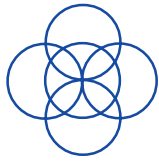


# Birth to 6 EVENTS



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](http://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 of 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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**A**fter 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

*continued on page 2*

# PARENT'S PERSPECTIVE

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’

*\* See Editor’s Note*

**... 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

# 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

*continued on page 5*

**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.

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# AUTISM PREVALENCE

## Study Profiles Rate of Autism in Wisconsin by Jill Sakai, reprinted with permission from

University Communications, University of Wisconsin-Madison.

A Wisconsin autism surveillance project reported February 8, 2007 that approximately five out of every 1,000 Wisconsin children born in 1994 display symptoms indicative of autism.

The Wisconsin Surveillance of Autism and Other Developmental Disabilities System, part of a national study overseen by the Centers for Disease Control and Prevention (CDC) in Atlanta, evaluated children in the first phase of a study to determine the prevalence of autism spectrum disorders in the United States. The national study is the largest effort to date to obtain accurate counts and monitor affected populations over time. The CDC today released the first set of results from the project, reporting autism prevalence in study sites nationwide among children born in 1994.

Reported cases of autism — a developmental neurological disorder characterized by avoidance of social interactions, poor communication skills and unusual behaviors — have increased dramatically more than the past 15 years, but it is unclear whether those increases simply reflect growing awareness and recognition of the disorder or something more, says Maureen Durkin, an epidemiologist in the University of Wisconsin-Madison School of Medicine and Public Health and leader of the Wisconsin project.

“The public health community was caught off-guard by the increasing numbers reported in the 1990s,” she says. “But there was no system in place for monitoring autism.”

The CDC-led study, launched in six states in 2000 and expanded to 14 states, including Wisconsin, in 2002, aims to fill that need by obtaining more accurate counts of children with autism in multiple geographic locations, comparing autism rates among different

groups of children and looking for changes in rates or populations over time. Rather than relying upon previously recorded autism diagnoses, trained clinicians evaluated information in children’s medical records against standardized psychiatric criteria to assign autism diagnoses.

For the Wisconsin survey, collaborators at UW-Madison’s Waisman Center and elsewhere analyzed medical records as of 2002 for all children in 10 southeastern Wisconsin counties who were 8 years old that year, an age past the usual time of autism diagnosis. The group surveyed 35,126 children, which represent nearly half the 8-year-olds in the state that year.

The researchers found evidence of autism in 5.2 per 1,000 Wisconsin children born in 1994, slightly lower than the average value of 6.6 per 1,000 children born that year in all the participating states.

Commenting on the CDC report, Durkin says, “The rates vary somewhat across states, but are all considerably higher than previously thought.”

The Wisconsin team found that autism was three to four times more common in boys than in girls, which agrees with previously published scientific reports. In ethnicity comparisons, they reported that autism prevalence was higher in non-Hispanic whites than non-Hispanic blacks and lowest of all among Hispanics.

The researchers also noted an apparent geographic difference, with autism rates more than twice as high in Dane County as in Milwaukee County.

“We don’t know what’s causing this,” Durkin says. “We see these dramatic ethnic and geographic differences that need further research.”

The researchers are still analyzing data for 8-year-olds in 2004 and 2006 and will conduct one additional

survey in either 2008 or 2010. The Wisconsin team is also studying rates of cerebral palsy in the same populations.

Although the data released today paint the most thorough statistical picture to date of autism in Wisconsin, the researchers worry that picture is still incomplete. Although most states in the autism surveillance program used both school and medical records to diagnose children, the Wisconsin team was denied access to school files on the grounds of the Family Educational Rights and Privacy Act, a federal law designed to protect the privacy of student educational records.

The team believes a complete reliance on medical records may miss children who have limited or no access to health care. If so, the actual prevalence of autism could be higher than their results indicate.

Since autism develops in very early childhood and persists throughout life, affected children often require special education and behavioral intervention to help them function in society.

“Autism spectrum disorders are a huge public health issue in this state, affecting between one-half to one percent of school-age children, and we have to be able to plan services accordingly,” Durkin says. “We want the best numbers we can get.”

One goal of surveillance is to complement research into the science underlying autism and other developmental disorders, including several studies currently pursued by other research groups in the Waisman Center and elsewhere at UW-Madison.

“Population changes give clues to understanding what’s going on in autism,” Durkin says. “Our goals ultimately are to better serve children and families with autism and to develop strategies for prevention.”

