

PARENT'S PERSPECTIVE

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.

EARLY DIAGNOSIS

Early Diagnosis of Autism

(Adapted from: *New Study Shows Half of Children with Autism can be Accurately Diagnosed at Close to 1 Year of Age*, Kennedy Krieger Institute, 2007; summary based on publication: **Social and Communication Development in Toddlers With Early and Later Diagnosis of Autism Spectrum Disorders**, *Archives of General Psychiatry*, July 2007)

Researcher Dr. Rebecca Landa (*Archives of General Psychiatry*, 2007) found that autism can be diagnosed at close to one year of age, which is the earliest the disorder has ever been diagnosed.

The study looked at 107 infants at high risk for ASD (siblings of children with autism), as well as 18 infants at low- risk for ASD (no family history of ASD).

Researchers assessed each child's development at 14, 18, and 24 months. Researchers were able to diagnose about half of the children who went on to have a diagnosis of ASD by 14 months by looking for the following:

- **Abnormalities in initiating communication with others:** Rather than requesting help to open a jar of bubbles through gestures and vocalizations paired with eye contact, a child with ASD may struggle to open it themselves or fuss, often without looking at the nearby person.
- **Compromised ability to initiate and respond to opportunities to share experiences with others:** Children with ASD infrequently monitor other people's focus of attention. Therefore, a child with ASD will miss cues that are important for shared engagement with others, and miss opportunities for learning as well as for initiating communication about a shared topic of interest. For example, if

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Educational criteria for autism are listed at Wisconsin DPI: Autism Eligibility Checklist <http://dpi.wi.gov/sped/pdf/elg-aut-001.pdf>

The following is from the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM IV)*:


DIAGNOSTIC CRITERIA FOR Autistic Disorder

- A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3)
1. qualitative impairment in social interaction, as manifested by at least two of the following:
 - a) marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction
 - b) failure to develop peer relationships appropriate to developmental level
 - c) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people)
 - d) lack of social or emotional reciprocity (note: in the description, it gives the following as examples: not actively participating in simple social play or games, preferring solitary activities, or involving others in activities only as tools or "mechanical" aids)
 2. qualitative impairments in communication as manifested by at least one of the following:
 - a) delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime)
 - b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
 - c) stereotyped and repetitive use of language or idiosyncratic language
 - d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level
 3. restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:
 - a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 - b) apparently inflexible adherence to specific, nonfunctional routines or rituals
 - c) stereotyped and repetitive motor mannerisms (e.g hand or finger flapping or twisting, or complex whole body movements)
 - d) persistent preoccupation with parts of objects
- B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:
1. social interaction
 2. language as used in social communication
 3. symbolic or imaginative play
- C. The disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder

EARLY DIAGNOSIS

a parent looks at a stuffed animal across the room, the child with ASD often does not follow the gaze and also look at the stuffed animal. Nor does this child often initiate communication with others. In contrast, children with typical development would observe the parent's shift in gaze, look at the same object, and share in an exchange with the parent about the object of mutual focus. During engagement, children have many prolonged opportunities to learn new words and new ways to play with toys while having an emotionally satisfying experience with their parent.

- **Irregularities when playing with toys:** Instead of using a toy as it is meant to be used, such as picking up a toy fork and pretending to eat with it, children with ASD may repeatedly pick the fork up and drop it down, tap it on the table, or perform another unusual act with the toy.
- **Significantly reduced variety of sounds, words and gestures used to communicate:** Compared to typically developing children, children with ASD have a much smaller inventory of sounds, words and gestures that they use to communicate with others. ☎

ARCHIVED Birth to 3
WISLINE
from August 9, 2007: 
*One Developmental
Pediatrician's Perspective on
Autism*
Tina Iyama, M.D.
[http://www.uwex.edu/ics/
stream/waisman/BT3/
index.htm](http://www.uwex.edu/ics/stream/waisman/BT3/index.htm)

DIAGNOSTIC CRITERIA FOR Asperger Syndrome from DSM IV

- A. Qualitative impairment in social interaction, as manifested by at least two of the following:
1. marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction
 2. failure to develop peer relationships appropriate to developmental level
 3. a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. by a lack of showing, bringing, or pointing out objects of interest to other people)
 4. lack of social or emotional reciprocity
- B. Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:
1. encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
 2. apparently inflexible adherence to specific, nonfunctional routines or rituals
 3. stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
 4. persistent preoccupation with parts of objects
- C. The disturbance causes clinically significant impairments in social, occupational, or other important areas of functioning
- D. There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years)
- E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than social interaction), and curiosity about the environment in childhood
- F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia

DIAGNOSTIC CRITERIA FOR Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) from DSM IV

This category should be used when there is a severe and pervasive impairment in the development of reciprocal social interaction or verbal and nonverbal communication skills, or when stereotyped behavior, interests, and activities are present, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes atypical autism — presentations that do not meet the criteria for Autistic Disorder because of late age of onset, atypical symptomatology, or subthreshold symptomatology, or all of these.

MEDICAL HOME SUMMIT: SMALL STEPS, BIG CHANGES
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For more information visit
<http://www.waisman.wisc.edu/cshcn/TRAININGS.HTML>

