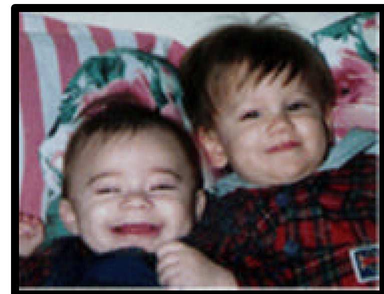
Learning to Live With Autism Part I: Discovery & Diagnosis

Jackie D. Igafo-Te'o, Bridges4Kids, March 28, 2006

In this article, the first installment in a series of 6 articles related to Autism, we will discover the basics of Autism. What is Autism? What are the signs? How is Autism diagnosed? Could we have prevented this? These are just a few of the burning questions that we will discuss. Resources will be provided in each section so that you can find more in-depth information and understanding on each topic.



As the parent of an 11 year old child with Autism, I can still remember the questions that swarmed around in my head when he was first diagnosed at age 3. Did I do something wrong? Did the spinal tap shortly after birth cause this? Was it something that I ingested during pregnancy? Is there something in our genes that is responsible for his Autism? Despite years of living with the diagnosis, those questions are still unanswered. Scientists around the world cannot seem to come to consensus on the cause nor any specific intervention that will make a difference for all children with Autism. One thing is for certain though: moving forward is the most important thing that you can do after the diagnosis. Getting a diagnosis does not "change" your child. Had I been able to take time out between crises to do the research, I probably would've been able to find an intervention that may have made a substantial difference in my son's development. Because of the "severity" of his Autism, that wasn't an option. Our days were filled with head banging, broken windows, bites, bruises…the list goes on. Just getting through each day was exhausting in and of itself.

Fast forward 8 years. The research being done today is nothing short of phenomenal. Every day, we are getting one step closer to finding out the cause of this disorder. Organizations dedicated to research, help and support for those with Autism are popping up around every corner. Therapies abound. If your child has just received the Autism diagnosis, there is hope - - and you are not alone.

What is Autism?

Autism is a neurological disorder that can impair communication, socialization and behavior. It is usually diagnosed within the first three years of life and is four times more common in boys than in girls[1]. However, some types of Autism may not be diagnosed until years later when the child enters school, due to late-occurring social deficits or difficulty playing with others. When this occurs, the child is usually too old to take advantage of early childhood intervention services and is evaluated for entry into the special education system.

[1] NICHCY National Center for Children with Disabilities, Autism and Pervasive Developmental Disorder Fact Sheet 1 (FS1), January 2004

Though awareness and understanding have greatly increased over the past few decades, many people are still unaware of the true affect of Autism. It can become an overshadowing factor in every aspect of life, including education, establishing and maintaining relationships, responding to pain and discomfort, and even in the ability to express emotion.

Symptom severity in Autism can range from mild to severe. For example, one child may intensely flap their arms to show excitement, another may display a smile under the same set of circumstances, while another child may sit in the corner and rock, leading the observer to believe that they may be incapable of showing or feeling emotion.

As parents reach the diagnosis, treatment and education stages of Autism, they will hear many different terms used to describe their child. This may include words such as autistic-like, non-verbal, developmentally delayed, autistic tendencies, savant, high-functioning, and low-functioning. The important thing to realize is that all children with Autism are different. What works for one may have zero effect on another. The combinations of signs and symptoms are endless. More important than the words used to describe the child is the underlying understanding that whatever the diagnosis is, children with Autism are able to learn, function productively in society and show positive gains with appropriate education and treatment plans in place. Without appropriate support, the child may never realize his full potential.

For more detailed information on Autism, here is a brief list of websites and resources:

- The National Institutes of Health's Autism Research Network: http://www.autismresearchnetwork.org/AN/
- The Autism Society of America: http://www.autism-society.org
- About Autism: http://www.autism.about.com
- A short document that explains Autism to children: http://www.njcosac.org/PDF/Fact%20Sheet%20for%20Kids.pdf
- A booklet (from the Autism Society of America) called "Growing Up Together" which talks to kids about having friends who have Autism: http://www.bridges4kids.org/pdf/Growing_Up_Booklet.pdf

What are the signs?

a. **Instead of using words, he may use gestures, grunting or pointing to express his needs.**

The child, who may be nonverbal or have low speech, may grunt or pull at your clothing in an attempt to lead you to the desired object or activity. For instance, if he is thirsty he may stand

at the refrigerator and cry, whereas another child may pull you to the cupboard and point to a cup, and then lead you and the cup to the refrigerator.

b. She repeats things instead of using rational, responsive language.