## What Are Children Trying to Tell Us?: Assessing the Function of Their Behavior

by Lise Fox and Michelle Duda

Reprinted from the *What Works Briefs* from the Center on the Social and Emotional Foundations for Early Learning. To read additional briefs, visit the CSEFEL site at: <http://www.vanderbilt.edu/csefel/whatworks.html>

*"I feel really sad about it, but I think Derek will have to find a different program," said Ms. Morden, an experienced preschool teacher in a large metropolitan city. "I don't know how to reach Derek. His behavior is so unpredictable. I can't have children coming to school and being afraid that they will be hit by Derek," she told her classroom assistant, Ms. Eacott. Ms. Morden simply did not understand why Derek was so aggressive. Both Ms. Morden and Ms. Eacott had observed Derek hitting and kicking other children on numerous occasions. The problem had become so severe that his peers had begun to avoid him altogether. The time had come to do something for Derek, but what?"*

### What Is Functional Behavioral Assessment?

Functional Behavioral Assessment (FBA) is used to understand the purpose or function of a specific problem behavior exhibited by a child. FBA is a process for developing an understanding of a child's problem behavior, and, in particular, how the behavior is influenced by environmental events. FBA should be considered when the behavior is thought to inhibit a child's performance and participation in

daily activities and routines. FBA identifies the environmental factors or events that consistently predict or result from a child's problem behavior. Once the purpose or function of the problem behavior is understood, support teams can design and use effective interventions that promote success and participation of the child in daily activities and routines. FBA is an essential component of the process of positive behavior support (see *What Works Brief* on positive behavior support, page 10).

*"Time to change centers," said Ms. Morden when the timer went off. Most of the children began to leave their centers and rotate to a new station. Derek stayed in the block area as four children arrived there to play. Ms. Morden redirected him, "Derek, it's time to go to art center." "No, I don't want to!" said Derek, who turned and kicked Amanda in the leg, causing her to cry. "Derek! That's not OK; kicking hurts," said Ms. Morden. "You've hurt your friend. You have a timeout." Ms. Eacott took Derek to the other side of the room, where he sat in the timeout chair for four minutes. Once again, Derek had hurt another child. "This is the umpteenth time this week he's done that. I've got to do something about this," said Ms. Morden. "Sooner or later, someone is really going to get hurt!"*

### How Does FBA Work?

FBA can be conducted individually or by a team (e.g., parent, teacher, behavior resource person). The process involves collecting information through the use of observation, interviews, and record reviews (e.g., school records, medical records, diagnostic reports). If done as a team, different members of the team might assume different roles (e.g., observing, interviewing, reviewing reports and records). The information gathered is used to understand what happens before the problem behavior, what the problem behavior looks like, and what happens after the problem behavior.

Interviews are used to collect information about the problem behavior from teachers or family members who are very familiar with the child. Interview questions are used to gain information about: (1) the nature of the behavior (e.g., what the child does, how frequently), (2) events that may predict the behavior, (3) what the child may gain or avoid through problem behavior, (4) how well problem behavior works for the child, and (5) what circumstances are not associated with the behavior. Interviews are helpful in the functional assessment process because they allow you to gather information about the child in multiple settings and from the perspectives of multiple people. Observations are used with the interviews to provide evidence or data on the factors that predict and maintain problem behavior. A popular and easy method for conducting observations is to watch the child and write down the events that immediately precede an occurrence of problem

### ARCHIVED Birth to 3 WISLINE

from June 14, 2007

*Monitoring Autism: The Wisconsin Surveillance of Autism and Other Developmental Disabilities System*

Maureen Durkin, PhD.

<http://www.uwex.edu/ics/stream/waisman/BT3/index.htm>

# FBA

behavior, describe the problem behavior using concrete terms, and write down the events that follow the problem behavior. This information can be written on index cards and collected for later analysis.

Once all the information (interviews, observations, and record review) is collected, the information is analyzed by the team or the individual. This approach is used to determine the purpose of the problem behavior—whether it occurs in order for the child to obtain something (e.g., attention, an object, an activity) or to escape something (e.g., difficult demands). The FBA process is complete when there is enough information that will lead to a hypothesis or summary statement describing the function or purpose of the problem behavior. The hypothesis statement will lead directly to interventions designed to prevent problem behavior and to teach the child new skills that will replace problem behavior (see *What Works Briefs* #10 on positive behavior support and #11 on functional communication training).

