

Learning the Language of Autism

Author shares insight into early intervention, resources and understanding autistic children.

By Jennifer Bulka, M.A., SLP

There is a long, sobering journey to take when first embarking upon the path to learn about childhood autism. As a social skills, speech and language pathologist, I meet with parents every day who are overwhelmed and fretful trying to figure out where to begin, what the succession of steps are and how to get the help they need for their child. This article is meant to be an introduction for new parents on the path and for those seeking early intervention strategies.

Navigating the Spectrum

The term Autistic Spectrum Disorder is truly a 'spectrum' of varying labels, behaviors, severities and degrees. The Autism Society of America defines autism as a complex developmental disability, the result of a neurological disorder affecting the functioning of the brain, that typically appears during the first three years of life.

Research into the causes of autism is inconclusive. Some hypotheses speculate a specific genetic link while others point to physiological or environmental factors. Diagnosis by psychologists or based on behavioral observations using a variety of formal, standardized tests and informal diagnostic screening tools in a variety of settings.

While there has been a rise in autism in California in the last 10-15 years, researchers can't agree on the reasons why. One theory is simply that the level of education among professionals and parents has increased awareness about autism and sharpened our ability to detect disorders earlier. A second explanation from Catherine Lord, Ph.D. from the University of Michigan and an expert on autism, is that we've broadened the definition of the disorder. Early detection and diagnosis has in turn led to an up-tick in the statistics. Some point to environmental causes (vaccinations, etc.) while others speculate a double dose (mother and father) of left-brain genes (Geek Syndrome, Wired Magazine 1999.)

Practitioners do agree that early intervention is the key to unlocking your child's optimum outcome. Speech and language pathologist Emily Rubin, a faculty member at Yale University and co-author of the Social Communication, Emotional Regulation and Transactional Support (SCERTS) Program with Dr. Barry Prizant, states that many researchers believe early intervention has a profound effect on the development and flexibility of the brain. They argue that early social and communicative experiences help shape behavior and brain development. While still speculative, researchers also agree that early intervention helps the brain to acquire certain social skills and language that do not develop in autistic children as they may in typical brain development (Dawson et al., 2000; Johnson, 2001). If you are worried about the stigma of labeling a child early in life, don't be – the experts say don't wait.

Early Detection

There are many diagnoses on the spectrum. Some of the labels under the umbrella of autism are PDD-NOS (Pervasive Developmental Diagnosis, Not Otherwise Specified) Asperger's, (high-functioning autism), autism accompanied with a diagnosis of ADD (Attention Deficit Disorder), Rett's Disorder (A

progressive disorder in girls), Childhood Disintegrative Disorder (normal development until two, then significant loss.)

Many children do not have verbal language on the more severe end of the spectrum. And the ones on the higher functioning side who are verbal don't have the "language maps" (intuitive understanding and social language) typical of children their age.

Children on the spectrum exhibit a wide variety of social language and social skills deficits, from communication (verbal or non-verbal) to social interaction to sensory integration disorders. Children with more severe types of autism may be easier to detect at an early age because their behavioral symptoms are more pronounced. Higher functioning children often go undetected by parents and professionals not trained in autism because their social behavioral symptoms may not be easily observable until the child enters a more intensive social situation that requires the use of social language, and its nuances, such as preschool.

It's difficult to detect the signs of autism before two years of age. Yet some researchers argue that there are behaviors in a child's first year of life that can be of concern. For new parents, it is key to familiarize yourself with normal developmental milestones (see www.talkingplayhouse.com for a language milestone chart.) If you are not around a lot of other children in your baby or toddler's age range you may misread developmental behaviors. While these are possible early signs they may not necessarily indicate your child is on the autistic spectrum. A full diagnostic assessment should be done by a team of specialists.

Language and Social Skills

According to Dr. Linda Lotspeich, director of neuropsychiatry/PDD Clinic at Stanford, "The first two markers to look for at two years are your child's language and social interactions." Developmental language milestones suggest that a child develops (at least) a one-word vocabulary by 18 months. Other signs to look for that specifically zero in on autism can be found at www.firstsigns.com.

Some observations to consider are: is your child using shared expressions, is your child using non-verbal as well as verbal communication for intent, does your child show a sense of "listening" by looking at you when you are talking? Is your child initiating interaction with you (verbal and/or non-verbally). Whether your child is verbal or non-verbal, if he is not reacting to typical play situations such as responding to a toy being taken away, smiling when given a favorite toy, exhibiting joy while playing with a favorite toy, there may be cause for concern. If your child is fixating on one toy for several weeks to the exclusion of others, or obsessed with lining up toys beyond a preliminary fascination, you may want to make note. Rubin states "...In fact, by 8 months of age, a child can be quite savvy at getting a parent's attention either by using a differentiated cry, vocalizing louder, and eventually coordinating vocalizations with gestures. These aspects of development (gaze, facial expressions, and sharing experiences) are subtle in comparison to more typically noted milestones such as sitting up, crying, and using first words."

If you're concerned about your child's language acquisition and social behaviors, keep a journal of behaviors. It may not be that any one of these behaviors in isolation is of concern, but when you put several behaviors together, you may find a profile of unusual behaviors starting to develop.

If your child is non-verbal and has some of these other behaviors over a consistent period of time, you may want to ask your pediatrician to refer you to a specialist. Lotspeich says that pediatricians are now being trained in what to look for with autism. A tool they often use for screening is called the Childhood Test of Autism (CHAT.)