She may use echolalia to self-stimulate or mimic conversation. For instance, she may not communicate using "typical" methods of speech, or by using sentences. For no apparent reason, she may repeat portions of a commercial, a movie or cartoon, or even something that she has heard someone say in the past. She may mirror back everything that she hears instead of giving an intelligible answer to a question. For instance, you might say "Sara, are you hungry?" She might respond "Sara, are you hungry?"

c. He does not respond to verbal cues. He may appear to be deaf and completely unresponsive.

He may appear to be deaf, at certain times and under certain circumstances, but then, unexplainably, may respond to desired sounds. For instance, he may be sitting in the floor two feet from you. You say "Michael, come here." He doesn't move. Then, not a minute later, he hears the introduction music to a cartoon coming on in the next room. He runs to the television at near warp speed as if his ears were tuned to respond only to that show.

d. She laughs or cries at inappropriate times, seemingly without logic or reason.

At any time, she may burst into uncontrollable crying for no apparent reason. The diligent parent checks her child over and finds no visible injuries. There is nothing obviously disturbing going on near the child that may have upset her. She is inconsolable no matter what the parent tries. She may go on like this for an extended period of time.

e. He prefers to be alone or seems to ignore those around him. He has difficulty being around or dealing with the presence of others.

Every time your sister brings your niece over for a visit, your son disappears. He seems to want nothing to do with her. When invited to join in a group activity, he shies away and finds a quiet corner where he can be alone. He may show discomfort or marked annoyance when forced to be in near proximity to another child.

f. She may sit in a spot on the floor and rock front-to-back or side-to-side. She may bang her head on the wall or cause self-injury.

She may start slamming her hand in the door, followed by screaming, and a repeat performance. She may do this kind of thing over and over again, despite the apparent pain. She may bite herself up and down both arms until there are visible bruises and punctures from the teeth on her skin. This might come in the form of head banging on the wall or the floor. Some children are on the opposite end of the spectrum in this regard. They may sit in a corner or in a place of their choice and rock for hours, as if nothing in the world matters or could affect them.

g. He has unexplainable tantrums or “meltdowns”.

While shopping at the local grocery store, your son suddenly covers his ears, closes his eyes and starts screaming. Everyone turns around. Some make comments about your inability to “control” your child. You have no idea why he is reacting so violently to his environment. While at home, a television show comes on that he seems to like. He watches intently and then goes on a violent rampage. He kicks doors, slams the lamp down, hits his sister in the head, and pounds the wall with his fists. He cries as if there is something causing him pain. Despite your most desperate attempts, you cannot figure out what prompted this episode.

h. She prefers to be left alone instead of being cuddled. She does not seem to crave or prompt her parents for affection.

This is one of the most difficult signs for a parent to cope with emotionally. While it is typical for children to crave their mother or father’s affection, hugs and kisses, your child may seem to be irritated by this close, personal contact. At a very young age, you may notice something a little different in the way your child does not crave affection or does not require close rocking or other physical bonding. Any parent who lacks this type of contact with their child can feel depressed and rejected.

i. He maintains little or no eye contact.

From a very young age, parents may see a lack of eye contact develop in their child. A baby who may have laughed and cooed while staring into your eyes a year ago, may now cringe and violently thrash when held at eye level. Children who lose the ability to maintain eye contact may redevelop the ability through intensive intervention.

j. She may show a need for sameness and resists change. She may become visibly distressed when change occurs.

While most children will not show any type of reaction to a change in schedule or the rearrangement of a room, she may become visibly distressed. Even the slightest change may set her off into a world of uncertainty and panic. Children with Autism seem to thrive on

consistency. From an early age, pictures may be used to show the non-verbal child what is next on a daily schedule. As she progresses, words may be added to the pictures until eventually, the pictures are replaced with phrases or complete sentences. For instance, your little girl may have a chart with her name on it at school. The chart may contain pictures of her schedule for the day. The first picture might be of a coat hanging on a hook, indicating that once she enters the classroom, she is to place her coat on a hook. Visual schedules that replace constant verbal reminders are a useful way to calm her and give her a sense of comfort.

k. He is unresponsive to conventional teaching methods.

From an early age, you may notice that he does not have any functional language, however, many children can develop good functional language which can aide in learning. This may limit teaching methods or cause the teacher to try non-conventional methods. He may not sing along with alphabet songs or seem to comprehend the alphabet. While watching early education videos, he may not pick up on the consistent teaching pattern meant to develop early learning and memorization skills. For example, he may not be able to count or seem to remember what he learned just the day before. It may require a significant amount of additional effort on behalf of both the child and the teacher. For some children, constant repetition may be the only way to learn new concepts. Using reality-based approaches to learning may not work in many cases as some children cannot decipher reality from fiction.

l. He plays with objects in an odd manner or forms inappropriate attachments to objects. He may spin objects, stack objects or use them in unconventional ways.