*After attending a workshop on FBA and talking with a few colleagues, Ms. Morden contacted Derek's grandmother to share her concerns. Derek's grandmother was in full support of finding new ways to help Derek with his behavior. Ms. Morden, Ms. Eacott, and Derek's grandmother met to discuss the challenges associated with Derek and to talk about the concept of FBA. The team agreed that conducting a FBA would be helpful. Ms. Morden, Ms. Eacott, and Derek's grandmother used observation cards to gather information about the events surrounding Derek's problem behavior. The teachers kept track of each time Derek hit or kicked one of his peers, the activity and time of day in which it occurred, the children he was*

*playing with, what happened immediately before the behavior, and what happened after the behavior. Derek's grandmother also provided several observation cards about problem behavior that Derek had at home. Additionally, Ms. Morden conducted interviews with both Ms. Eacott and Derek's grandmother to gain their insights about Derek's challenging behaviors.*

*After two weeks of collecting information, the team met to discuss Derek's behavior. Ms. Morden began the discussion by asking the team to share their perceptions after focusing on Derek these past few weeks. Ms. Eacott responded, "I noticed that Derek appeared to have the most difficulty during the learning centers and circle time. Every day that he was asked to go to the art center, he hit or kicked one of his peers, and he was given a timeout. However, when he spent time in the block center, Derek's behavior was better. In fact, he wasn't aggressive at all." Ms. Morden nodded in agreement. "That's right, Derek loves building with blocks. But he sure doesn't like to do writing or coloring. I try to get him to color or write his name when the other children are doing their homework, and he starts crying and tears up the paper," said his grandmother. Derek's grandmother also shared, "If I give him something else to do that he likes, he can sit with the other children; he just won't work on writing his name or coloring like the rest of them." "That brings me to another idea," said Ms. Morden. "In the interviews, both of you noted that Derek likes to make choices, and the observation cards show that he is less aggressive in activities where he has a lot of choices, like blocks or dramatic play. Derek is much better when he gets to pick the toy or the activity. My observation cards also show that a lot of*

*problem behavior happens in circle time where Derek has to follow the rules of the group. It seems like he is having problem behavior in circle time so that he can leave and go to timeout."*

*Based on the functional assessment information, the team agreed that Derek hit or kicked other children in order to escape from difficult tasks or those he doesn't like, particularly the art center and circle time. They also agreed that Derek was least aggressive during block center and in activities where he had opportunities to make choices such as dramatic play, sensory table, and computer. With those ideas in mind, the team decided that they should try to give Derek more help in the art center and during circle time and give him more opportunities to make choices. To make circle time more interesting, Ms. Morden decided to provide Derek with choices of where to sit, allow him to select the song or story, and to provide more manipulatives within the activities. She also decided to ask Derek if he wanted to leave circle if he became distracted. She decided it would be better to let him leave circle on her terms, rather than after he had caused a disruption. She also restructured the art center so that there were obvious choices of activities (e.g., draw, easel paint, or paste) and made sure that an adult helped Derek get started. She also provided magic markers in the art center as a choice for Derek because he seemed to have problems using crayons or pencils.*

## **Who Are the Children Who Have Participated in Research on FBA?**

FBA has been used effectively with individuals from age 2 to adulthood. Researchers have successfully completed FBAs with children and families from a wide variety of


ethnic and socioeconomic backgrounds, as well as children who are from at-risk environments, have behavior disorders, or have developmental delays. Researchers have also studied the effects of FBA in a wide variety of settings including Head Start, special education classrooms, early education programs, family homes, and the community.

*A month later, Derek's grandmother visited the classroom. "Derek's doing so much better!" said Ms. Eacott. "Now that Ms. Morden and I have helped Derek with circle time and art, he's a different person. He hasn't hit anyone in two weeks!"*

*"I think the choices have helped too," said Ms. Morden. "Now that Derek has more opportunities to pick which activities to do, he seems like a happier boy. I'm also realizing that sometimes we were asking Derek to do things that were too difficult for him. I'm going to provide him with a little more one-to-one attention and see if we can help him with some of his learning problems." Derek's grandmother asked about his participation in circle time because she was worried that he would not be ready for kindergarten if he could not sit with the group. Ms. Morden reported, "On most days, Derek sits for circle the entire time, he knows that he can ask to leave, but usually he doesn't want to. Frankly, I*

*think circle time is more interesting for all the children now that we have made the changes for Derek."*

## What Changes Might Occur as a Result of FBA?

FBA alone does not change a child's behavior. However, once a FBA is used to identify the purpose or function of the child's problem behavior, interventions can be selected that are based on the child's needs. Interventions that are "assessment-based" or follow the FBA have resulted in significant and rapid changes in children's problem behavior, as well as the development of age-appropriate and socially appropriate behaviors taught in replacement. 

## Where Do I Find Information on Implementing This Practice?

See the CSEFEL Web site (<http://www.vanderbilt.edu/csefel/>) for additional resources.

