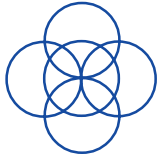


Birth to 6 EVENTS



Waisman Center

A BULLETIN FOR THOSE WHO WANT TO LEARN MORE ABOUT SERVING YOUNG CHILDREN WITH SPECIAL NEEDS AND THEIR FAMILIES

Issue 57—Fall 2007

An unexpected childhood An autism mom asks: What makes a child perfect?

Written by Kristina Chew, this essay was originally published September 10, 2003 in the Princeton Alumni Weekly and is reprinted here with permission. Kristina is a professor of ancient Greek and Latin at a college in northern New Jersey. She and her husband are parents of Charlie, a now 10 - year old boy with autism. She writes about her family's life with autism at Autism Vox www.autismvox.com
Editor's Note: The statistics listed in this article on the prevalence of autism have recently been updated. See Study Profiles Rate of Autism in Wisconsin on page 6 for details. In addition, there is insufficient scientific evidence currently linking thimerosal in vaccines to autism. For more information, refer to <http://www.cdc.gov/od/science/iso/thimerosal.htm>




Autism spectrum disorders have received a lot attention in the popular press lately. Categories within the “spectrum” include autism, Asperger syndrome, and Pervasive Developmental Disorder, Not Otherwise Specified (PDD-NOS). Some Birth to 3 and Early Childhood Special Education Programs report serving an increasing number of children either diagnosed with these disorders, or with sensory, social, or emotional issues but lacking a specific diagnosis.

This issue of the Birth to 6 EVENTS newsletter focuses on infants and young children with autism spectrum disorders (ASD) and related challenges. Most of the articles in this issue have been reprinted to demonstrate the wealth of information on this subject available on the web.

It opens with a beautifully written piece from a mother of a child with autism, and relays some of her struggles and joys in parenting a child with this disorder.

Highlights from this issue include: ways to assess meaning behind challenging behaviors through a process called Functional Behavior Analysis, the topic of Positive Behavioral Support, and an overview of services and resources for children with autism and their families.

The lack of social engagement that is the hallmark of these disorders can be especially difficult for families. We hope this issue supports you as you work to support them and their children.

The newest addition to the newsletter is the Waisman Center icon at the end of stories. Look for this “end icon” to let you know when an article is done. 

Arianna Keil, editor

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After my son, Charlie, was born in May 1997, I purchased a sweater with a big orange P on the front. What will he be when he grows up, friends and relatives wondered aloud. And, with a wink: What college?

Charlie is six now. Cleaning out drawers the other day, I took out the sweater, long outgrown. “What letter?” I asked, pointing to that big P.

“Orrwange,” said Charlie. Behind his glasses, both pupils slid into the corners of his eyes.

“What letter?” I asked again, not

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pointing this time. Charlie can focus only on one thing at a time, whether that something is big, or orange, or the letter P.

“Orrwange. Oh-ange.” A shake of his shoulders and Charlie turned his head toward the sweater. “Orrrrrrr—P. Is P.”

“Good job!” I clapped and kissed his cheek. With a resolute “Go pay! Down-stairs!” Charlie left to play. I folded the little sweater and stowed it away.

Charlie has autism, a neurobiological disorder that profoundly impairs an individual’s ability to communicate and to interact socially. Charlie’s brain is not wired to discern the cues “neurotypical” people rely on for communication: facial expression, body language, and a range of signs and gestures that most of us simply “read” by instinct. We do not know when Charlie has a stomachache; he can’t tell us what hurts. Charlie can make requests but he can’t use words to explain how he feels – if he’s tired or sad, for example.

Individuals with autism talk most readily about the concrete and physical; some can repeat long scripts of their favorite videos. But they must be taught the functional, social aspect of language, such as saying “hello,” or taking a turn in a conversation. Autistic people develop ritual practices – running back and forth across a room, or tracing their hands along walls or the edge of kitchen counters, for example – to gain a sense of where they are; these mechanisms help regulate a sensory overload. When these fragile mechanisms break down, an autistic person’s discomfort is apparent.

Autism once was considered a rare disorder that affected four to five in 10,000 children. National organizations including the Princeton-based National Alliance for Autism Research now report that one in 250 children has autism.* Why the number of children diagnosed has risen so rapidly is unknown. Some respected public health officials attribute the apparent upsurge to “increased awareness” of the disorder, especially of its milder form. But the California

three words. For two years, Charlie was in an intensive in-home therapy program, 40 hours each week. Under the guidance of a behavior consultant, a small armada of therapists filled Charlie’s hours with drills and programs to teach him to sit at a table and look at others, to imitate others’ actions, to shape his speech from babble to specific sounds to words to sentences, to build with Legos, and to identify the parts of his body, the rooms in the house, the furniture in those rooms, the colors, his name.

When Charlie was four we moved back to New Jersey, which has some of the nation’s best autism schools. My son writes “Charlie” in wobbly letters, mumbles the Pledge of Allegiance, answers questions (“Who are the boys in your class?” “Joey, Sean,

Jake!”) with brio, and, as his dad returns home, yells out, “Daddy be back Daddy cumminn home!”

