

Autism 101:

From red flags to a new normal

by Alexandra H. Solomon, PhD

What is Autism?

The United States is facing an autism epidemic. The latest statistics from the Centers for Disease Control and Prevention (CDC) suggest that 1 in every 88 children in the U.S. is diagnosed with an Autism Spectrum Disorder (ASD). The number of children with ASDs has greatly increased from the 1980s when children were diagnosed at a rate of 2-5 in 10,000 (Kogan et. al., 2009). Little debate remains about whether these statistics reflect an increase in actual cases or an expanded level of awareness, identification, and diagnosis of these disorders. Even when taking into account wider diagnostic criteria, research suggests the increase in the number of disorders is real (Hertz-Picciotto & Delwiche, 2009).

As the term suggests, ASDs occur on a spectrum from “full blown” autism, to Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), to the mildest version, Asperger’s syndrome. Although the names of the diagnostic labels are likely to change with the publication of the American Psychiatric Association’s latest diagnostic manual, DSM-5 (Swedo, 2009), a child with an ASD presents with a variety of symptoms that impact the quality of his life and the functioning of his family.¹

Research suggests that the brains of people with autism² show pervasive underconnectivity that limits the individual’s ability to respond to internal and external stimuli in a flexible manner (Minshew & Williams, 2007).

At its core, autism is a problem with dynamic intelligence which leads to a breakdown in the Guided Participation Relationship (GPR), the “intensive but implicit learning process [which occurs] initially with parents and then with other adults” in every culture throughout recorded history (Gutstein, 2009, p. 61). In other words, while typically-developing children crave the excitement of exploring new territory side-by-side with a supportive guide like a parent or teacher, children on the autism spectrum tend toward rote, familiar experiences. While children with autism can have average or above average static abilities (categorizing, organizing, imitating, and computing), they tend to have severe impairments in dynamic intelligence (anticipating, inferring, reflecting, and expanding).

Although not formally included in the current diagnostic definition, children with autism nearly always present with sensory problems such as high pain tolerance, auditory hypersensitivity, tactile defensiveness (e.g., discomfort with tags on shirts, sand, and even snuggles), and may exhibit “sensory-seeking behaviors” such as crashing, squeezing, spinning, and flapping. Other co-existing, common problems include hyperlexia (premature reading abilities that exceed reading comprehension), seizures, sleep disturbances, food allergies, eczema, general gastrointestinal distress, gut imbalances (often related to bacteria and yeast), constipation, diarrhea, immune system dysregulation, and high levels of environmental toxins relative to children who are not diagnosed with autism.

Children with autism present with disparate symptom profiles. Some parents report that their children seemed

“different” from birth, while other parents (perhaps as many as 50%) report many months of typical development followed by a regression (the loss of previously acquired language, motor, and social skills), usually between the child’s first and second birthday (Werner, Dawson, Munson, & Osterling, 2005).

Many questions remain about what causes autism, but there is growing consensus that autism is caused by complex gene/environment interactions (Herbert, 2005). Genes “load the gun” and the environment “pulls the trigger,” making autism a complex, multi-systemic, environmentally-affected condition – an ongoing biological process rather than a hardwired brain state (Herbert, 2005; Jepson, 2007; Sears, 2010). Given the exponential rise in cases, autism cannot be strictly genetic, as our gene pool cannot shift that quickly (Jepson, 2007), but the examination of environmental triggers, including vaccines, has become controversial and politicized. Now more than ever, prospective parents are educating themselves about careful and healthy choices pre-pregnancy, prenatally, and in the early weeks and months of a child’s life that may reduce a child’s chance of facing this diagnosis.

The journey to diagnosis

Every parent of a child with an ASD has a story about those early moments when they began to worry that something was “not quite right” with their child’s development. In recent years, groups like Autism Speaks have worked hard to educate parents about early warning signs, because research indicates that early and intense intervention can go a long way toward mitigating the impact of autism on a child (see text box for a description of early warning signs). Concerned parents often discuss issues regarding their child’s development with their pediatrician. Ideally, the pediatrician would make a referral to a neuropsychologist who can evaluate the child using the two “gold standard” diagnostic tools: the Autism Diagnostic Observation Schedule (ADOS; Lord, Rutter, Dilavore, & Risi 2002) and the Autism Diagnostic

Interview (ADI-R; Rutter, LeCouteur, & Lord, 2003). The ADOS is a protocol that consists of a series of structured and semi-structured tasks that involve social interaction between the examiner and the child. The ADI-R is a structured interview conducted with the parents.