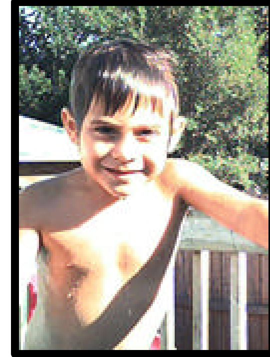
While most children will pretend to race two cars on the floor, he may line them into perfectly straight lines instead of playing with them. He may become visibly irritated if anyone touches or moves one of the cars even a fraction of an inch. He may walk around the house with cans of peas all day or stack them one on top of another until the stack is higher than his own head. He may bang building blocks together or spin them in circles.

m. She displays over sensitivity or under sensitivity to pain, light, certain colors, or sound.

From an early age, some children seem to respond to pain or discomfort in ways that stun their parents or caregivers. She may sit and slam her fingers in the door, scream, and then do so again and again until someone stops her or physically removes her from the room. This leaves you to question whether she feels the pain or whether the pain is dulled somehow. She may cry but the crying does not seem to deter her from repeating the action. While watching a commercial on television, she may suddenly cover her ears or shut her

eyes. This may be due to a particular sound being amplified in her ears or a color that hurts her eyes. For example, she may become very upset upon entering a store with fluorescent lighting and glaring white floors.

n. He does not show a fear of imminent danger.



This is one of the more unsettling signs that may surface anytime in the child's life. For some, this never becomes an issue. For others, the lack of fear has led to instances where a child has died or has experienced great bodily injury. Your child may be extremely drawn to cars. He may draw them on paper, know every make and model upon sight, know the manufacturer's history – he may even collect or build models of them. He may then extend that interest into a dangerous situation without realizing imminent danger. For instance, your son may love the Dodge Viper. Anytime he sees this car on television, he may jump and flap his arms with excitement. Seeing one of these rare cars in person is enough of a stimulating situation to cause him to dart into traffic to go to the car without realizing the danger. He may risk his life just to touch the car.

o. She seems delayed in gross or fine motor skills development.

She may have apparent delays involving hand-eye coordination and the ability to use gross motor skills while watching the target object. For example, she may lack the coordination necessary to catch a ball that is thrown to her, she may be unable to time her jumps while jumping rope, she may be unable to ride a two-wheel bicycle, or to coordinate their arms and hands in order to perform complete jumping jacks.

For more information on the signs of Autism, visit http://www.firstsigns.org/

How is Autism Diagnosed?

Children diagnosed with Autism are delayed or affected in three major areas which include social interaction, communication and behavior.

The Autism Society of America's website section on Diagnosis and Consultation[2] states…

"There are no medical tests for diagnosing autism. An accurate diagnosis must be based on observation of the individual's communication, behavior, and developmental levels. However, because many of the behaviors associated with autism are shared by other disorders, various

[2] From the Autism Society of America's website online at http://www.autism-society.org/site/PageServer?pagename=DiagnosisConsultation.

medical tests may be ordered to rule out or identify other possible causes of the symptoms being exhibited. At first glance, some persons with autism may appear to have mental retardation, a behavior disorder, problems with hearing, or even odd and eccentric behavior. To complicate matters further, these conditions can co-occur with autism. However, it is important to distinguish autism from other conditions, since an accurate diagnosis and early identification can provide the basis for building an appropriate and effective educational and treatment program. A brief observation in a single setting cannot present a true picture of an individual's abilities and behaviors. Parental (and other caregivers' and/or teachers) input and developmental history are very important components of making an accurate diagnosis."

Children diagnosed with Asperger's Syndrome usually do not experience any delays in the development of communication skills, only in the ability to communicate on a social level and in the pragmatic use of language.

The DSM IV[3] states…

"The essential features of Asperger's Disorder are severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behavior, interest, and activity. The disturbance must clinically significant impairment in social, occupational, and other important areas of functioning. In contrast to Autistic Disorder, there are no clinically significant delays in language. In addition there are no clinically significant delays in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior, and curiosity about the environment in childhood."