Getting an Evaluation

Comprehensive soup-to-nuts diagnostic assessments for autism are lengthy and draining but necessary. Places like UCSF's Autism/PDD Clinic, Children's Health Council, and Stanford Neuropsychiatry/PDD Clinic do such evaluations. Testing can take anywhere from two days to five weeks depending upon the child's needs, the queue, scheduling and the need for further testing. The members of the team may include a pediatric/child psychologist, speech and language pathologist, occupational therapist, behavioral therapist, and sometimes a physical therapist. Once you've gotten a full diagnostic evaluation you can decide on an intervention plan with your diagnostic team.

Choosing Your Team

Once you have received the evaluation results and recommendations, you will hire the individual professionals who can help your child. You most likely won't find the experts in each discipline under one roof; each discipline is very specialized so beware of "one-size-fits" all practices. Another important organizational tool will be to map out a plan all team members can use to easily communicate so that all parties are working closely together on a timely basis, even if from different organizations.

Here are some ideas to keep in mind when choosing a professional to address the specific needs: area of expertise (specifically expertise with children on the spectrum), geographic convenience, availability to other practitioners and

willingness to engage in whole-team meeting from time-to-time (there is usually a fee involved), philosophy with regard to each respective approach, their knowledge and methods in working with other disciplines, and their participation in community outreach and involvement for autism. The key to choosing a practitioner is how willing they are to work with other team members including school professionals. Flexibility is an ongoing theme throughout everything we do with children on the spectrum including the practitioner's approach and lesson plan for your individual child. You'll want to find out how their approach applies the skills from therapy to communication and behavior in everyday living. How do they work with your child outside the therapy? How do they involve you as parents and other caregivers. How do they work with school professionals and prepare you for the process?

Early Assessment

Psychologists often are the first step in assessment. Psychologists conduct many tests and gather information in a variety of ways. Tests include parent interviews, observation of the child in the clinic and at home, an interview with school personnel and the child's pediatrician and more. Once the psychologist has made a diagnosis, most parents move on to further testing with speech and language pathologists, behavioral therapist and occupational and/or physical therapists depending upon the assessment team's recommendations.

Early Intervention Therapies

A large part of your child's work is going to be with a speech and language therapist who specializes in social pragmatic language and social skills.

Emily Rubin of SCERTS says, "Although many argue that there is only one method that works, this claim is not supported by research. There are, in fact,

a range of educational programs and methods that are effective at supporting both social and communicative growth in children with autism."

Speech and Language

Speech and language pathologists assess all pragmatic aspects of language in the three major areas. First, they look at the communicative intent, the child's response to social situations, the language used during a variety of social activities and settings. Second, they look at the child's receptive language, such as understanding and comprehension of language. Third, they evaluate the child's expressive language—syntax and semantics. Testing includes standardized and non-standardized assessments, parent, teacher and other allied professional interviews, observations at home, in class and the clinic with other children. They also create and teach the non-verbal communication systems which you will become well acquainted with, if your child is non-verbal. Treatment includes perceptual awareness, social groups for interactive skills, play facilitation, one-on-one therapy, positive social behavior training, and training and development on communication devices.

The critical treatment intervention components to consider in addition to social pragmatic language and social skills with a speech/language pathologist are behavioral methodologies, occupational therapy, physical therapy (if needed), and counseling. One treatment that continues to garner success, albeit limited is the rigorous behavioral methodologies of Applied Behavioral Analysis/Discrete Trial Training (ABA/DTT), created by Dr. Ivar Lovaas back in the 70s. It is an intensive therapy that lasts six-plus hours a day for up to 40 hours a week.

ABA is one of the most popular methods to help autistic children shape behaviors early in development, yet it is somewhat controversial due to its limitations for "generalization" or carrying over to real-life situations. Dr. Bryna

Seigel of UCSF's Autism/PDD Clinic, and author of *Parent Training, Helping Children with Autism Learn: A Guide to Treatment Approaches for Parents and Professionals* says, "ABA can be a powerful and useful parent training tool...however, the first way a child learns is not the only way learning will be open to him." Seigel's work emphasizes parent training so that parents are empowered with the ability to facilitate language and behavior development and help carry over the tasks learned from ABA into more generalized every day living activities.

Occupational Therapists

Occupational Therapists work on sensory activities to help with sensory integration or SI—a therapeutic approach for children who have difficulty organizing and interpreting the sensory signals in their environment. Treatment includes modulation, visual-perceptual skills, balance, eye-hand coordination, attention span activities, strength and endurance, self-help and other motor skills. Some examples of sensory integration dysfunction or disorder are hand-flapping, hyper or hypo-active behavior when trying to set, sensitivity (and focused obsession) to environmental stimuli such as lights, noises, clocks ticking, fans, etc. (Caroline: this really is an "etc.")

Conclusion

Once you have all the right pieces in place, you will see your child begin to develop ways of communicating and, what appears to be a distressing situation now, will unfold to be a rewarding (nevertheless challenging) experience. I found Dr. Lotspeich's advise to be the most important of all, "Parents should first care of themselves, simply stated but at time very hard to do. In my clinical experience children with autism benefit greatly when parents take of themselves. When parents take care of themselves they have more energy and enjoyment to share with their children."