Practical information on FBA can be found in journals, including the following: *Young Children*, *Teaching Exceptional Children*, *Young Exceptional Children*, and *Young Exceptional Children Monograph Series: Practical Ideas for Addressing Challenging Behaviors*.

See the following Web sites and articles for examples on how to implement aspects of FBA:

OSEP Technical Assistance Center on Positive Behavioral Interventions and Supports (PBIS) <http://www.pbis.org>  
 Online Academy (Sponsored by the University of Kansas and the Office of Special Education Programs) <http://onlineacademy.org>

Rehabilitation Research and Training Center on Positive Behavior Support <http://rrtcpbs.fmhi.usf.edu/>

Janney, R., & Snell, M. E. (2000). *Teachers' guides to inclusive practices: Behavioral support*. Baltimore, MD: Paul H. Brookes. (Available at <http://www.brookespublishing.com>.)

Kaiser, B., & Rasminsky, J. S. (1999). *Meeting the challenge: Effective strategies for challenging behaviours in early childhood environments*. Ottawa, Canada: Canadian Child Care Federation. (Available through NAEYC; see <http://www.naeyc.org>.)

O'Neill, R. E., Horner, R. H., Albin, R. W., Sprague, J. R., Storey, K., & Newton, J. S. (1997). *Functional assessment and program development for problem behavior: A practical handbook*. Pacific Grove, CA: Brooks/Cole.

Tobin, T. J., & von Ravensberg, H. (2001). *Parent's guide to functional assessment and support*. Eugene, OR: Educational and Community Supports, University of Oregon. (Available for free at <http://darkwing.uoregon.edu/~ttobin>.)

## What Is the Scientific Basis for This Practice?

For those wishing to learn more about the topic, the following resources provide additional information:

Blair, K. C., Umbreit, J., & Bos, C. S. (1999). Using functional assessment and children's preferences to improve the behavior of young children with behavioral disorders. *Behavioral Disorders*, 24(2), 151-166.

Dooley, P., Wilczenski, F. L., & Torem, C. (2001). Using an activity schedule to smooth school transitions. *Journal of Positive Behavior Interventions*, 3(1), 57-61.

Harding, J., Wacker, D. P., Cooper, L. J., Asmus, J., Jensen-Kovalan, P., & Grisolano, L. A. (1999). Combining descriptive and experimental analyses of young children with behavior problems in preschool settings. *Behavior Modification*, 23(2), 316-333.

Kamps, D. M., Ellis, C., Mancina, C., Wyble, J., & Greene, L. (1995). Case studies using functional analysis for young children with behavior risks. *Education and Treatment of Children*, 18(3), 243-260.

Kern, L., Ringdahl, J. E., Hilt, A., & Sterling-Turner, H. E. (2001). Linking self-management procedures to functional analysis results. *Behavioral Disorders*, 26(3), 214-226.

# Positive Behavior Support: An Individualized Approach for Addressing Challenging Behavior

by Lise Fox

Reprinted from the *What Works Briefs* from the Center on the Social and Emotional Foundations for Early Learning.

To read additional briefs, visit the CSEFEL site at: <http://www.vanderbilt.edu/csefel/whatworks.html>

## What Is Functional Behavioral Assessment?

In high-quality early childhood programs, most children will respond to the teacher's use of social skills instruction, redirection, and prevention strategies (e.g., environmental arrangement, catching children being good, etc.). For many children with challenging behavior, the teacher is able to address the child's needs and teach the child the expectations of the classroom. Unfortunately, there are a few children who do not respond to the teacher's efforts. These children continue to exhibit challenging behavior despite well-designed classroom environments and the use of developmentally appropriate teaching and child guidance practices. The following example illustrates this dilemma.

*Jack teaches in a Head Start center with eight classrooms. His center has been NAEYC accredited for the past six years. Jack has a bachelor's degree in early education and serves as a mentor to new teachers at the center. This year, Jack has been very worried about the challenging behavior of one of the children in his class. Amy is a 4-year-old child with some language delays and significant problem behavior. Amy hits other children, pulls hair, bites, destroys toys and materials, and resists redirection by hitting, screaming, and scratching adults.*

*This is the first time that Amy has been in a group care setting. In the first months of her enrollment, Jack thought that Amy just needed to learn the classroom expectations and get used to being with other children. Now it is January, and Amy's behavior has not improved. Jack has tried*

*talking with Amy's parents, establishing a home/school plan to remind Amy of the classroom rules, and has asked the Head Start mental health consultant to provide recommendations. Currently, the mental health consultant works with Amy for 30 minutes each week. Unfortunately, Amy's behavior is unchanged. Jack is ready to "throw in the towel," for he isn't sure at this point if he can meet Amy's needs. After much discussion, the mental health consultant and Jack decide to try a new approach to working with Amy, Positive Behavior Support.*

Positive Behavior Support may be the solution for Jack and Amy. Positive Behavior Support, or PBS, is a process that provides teachers and families with a way to understand and address a child's persistent challenging behavior.