Children diagnosed with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) may experience difficulty in areas similar to both Autism and Asperger's Syndrome, but do not fall directly into either diagnostic category. For example, the child may experience difficulty in communication skills and in social interaction, but does not display behavioral challenges. These three types of Autism are commonly called Autism Spectrum Disorders (ASD). To make matters even more confusing for parents, these three types of Autism, along with two other types of developmental disorders, fall under the "umbrella" category called Pervasive Developmental Disorder (PDD). There are five disorders which make up the category of PDD: Autistic Disorder (Autism), Rett's Syndrome (or Rett's Disorder), Childhood Disintegrative Disorder, Asperger's Syndrome, and Pervasive Developmental Disorder Not Otherwise Specified (PDD NOS) (fig.1). There has been some confusion regarding the difference between the two terms PDD and PDD NOS. Some doctors use the term PDD as a shorter version of PDD NOS, whereas other doctors are hesitant to diagnose a specific PDD (such as Autism) and will use the umbrella term of PDD instead.

The National Dissemination Center for Children with Disabilities (NICHCY) fact sheet on Pervasive Developmental Disorders[4] states:

"Generally, an individual is diagnosed as having PDDNOS if he or she has some behaviors that are seen in autism but does not meet the full DSM-IV criteria for having Autistic Disorder. Despite the DSM-IV concept of Autistic Disorder and PDDNOS being two distinct types of PDD, there is clinical

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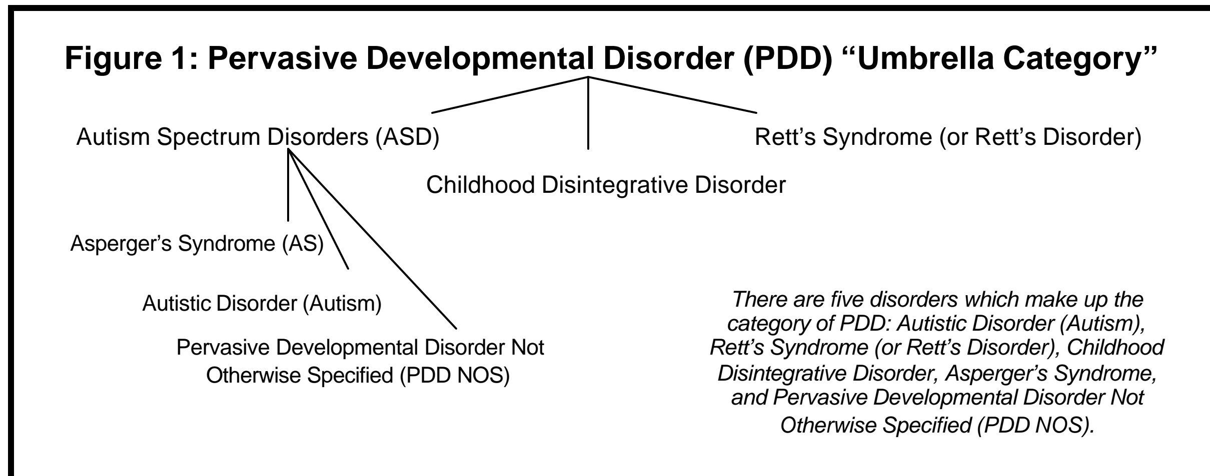
[3] DSM IV, Asperger's Disorder, 299.80

[4] NICHCY National Center for Children with Disabilities, Pervasive Developmental Disorders (PDD) Fact Sheet (FS20), Updated, October 2003

evidence suggesting that Autistic Disorder and PDDNOS are on a continuum (i.e., an individual with Autistic Disorder can improve and be rediagnosed as having PDDNOS, or a young child can begin with PDDNOS, develop more autistic features, and be rediagnosed as having Autistic Disorder). However, amidst all this confusion, it is very important to remember that, regardless of whether a child's diagnostic label is autism, PDDNOS, or MSDD, his or her treatment is similar."



Interested in doing more research on the diagnosis of Autism? For more information on Diagnostic Tools and Screening Instruments, visit…

- The Autism Society of America's sections on screening and diagnostic tools: http://www.autism-society.org/site/PageServer?pagename=DiagnosisConsultation#Screening and http://www.autism-society.org/site/PageServer?pagename=DiagnosisConsultation#DiagTools
- The American Academy of Pediatrics (AAP) has published a report titled "The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children" which can be downloaded at: http://aappolicy.aappublications.org/cgi/content/full/pediatrics;107/5/1221
- AAP's "Practice Parameter: Screening and Diagnosis of Autism" can be downloaded at http://www.aan.com/professionals/practice/pdfs/gl0063.pdf

What went wrong? Could we have prevented this?

Current reports show the incidence rate of Autism at 1:166[5] children. This number is very disturbing especially considering that just a few decades ago, the incidence rate stood at 1-2:10,000[6]. The numbers are rising – there is no doubt about that – and Autism has become an epidemic...but what is the cause? Some researchers claim that the numbers aren't necessarily "rising" but are the result of better diagnosis and awareness.