Receiving the news that their child meets criteria for an ASD diagnosis constitutes a pivotal moment in a parent’s life, resulting in a narrative of “life before” versus “life after” the diagnosis. Parents are likely to experience a range of emotions, including shock, anger, fear, relief, and sadness. They may feel confused about how to proceed and with whom to share this news. Parents are confronted with multiple realities; although their child is still the very same child they love so deeply, they are now faced with a mighty challenge.

Creating a treatment plan

Once a diagnosis is confirmed, parents are launched into a complicated world of treatment choices. There are many available therapies, and parents are likely to spend countless hours reading about autism on the Internet and wishing for advanced degrees in biochemistry, education, culinary arts, and law in order to properly digest that information. While a child with autism needs a comprehensive treatment plan intended to minimize the impact of the autism on the child and maximize the child’s potential, creating this treatment plan is one of the most difficult responsibilities parents face.

When advising parents about how to create a comprehensive treatment plan, the non-profit organization, Talking About Curing Autism (TACA), utilizes the metaphor of a three-legged stool to represent the multiple domains involved. Each “leg” is important, and if any of these legs are not properly attended to, the family and/or the child with autism becomes out of balance. The first leg represents traditional therapies like Applied Behavior Analysis (ABA), Relationship Development Intervention (RDI), The Developmental, Individual Difference, Relationship-Based Model (DIR/Floortime), speech

therapy, occupation therapy, and educational supports. The second leg represents biomedical interventions like the Autism Research Institute (ARI) approach (www.autism.com). The third leg represents emotional support for the family. A computer analogy is sometimes used to describe the recursive relationship between traditional therapies and biomedical interventions. Biomedical interventions repair the hard drive (heal the child's body), and the traditional therapies reinstall the software (allow the child to re-do missed developmental milestones).

Traditional autism therapies

Traditional therapies like ABA, RDI, and DIR/Floortime give children with autism the opportunity to gain social, relational, play, and academic skills, and they are usually provided in a one-on-one or small group setting for many hours a week. TACA's website has useful descriptions of many of these therapies. Private providers offer these therapies, and autism health insurance legislation, recently enacted in some states including Illinois, can help make these therapies affordable to socioeconomically diverse families. State-funded early intervention programs (for children from birth to age three) also provide these therapies at a clinic or in the child's home (usually on a sliding-fee scale). These therapies can also be written into a school-aged child's Individualized Education Plan (IEP), as special education legislation mandates a free and appropriate education for all children. Parents also may be eligible for parent counseling, training, and support through their child's school. Parents sometimes need to work with a special education attorney or a legal aid clinic in order to obtain and negotiate a comprehensive IEP.

Biomedical interventions

Biomedical interventions address the physiological imbalances underlying autism. From this perspective, autism is increasingly considered a treatable and preventable biochemical disorder, and supporters of this paradigm shift argue that autism, which has traditionally

been defined behaviorally, is in fact "merely one symptom of an underlying disease process that affects the immunological system, the gastrointestinal system, and the toxicological system, as well as the neurological system" (Jepson, 2007, p. 44). The Autism Research Institute (ARI), created by Dr. Bernard Rimland in 1967, provides training for health care providers so they can attend to the various medical concerns underlying autism. While this paradigm shift remains somewhat controversial, researchers continue their efforts to elucidate the extraordinarily complex relationships between genes, environmental triggers, the body, and the brain in autism (Buie et. al., 2010).

Emotional support for families

It is often said that caring for a child with autism is a marathon, not a sprint, which means that every member of the family system is likely to need emotional support. Parents may find it helpful to join a support group. Some are facilitated and/or topic-based, and some are just ways for parents to join with other parents who "get it." Developing support systems with other families who face similar challenges can offer tremendous healing and reduce parents' feelings of isolation. Typically-developing siblings may need support as well, as research indicates that they face increased risk of emotional and behavioral problems (Petalas, Hastings, Nash, Lloyd, & Dowey, 2009). Family support may come in a variety of forms (support group, therapist-facilitated program, individual therapy, family therapy, and/or books) and is a crucial piece of the puzzle.