## What Is Positive Behavior Support?

Positive Behavior Support (PBS) is for children who persist in challenging behavior and do not respond to general child guidance procedures. PBS is an approach to developing effective and individualized interventions for children with severe challenging behavior. PBS was developed both from the science of applied behavior analysis and the values of child-centered approaches to learning. In PBS, interventions are designed based on understanding the purpose of the challenging behavior. The positive strategies used to change behavior include teaching new skills, preventing the occurrence of challenging behavior, and supporting the child in achieving meaningful, long-term outcomes.

## How Does PBS Work?

PBS begins with bringing together a team of individuals who are concerned and knowledgeable about the child. PBS is most effective when families and teachers work together and use the process across all environments. In this approach, challenging behavior is viewed as having meaning or serving a purpose for the child. A process called functional assessment is used to determine the purpose or function of challenging behavior (see *What Works Brief* on functional assessment on page 7). Once the function of the behavior is identified, the team develops a behavior support plan. The behavior support plan includes (1) specific strategies for modifying the curriculum, environment, activity, or interactions with the child to prevent occurrences of the challenging behavior; (2) specific teaching procedures to teach the child a new skill to use in place of the challenging behavior; and (3) strategies to ensure that new skills are learned and acknowledged, and that challenging behavior is not maintained.

*In Jack's classroom, PBS was implemented for Amy. The first step was to bring together the team of interested, concerned adults. Jack and the mental health consultant worked together to convene a team including Amy's parents and Jack's teaching assistants. The team met one day during lunch and talked about Amy's behavior, the need to understand her behavior, and the importance of finding effective strategies to teach her new skills. Amy's parents were very eager to develop strategies for interacting with Amy because they were experiencing similar challenges at home.*

The second step of the PBS process was to conduct a functional assessment. The functional assessment process included observing Amy during her routines at school and home. Each member of the team wrote down what happened before Amy's challenging behavior and what happened after each challenging behavior episode. The team got back together and reviewed the information that they had collected.

The team learned from their observations that Amy was most likely to engage in challenging behavior when a child tried to play with a toy that Amy had chosen or when another child entered into her play space. When Amy attacked the child by hitting, biting, or grabbing a toy, the teacher would comfort the hurt child and then take the hurt child to another center or activity. Thus, Amy would be successful in getting that child to leave the activity or leave the toy. The team also realized that when Amy attacked adults who were redirecting her (usually to help her make a transition to a new activity), the adult would leave Amy alone when she began scratching or hitting. Amy was very successful at getting her own way. The team discussed these observations and determined that Amy was using her challenging behavior to avoid sharing toys or engaging in activities that she did not like. Amy's parents described similar experiences of challenging

behavior at home. Amy would attack her mother when she asked Amy to do simple tasks like put her plate in the sink or pick up her toys. Amy would also bite and pinch her parents when they tried to help her make the transition from a desirable activity (e.g., playing in the park) to an activity that she did not want to do (e.g., get in the car to go home).

The team developed a behavior support plan based on their new understanding of Amy and the function or purpose of Amy's challenging behavior. The following prevention strategies were used: warning Amy of transitions with a countdown cue (e.g., "five more minutes, three more minutes, one minute, time for circle"); watching Amy carefully during center time and facilitating peer interaction when peers approached Amy; and setting a timer for Amy that showed her how long she could play with a highly desired object before offering the toy to another child. In addition to these strategies, the team modified activities and transitions that were difficult for Amy. For example, at circle time, the teachers added a choice board that allowed Amy to pick the song that would be sung on arrival at circle.

The support plan also included new skills to teach Amy. If the goal was that Amy would no longer need to use challenging behavior, she needed to learn some new ways to get her needs met. The team

decided that Amy needed to learn how to take turns with peers and how to comply with transition requests. They set up play situations with peers where Amy could be taught to take turns. The team also made a schedule for Amy (a laminated piece of cardboard with fasteners that held photographs) of the activities of the day. The schedule was reviewed with Amy each day and prior to each activity. The fasteners allowed for changes to be made in the schedule (e.g., by adding new photos or drawings) and allowed Amy to peel off each photo upon completion of the activity and place it in a finished envelope. A similar schedule was created for activities at home. The schedule helped Amy anticipate transitions and could be used to cue Amy with countdowns.