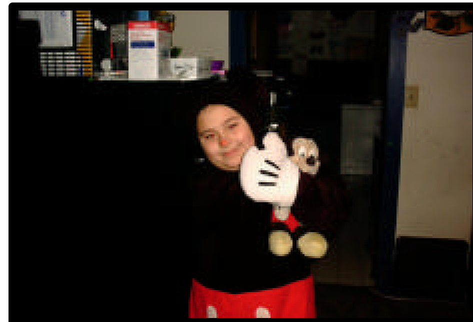
[5] Centers for Disease Control and Prevention, 2004
[6] EPAA Vol. 12 No. 11, March 16, 2004, Dana Lee Baker, University of Missouri-Columbia, Page 3, Public Policy and the Shaping of Disability: Incidence Growth in Educational Autism

Are some children destined to have Autism based on their genetics? Are their brains different? Is it because their mothers didn't show them enough affection? Are the immunizations that we give our children to keep them safe actually causing them harm? Is the environment a contributing factor? These are the proverbial million dollar questions confronting parents and scientists around the world. The debate is brewing over whether Autism is hereditary, is caused by varying types of chemical misfires during early childhood, or is caused by mercury in childhood vaccines. For every child with Autism, there is a theory.

Interested in doing research into those theories? Here are some resources:

- Safe Minds - http://www.safeminds.org/
- National Alliance for Autism Research - http://www.naar.org/
- Exploring Autism: The Genetics of Autism - http://www.exploringautism.org/
- The Autism Research Institute - http://www.autismwebsite.com/ari/dan/dan.htm
- The Children's Hospital of Philadelphia: Vaccine Education Center - http://www.chop.edu/consumer/jsp/division/generic.jsp?id=75818
- Cure Autism Now - http://www.cureautismnow.org/
- Evidence of Harm - http://www.evidenceofharm.com/

Conclusion



No matter what the cause, these children are our future. It is our responsibility to do whatever it takes to see that they have every opportunity to succeed and to live a full and happy life. The things that we do today will undoubtedly make an impression on their future. Regardless of the therapies or interventions that you decide upon for your child, always remember that these are still just children. Choose wisely. Be sure to weigh the potential gains along side the potential losses. No therapy or treatment is worth risking a child's life. Children with Autism need time to play, to day dream and to create - - just like other children. Make it a priority to never get so involved in trying to "fix" your child that you forget that inside is a child who just wants to be loved and accepted.

Upcoming Articles in this Series

Learning to Live with Autism Part II: Raising a Child with Autism
Learning to Live with Autism Part III: The Medical Side
Learning to Live with Autism Part IV: Safety Issues
Learning to Live with Autism Part V: Unraveling Myths
Learning to Live with Autism Part VI: Lessons Learned and Advice for Newly Diagnosed Families

About the Author

Jackie Igafo-Te'o currently resides in Michigan with her husband and their three children. Their oldest child, currently age 12, has ADHD and has written a book about his life and how he deals with ADHD (http://www.bridges4kids.org/SoMuchMoreToMe.pdf). Their middle child, currently age 11, is an artist. He dreams of one day becoming an animator and moving to Hollywood to work at Universal Studios. He was diagnosed with Autism at the age of 3, Impulse Control Disorder at age 9 and bipolar disorder at age 11, after being misdiagnosed several times from birth through 2 years. Their youngest child, currently age 9, has written a book to express her feelings on being a sibling of a child with Autism (http://www.bridges4kids.org/MyBrotherHasAutism.pdf). The book was illustrated by her brother, who has Autism.

Jackie currently serves as Webmaster and Director of Information Technology & Information Systems for Bridges4Kids. Before co-founding Bridges4Kids, Mrs. Igafo-Te'o was employed by several organizations that work for the betterment of children, teens and families in Michigan and Ohio. She currently co-chairs Michigan's Autism Spectrum Disorder Workgroup's Interventions Subcommittee. Jackie has served as Parent Representative for *Early On* Jackson County and currently volunteers as webmaster for The Developmental Disabilities Council's Family Support Workgroup, disAbility Connections of Jackson, The Learning Disabilities Association of Michigan, The Michigan Positive Behavior Support Network, and The Michigan Lead Safe Partnership. She also maintains websites for other organizations and groups including The Autism Society of Michigan, Wrightslaw's Yellow Pages for Kids, Early Childhood Michigan and Detroit Parent Network. Her volunteer work on a military family support website has earned military honors two years in a row.

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