Peter did not respond to his mother's attempts to implement the motivational procedures and instead engaged in tantrums that included crying, screaming, hitting, and pulling his mother's hair. Within a couple weeks of implementing PRT, however, Peter's tantrums decreased in both frequency and intensity and he gradually began to use verbal attempts to communicate.

Lisa was taught to provide natural reinforcers (i.e. preferred toys, activities, and foods) contingent upon Peter's attempts to verbally communicate. Initially, all of Peter's verbal attempts to use expressive communication to request desired items were a single vowel sound /a/.

Thus, whether he was requesting a ball or a toy car, Peter demonstrated his motivation to respond by reaching out his hand

and saying, "Aaaaaaaaahhhh." In time, Peter's attempts to communicate more closely approximated the label of the desired items. That is, Peter began saying, "Ba" for ball and "Ca" for car, or "Uh" to be picked up.

As his word attempts increased and his word differentiation developed, joint attention also emerged and Peter began to consistently and spontaneously use single words to request desired items and communicate his needs while looking at his mother or other familiar adult. Shortly after, Peter began combining two words such as "open door," "blue ball," and "all done" and occasionally using three-word-utterances such as "more cookie please."

Lisa also incorporated the motivational procedures of PRT in various community settings, allowing Peter to be exposed to the same stimuli, events, and people as typically developing children. For example, Lisa created numerous learning opportunities for Peter at the park, beach, and playground.

At the beach, for example, she taught Peter how to dig in the sand by providing natural reinforcers contingent upon Peter's attempts to say words such as sand, water, and shovel.

Peter also was included on trips to the grocery store and meals with his family in restaurants. At the grocery store, Peter added preferred food items to the grocery cart by attempting to verbalize the label of each item (e.g. cookies, juice, crackers). Thus, Lisa implemented PRT throughout daily activities such that Peter was motivated to respond across all natural settings and environments.

Consistent with the breadth of the comprehensive model, Lisa also enrolled Peter in a full inclusion preschool at 3-years-old so that Peter would benefit from social interaction with typically developing peers. Lisa played an integral role in coordinating services with the preschool by assisting the teachers and instructional assistants to ensure that the intensity of intervention remained high.

The preschool staff was taught to incorporate the motivational techniques throughout the day so that Peter would benefit both socially and academically. For example, the staff optimized the preschool curriculum for all children by incorporating the motivational procedures of PRT to facilitate interactions between Peter and his peers.

Thus, during an art activity, the pre-school staff prompted both Peter and his peers to request items from one another such as paper, glue, and crayons. By the end of his first year of preschool, Peter consistently requested items from his peers, participated in age appropriate games with his classmates, and had several preferred friends he commonly interacted with both in the classroom and on the playground.

Additionally, he learned to name a variety of shapes, label colors, identify the letters of the alphabet, and count up to 20 with one-to-one correspondence. Peter's language also continued to improve until he was within the range of a typically developing 4-year-old child.

Today, Peter is 5 1/2-years old. He is about to enter kindergarten, and has no syntactical delays. He socially communicates with his peers and plays appropriately with them. He no longer requires special education services, and Lisa reports that he is "one of the most popular kids in his class."

Peter has a best friend and a number of close friends, attends birthday parties, has regular play dates, and he and his friends love to make believe they are popular television characters.

Adapted from Pivotal Response Treatments for Autism: Communication, Social, & Academic Development by Robert Koegel and Lynn Kern Koegel. To see a video clip of Peter before, during, and after PRT treatment, go to www.brookespublishing.com/autism/prt/video.htm

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