The final piece of the support plan involved changing the way adults responded to Amy when she exhibited challenging behaviors. The team decided that when Amy was aggressive to another child, Amy would be guided to another play area. The adult might say, "Amy, you are having a hard time playing blocks, you need to pick a new activity." After a few minutes and when Amy was calm, the adult would allow Amy to return to the block area with the adult supporting Amy and her peers' social interaction. The team also decided that when they told Amy that it was time to change activities, the adult

## Wisconsin Early Childhood Collaborating Partners: Building Protective Factors with Families

Training of Trainers  
October 22  
Pyle Center, Madison



needed to follow through with the request. Each team member agreed to use these strategies consistently.

## Will PBS Really Work for Children?

Research has shown that this approach can produce rapid changes in behavior with significant changes in challenging behavior when the plan is implemented consistently. PBS works because the behavior support plan prevents challenging behavior from occurring, teaches the child new skills, and includes strategies to make sure that challenging behavior is no longer effective for the child. The support plan will only work if all three pieces (prevention strategies, instruction in new skills, and responses to behavior that ensure that challenging behavior is not effective) are implemented. The effectiveness of this approach is also dependent on “buy-in” from the team, the consistency with which the support plan is implemented across all environments, and the team’s commitment to ongoing support of the child.

## Isn’t PBS Just “Giving in” to the Child?

PBS is for children who persist in challenging behavior and do not respond to general child guidance procedures. In PBS, caregivers meet children where they are. For example, if the child throws a tantrum to get out of an activity, PBS is used to teach the child a socially appropriate way to request a break. In addition, if a child has a tantrum to leave an activity, caregivers will examine that activity to see if it can be made easier or more enjoyable for the child. When the child learns that activities are enjoyable and that he or she can request a break using appropriate behavior, the challenging behavior will no longer be needed to serve that purpose by the child.

*The plan developed for Amy worked very well. In examining Amy’s behavior, the team realized that Amy had delays in her social skills and needed long-term*

*support. The teachers learned from Amy’s parents that Amy did not have many play opportunities with other children outside of school. The team talked about different strategies that could be used to support Amy’s social development. Amy’s parents suggested that they would try and get Amy to places where she could play with other children (e.g., park, cousin’s house, gymnastics class). Jack offered to help Amy develop friendship skills with other children in the classroom and introduce Amy’s parents to the parents of children Amy seemed to like. Amy’s parents were also interested in child care options for Saturday when they both frequently worked. At the time, Amy was cared for by her 15-year-old brother who watched television with her most of the day. Jack recommended a Saturday program at the Children’s Museum and offered to call and see if they might be able to provide a scholarship for Amy.* ☺

## Where Do I Find Information on Implementing This Practice?

See the CSEFEL Web site (<http://www.vanderbilt.edu/csefel/>) for additional resources.

Boulware, G. L., Schwartz, I., & McBride, B. (1999). Addressing challenging behaviors at home: Working with families to find solutions. *Young Exceptional Children*, 3(1), 21-27.

Janney, R., & Snell, M. E. (2000). *Teachers’ guides to inclusive practices: Behavioral support*. Baltimore, MD: Paul H. Brookes. (Available at <http://www.brookespublishing.com>.)

Kaiser, B., & Raminsky, J. S. (1999). *Meeting the challenge. Effective strategies for challenging behaviours in early childhood environments*. Ottawa, Canada: Canadian Child Care Federation. (Available through NAEYC; see <http://www.naeyc.org>.)

Neilsen, S. L., Olive, M. L., Donovan, A., & McEvoy, M. (1998). Challenging behaviors in your classroom? Don’t react, teach instead. *Young Exceptional Children*, 2(1), 2-10.

## What Is the Scientific Basis for This Practice?

*For those wishing to learn more about the topic, the following resources provide additional information:*

Blair, K. C., Umbreit, J., & Bos, C. S. (1999). Using functional assessment and children’s preferences to improve the behavior of young children with behavioral disorders. *Behavioral Disorders*, 24(2), 151-166.

Carr, E. G., Horner, R. H., Turnbull, A. P., Marquis, J. G., McLaughlin, D. M., McAttee, M. L., Smith, C. E., Ryan, K. A., Ruef, M. B., Doolabh, A., & Braddock, D. (1999). *Positive behavior support for people with developmental disabilities: A research synthesis*. Washington, DC: American Association on Mental Retardation.