Loving what is: Establishing a new normal

Raising a child with autism takes a toll; parents of children with autism have been found to have higher stress levels than both parents of typically-developing children (e.g., Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005; Brobst, Clopton, & Hendrick, 2009) and parents of children with other developmental disabilities (e.g., Abbeduto, et al., 2004). Families with a child with autism also report less adaptability and cohesion, and lower levels

of marital satisfaction, than norm groups (Higgins, Bailey, & Pearce, 2005). Parents of a child with autism are nearly twice as likely to divorce as parents without a child with autism (Hartley et al., 2010). Further, the risk of divorce for parents without a child with autism decreases as the child reaches late childhood and early adulthood, while the risk of divorce for parents with a child with autism remains high through adolescence and early adulthood (Hartley et al., 2010).

On the other hand, raising a child with autism can unify a family. Research indicates that a considerable number of families with children with autism “display factors of resilience – reporting that they have become stronger as a result of disability in the family” (Bayat, 2007, p. 702). Tapping into that resilience takes time and support, but it can be done.

¹ Because boys are four times as likely as girls to be diagnosed with autism, the masculine pronoun will be utilized here (Kogan et al., 2009).

² In this paper, the term autism will be used to refer to the entire spectrum of Autism Spectrum Disorders (ASDs).

Learn the Signs of Autism

The following red flags may indicate a child is at risk for atypical development, and is in need of an immediate evaluation.

In clinical terms, there are a few “absolute indicators,” often referred to as “red flags,” that indicate a child should be evaluated. For a parent, these are the “red flags” that your child should be screened to ensure that he/she is on the right developmental path. If your baby shows any of these signs, please ask your pediatrician or family practitioner for an immediate evaluation:

- No big smiles or other warm, joyful expressions by six months of age
- No back-and-forth sharing of sounds, smiles, or other facial expressions by nine months or thereafter
- No babbling by 12 months
- No back-and-forth gestures, such as pointing, showing, reaching, or waving by 12 months
- No words by 16 months
- No two-word meaningful phrases (without imitating or repeating) by 24 months
- Any loss of speech, babbling, or social skills at any age

(<http://www.autismspeaks.org/what-autism/learn-signs>)

Developmental Milestones by Age

Milestones enable parents and physicians to monitor a baby’s learning, behavior, and development. While each child develops differently, some differences may indicate a slight delay and others may be a cause for greater concern. The following milestones provide important guidelines for tracking healthy development from four months to three years of age.

Before your child’s next visit to the physician, please take the time to see if your child has met his/her key milestones.

These milestones should not be used in place of a screening, but should be used as discussion points between parents and physicians at each well visit. If a child does not have the skills listed – or if there is a loss of any skill at any age – be sure to let your physician know.

Check to see if your child is achieving these typical milestones at each age level.

By 3-4 months

- Watches faces with interest and follows moving objects
- Recognizes familiar objects and people; smiles at the sound of your voice
- Begins to develop a social smile
- Turns head toward sounds

By 7 months

- Responds to other people's emotions
- Enjoys face-to-face play; can find partially hidden objects
- Explores with hands and mouth; struggles for out-of-reach objects
- Responds to own name
- Uses voice to express joy and displeasure; babbles chains of sounds

By 12 months

- Enjoys imitating people; tries to imitate sounds
- Enjoys simple social games, such as "gonna get you!"
- Explores objects; finds hidden objects
- Responds to "no;" uses simple gestures, such as pointing to an object
- Babbles with changes in tone; may use single words ("dada," "mama," "Uh-oh!")
- Turns to person speaking when his/her name is called

By 24 months

- Imitates behavior of others; is excited about the company of other children
- Understands several words
- Finds deeply hidden objects; points to named pictures and objects
- Begins to sort by shapes and colors; begins simple make-believe play
- Recognizes names of familiar people and objects; follows simple instructions
- Combines two words to communicate with others, such as "more cookie?"