I take support from parents of other special-needs children, some of them also Princeton alumni. Nicoletta LaMarca-Sacco ’90 calls herself a “mother in two different worlds.” She is raising her 2-year-old typical daughter, Francesca, and her 5-year-old son, Felice, who has autism. Felice’s first words appeared when he was two; he then lost his language. At age three he spoke in phrases, but true sentences were not heard until he was four. Now at five, though delayed, he has nearly caught up with his typical peers. Felice has daily home therapy sessions, special education, afterschool activities (gym and tap dance), and a lot of one-on-one time with his very busy mom.

Nicoletta and I are autism moms now, a role that requires us not only to provide for our sons’

... to help ensure that our society offers opportunities for all children to learn in the ways they can learn, and to grow in the ways they are able.

Department of Developmental Disabilities documented a 273 percent increase in “full syndrome autism” in that state between 1987 and 1998. Though the theory is not commonly accepted by physicians, many parents link the onset of their children’s autism to mercury poisoning from vaccines and from metals and chemicals in the environment; children born with weak and compromised immune systems may be particularly susceptible.*

Experts now speak of autism as a spectrum. At the “high-functioning” end is Asperger’s disorder; individuals with Asperger’s have normal and even above-average intelligence. Those with severe autism often are non- or minimally verbal, and may engage in acts such as head-banging, and in repetitive behaviors such as hand-flapping. Charlie is somewhere in the middle. At the age of six, he can speak in sentences of two and

* See Editor’s Note

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special needs, but to help ensure that our society offers opportunities for all children to learn in the ways they can learn, and to grow in the ways they are able. No just society can afford to withhold proven and effective educational services from disabled children. Cyberspace has proved a boon for autism parents, whose family needs can make it impossible to attend educational conferences and rallies in support of funding for autism research, not to mention a shared cup of tea. Though we are classmates, Nicoletta and I met through Mosaic, an e-mail discussion list for mothers of children with autism in northern New Jersey. We both had attended a conference organized by Princeton and the Eden Institute; Nicoletta later wrote that she was saddened that Felice might not have the chance to attend our alma mater. I wrote back, and we met in person.

As the parent of a child with special needs, my hopes for my son's future have been rewritten. Charlie will require special education services through his school years. College, driving a car, marriage, grandchildren – these are all uncertainties. In the lives of children like Charlie and Felice, graduation from high school, having friends, and saying "I'm thirsty" are cause for joyous celebration.

What is achievement? What makes a child "perfect"?

Charlie is learning to say more and more every day.

"Ow," he says.

I run to Charlie, who perhaps has stubbed a toe. A sparkle comes to his eyes.

He smiles. "Burgers and fries!"

"Where do you get that?" I ask.

"Burgers, fries burgers, fries and burgers!"

"Where do you get that – your favorite restaurant . . ."

Charlie's eyebrows twist.

"At Mc . . ." I whisper.

"Makk," says Charlie, wriggling from his shoulders to his arms to his knees. Then he's still, tilting his head to the right and looking out of the corners of those big brown eyes.

Charlie says, "MakkDonallls! Burgers ann fries! Burgers fries fries burgers."

Children with autism neither must be ignored nor contained in the guise of a "tragedy," or even as a "blessing," though many of us parents do view our children as a special, and most precious, most perfect, gift. Some children very nearly will recover from the effects of autism, while others will learn ways of communicating that do not involve banging their heads on the floor. Whatever the outcome, we try never to forget that these are kids before they are a cause – losing their baby teeth, jumping in puddles, going to get their backpacks at the end of the school day, and saying "Mommy" with a smile and a look at the teacher. ☺

Diagnostic Criteria

From The American Academy of Pediatrics's *Understanding Autism Spectrum Disorders* (2006)
The following are descriptions of autistic disorder, Asperger syndrome, and PDD-NOS:

Autistic disorder is the term when a child meets all the necessary criteria listed in the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) (see box, page 4). Children with autistic disorder have problems with language skills that are absent, delayed, or abnormal; problems relating to others socially; and unusual or repetitive behaviors. While social symptoms are usually present in the first year of life, language problems show up in the second year and stereotypic behaviors show up later. Many of these children will have intellectual deficits; others might *appear* to have deficits when, in fact, scores on intelligence tests are low because of lack of cooperation. Others may have normal scores on intelligence tests, yet they may have trouble with abstract and real-life reasoning. Children with autism are often labeled as *high functioning* when intelligence is in the normal range.

Asperger syndrome is usually not diagnosed until preschool or later. This is because early speech development, especially language and sentence structure, is relatively normal. Sometimes children with Asperger syndrome speak in an odd way. Some children may speak in the same tone of voice without raising or decreasing the pitch of their voice. Other children may speak in language above what you would expect for their age like "little professors." They may make little eye contact while talking and may have trouble maintaining a back-and-forth conversation. They usually obsess over 1 or 2 topics and will talk about these topics whether the listener is interested. Children with Asperger syndrome often interpret language literally and may have particular trouble with humor, teasing, and figures of speech. Many may also have problems with motor coordination. Intelligence is normal. Some experts do not consider this a separate disorder from high-functioning autism.

Children with **pervasive developmental disorder-not otherwise specified** (PDD-NOS) or atypical autism show some signs of autism or other PDD, but don't meet the criteria to be diagnosed with one specific disorder.

Autistic Disorder, Asperger's Syndrome and PDD-NOS are all Pervasive Developmental Disorders included on Chart 1: Diagnosed Conditions for the Wisconsin Birth to 3 Program. Children with diagnoses on Chart 1 are eligible for early intervention programming without documentation of developmental delay.