Dunlap, G., & Fox, L. (1999). A demonstration of behavioral support for young children with autism. *Journal of Positive Behavior Interventions*, 1(2), 77-87.

Kamps, D. M., Ellis, C., Mancina, C., Wyble, J., & Greene, L. (1995). Case studies using functional analysis for young children with behavior risks. *Education and Treatment of Children*, 18(3), 243-260.

Kern, L., Ringdahl, J. E., Hilt, A., & Sterling-Turner, H. E. (2001). Linking self-management procedures to functional analysis results. *Behavioral Disorders*, 26(3), 214-226.

## Supporting Children to Participate Successfully in Everyday Life by Using Sensory Processing Knowledge by Winnie Dunn, PhD, OTR, FAOTA

*Infants & Young Children*, Vol 20, No. 2, pp 84-101

Full text link: [http://depts.washington.edu/isei/iyc/20.2\\_dunn.pdf](http://depts.washington.edu/isei/iyc/20.2_dunn.pdf)

This article from the spring 2007 issue of *Infants & Young Children* explores how children's and adults' sensory processing affects their everyday life experiences. The article is divided into 3 parts. The first section reviews a model of sensory processing. The second section describes behaviors often associated with different types of sensory processing patterns. The article's final section discusses the implications for sensory processing knowledge in early intervention planning, and offers applied, real-world techniques for working with children within each processing pattern.

In 1997, Dunn formulated a model of sensory processing based on neurological thresholds and self-regulation strategies. This model was tested in various age groups, as well as in people with and without disabilities. Research has demonstrated that sensory response patterns and response intensity are normally distributed among people without disabilities across all ages. Research has also shown that people with certain disabilities (such as autism, Asperger's syndrome, and schizophrenia) are more likely to have both distinctive and more intense patterns of sensory processing as compared with their peers without disabilities. With more extreme sensory responses, sensory processing is more likely to interfere with daily life.

Within Dunn's model, neurological thresholds and self-regulation strategies are both considered to be on a continuum. At the ends of the continuum, thresholds are categorized as either high or low, and self-regulation as either passive or active. Individuals with low thresholds will notice and

respond to stimuli readily, whereas those with high thresholds will miss stimuli that others notice because stronger stimuli are needed for nervous system activation.

**"For those who serve vulnerable children...and their families, it is important to link patterns of sensory processing to everyday life behaviors as part of assessment; the relationship between sensory processing and everyday life informs intervention possibilities."**

Individuals with a passive self-regulation style often let things happen around them and then react. Conversely, people with an active self-regulation strategy attempt to control the amount and type of sensory input coming to them.

Four basic patterns of sensory processing emerge from the intersection of these two continua:

- **sensation seeking** (high thresholds and active self-regulation),
- **sensation avoiding** (low thresholds and active self-regulation),
- **sensory sensitivity** (low thresholds and passive self-regulation), and
- **low registration** (high thresholds and passive self-regulation). The author stresses that no one individual has only one pattern of sensory processing, and each individual has a unique pattern of sensory processing.

Awareness of these four patterns of sensory processing can help adults working with children understand motivation behind some behavior. Equally as important, these patterns can also point to strategies for behavior modification. Occupational therapists are often trained specifically in applying

sensory processing knowledge to supporting children in daily activities; consultations with these professionals can often prove helpful when designing effective interventions for everyday life settings.

The article outlines specific intervention strategies for supporting children within each of the four sensory response

patterns. These charts suggest activities focused on the six main senses (touch, movement, visual, auditory, taste/smell, and body position/proprioception) when bathing, dressing, feeding, playing with, settling for bed, and going on outings with a child (see examples on the next page). Vignettes of individualized intervention planning are included to demonstrate the potential impact of sensory processing knowledge on a child's participation in daily routines. 🌐

### Examples of strategies for supporting children who...

#### **Miss cues in everyday life (low registration):**

Bathing: Use rough and varied textures for washcloths and towels (touch)

Playing: Place mirrors at floor level, add colored tape to door jams (visual)

#### **Create opportunities for sensation in everyday life (sensation seeking):**

Dressing: Place clothing items in different places to increase opportunities for moving (movement)

Outings: Tell child what you see, hear, and smell; ask what they are noticing (auditory)

#### **Move away from sensations in everyday life (sensation avoiding):**

Mealtime: Use one food temperature and limit textures (touch)

Bedtime: Use unscented products on bedding, hands (taste/smell)

#### **React quickly to sensations in everyday life (sensory sensitivity):**

Playing: Crawl in tight spaces; carry/push heavy objects (body position)

Bathing: Pick one stable position for bathing (movement)

# RESOURCE PEARL

## RESOURCE PEARL



### Tips for your everyday life

#### The Power of Vinegar

From Rene' Forsythe, Northeast REsource Representative

I've been trying to find a solution to this problem for years! A friend just shared this with me, and now I'll share it with you.