By 3 years

- Expresses affection openly and has a wide range of emotions
- Makes mechanical toys work; plays make-believe
- Sorts objects by shape and color, matches objects to pictures
- Follows a 2- or 3-part command; uses simple phrases to communicate with others, such as "go outside, swing?"
- Uses pronouns (I, you, me) and some plurals (cars, dogs)

By 4 years

- Cooperates with other children; is increasingly inventive in fantasy play
- Names some colors; understands concepts of counting and time
- Speaks in sentences of five to six words
- Tells stories; speaks clearly enough for strangers to understand
- Follows three-part commands; understands "same" and "different"

By 5 years

- Wants to be like his/her friends; likes to sing, dance, and act
- Is able to distinguish fantasy from reality
- Shows increased independence
- Can count 10 or more objects and correctly name at least four colors
- Speaks in sentences of more than five words; tells longer stories

(<http://www.autismspeaks.org/what-autism/learn-signs/developmental-milestones-age>)

References

- Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., Murphy, M. M., & Floyd, F. (2004). Psychological well-being and coping in mothers of youths with Autism, Down Syndrome, or Fragile X Syndrome. *American Journal on Mental Retardation*, 109(3), 237-254.
- Baker-Ericzen, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research & Practice for Persons with Severe Disabilities*, 30(4), 194-204.
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 51(9), 702-714.
- Brobst, J.B., Clopton, J.R., & Hendrick, S.S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities*, 24(1), 38-49.
- Buie, T., Campbell, D.B., Fuchs, G.J., Furuta, J.L., VandeWater, J., Whitaker, A.H., Winter, H. (2010). Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: A consensus report. *Pediatrics*, 125(1), S1-S18.
- Gutstein, S. E. (2009). *The RDI book: Forging new pathways for autism, Asperger's and PDD with the Relationship Development Intervention Program*. Houston, TX: Connection Centers Publishing.
- Hartley, S. L., Barker, E. T, Seltzer, M. M., Floyd, F., Greenberg, J., & Orsmond, G. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24(4), 449-457.
- Herbert, M. R. (2005). Autism: A brain disorder or a disorder that affects the brain? *Clinical Neuropsychiatry*, 2(6), 354-379.
- Higgins, D. J., Bailey, S. R., & Pearce, J. C. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism*, 9(2), 125-137.
- Hertz-Picciotto, I., & Delwiche, L. (2009). The rise in autism and the role of age at diagnosis. *Epidemiology*, 20(1), 84-90.
- Jepson, B. (2007). *Changing the course of autism: A scientific approach for parents and physicians*. Boulder, CO: Sentient Publications.
- Kogan, M. D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., Ghandour, R. M., Singh, G. K., Strickland, B. B., Trevathan, E., & vanDyck, P. C. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics*, 124(4), 1-11. doi: 10.1542/peds.2009-1522
- Lord, C., Rutter, M., Dilavore, P., & Risi, S. (2002). *Autism Diagnostic Observation Schedule*. Los Angeles, CA: Western Psychological Services.
- Minshew, N. J., & Williams, D. L. (2007). The new neurobiology of autism: Cortex connectivity and neural organization. *Archives of Neurology*, 64, 945-950.
- Petalas, M. A., Hastings, R. P., Nash, S., Lloyd, T. & Dowey, A. (2009). Emotional and behavioral adjustment in siblings of children with intellectual disability with and without autism. *Autism*, 13(5), 471-483.
- Rutter, M., LeCouteur, A., & Lord, C. (2003). *The Autism Diagnostic Interview, Revised (ADI-R)*. Los Angeles, CA: Western Psychological Services.
- Sears, R. (2010). *The Autism book: What every parent needs to know about early detection, treatment, recovery, and prevention*. New York, NY: Little, Brown and Company.
- Swedo, S. (2009). *Report of the DSM-5 neurodevelopmental disorders working group*. Retrieved March 1, 2011 from <http://www.psych.org/MainMenu/Research/DSMIV/DSMV/DSMRevisionActivities/DSM-V-Work-Group-Reports/Neurodevelopmental-Disorders-Work-Group-Report.aspx>.
- Werner, E., Dawson, G., Munson, J., & Osterling, J. (2005). Variation in early developmental course in autism and its relation with behavioral outcome at 3-4 years of age. *Journal of Autism and Developmental Disorders*, 35(3), 337-350.

Additional resources

www.autism.com
www.autismspeaks.org
www.generationrescue.org
www.taca.org



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