Do your dishrags get smelly and never seem to totally freshen after being laundered? Try adding a cup of vinegar to the wash load and they'll come out smelling fresh and clean.

You could also try soaking them in a solution of vinegar and water prior to washing. I keep a covered pail of this solution under my kitchen sink and throw them in until I am ready to wash them. ☺

## Wisconsin Model Early Learning Standards Trainings

### WMELS Training

CESA 5

October 16

Marshfield

Contact: Marshfield Mid-State Technical College (715) 387-2538

### WMELS Event: Observation and Recording

*Kenosha Association for the Education of Young Children*

October 25

Bristol

Contact: Janice Scheppler (262) 697-4562

### WMELS Reflective Teaching: Health and Physical Development

*Kenosha Association for the Education of Young Children*

November 15

Kenosha

Contact: Patti Robinson (262)862-6037

## 2007 NAEYC Annual Conference & Expo

November 7-10

Chicago, Illinois

<http://www.annualconference.naeyc.org/>



# SERVICES & RESOURCES

## Services and Resources for Children with Autism Spectrum Disorders and their Families

Prepared by Linda Tuchman

Young children ages birth through five years of age with autism spectrum disorders, and their families, are eligible for numerous services and resources in Wisconsin. Below is a summary of services, resources and supports that children with autism and their families may access through these programs: Wisconsin Birth to 3 Program, Intensive In-Home Intervention Treatment (Children's Long Term Care Waiver), Early Childhood Special Education, and other early childhood community programs.

### Wisconsin Birth to 3 Program

This information is summarized from a list of recommendations generated by the Wisconsin Birth to 3 Program Autism Work Group. The group was convened by the Wisconsin Department of Health and Family Services, Birth to 3 Program in 2004 to identify roles for Birth to 3 Programs in serving children with autism spectrum disorders and their families. The timing of this group coincided with the initiation of the Intensive In-Home Autism Benefit under the Children's Long Term Care Waiver Program. A primary focus of the group's work was to examine the mission, purpose, and regulations of the Birth to 3 Program as well as the research on early identification and interventions for infants and toddlers with or suspected of having an autism spectrum disorder.

**Eligibility:** Most children who demonstrate early signs or autism or other related conditions, will qualify for early intervention based on determination of a developmental delay. A diagnosis of autism is not necessary for a child to receive early intervention. Birth to 3 Programs are not responsible for diagnostic services unless a diagnosis is needed for eligibility or program planning. In many situations, family reports, observations and information about the child's abilities and needs across the developmental areas would be sufficient to determine eligibility and plan early intervention services.

However, a child with a diagnosis of a Pervasive Developmental Disorder (PDD), including autistic disorder, asperger's syndrome, and PDD-Not Otherwise Specified (NOS) as specified in DSM-IV would be eligible for the Birth to 3 Program. (See pages 3-5.) Eligibility would be based on having a diagnosis on Chart 1 of the Diagnosed Conditions guidance, available at this site: [www.waisman.wisc.edu/birthto3/EVALANDASSESS.HTML](http://www.waisman.wisc.edu/birthto3/EVALANDASSESS.HTML)

**Assistance in Obtaining Diagnosis:** Children often come to the Birth to 3 Program prior to receiving an autism spectrum diagnosis. When a Birth to 3 provider suspects that a child referred to or enrolled in a Birth to 3 Program shows characteristics on the autism spectrum, Birth to 3 providers have a role in helping families access information about autism spectrum disorders and seek a diagnosis. This may include making a referral to a primary care physician, a diagnostic professional or team, and/or other local, state and national resources. Another important role for Birth to 3 staff in the diagnostic process is to document and share information with the diagnostic team about their experiences with the child. This may include reports of assessments and observations that describe a child's developmental strengths and needs. As mentioned above under eligibility, Birth to 3 Programs are not responsible for diagnostic services unless a diagnosis is needed for eligibility or program planning.

**Services:** The Birth to 3 Program's primary role is to support the family's primary relationship with their child. The mission of the Birth to 3 Program is to enhance a child's development and work in partnership with the family to support the family's knowledge, skills, and abilities as they interact with and raise their child. The Birth to 3 Autism Work Group emphasized the importance of routine or activity-based intervention. This approach:

- Emphasizes addressing the family's highest priorities and establishing strategies for intensive engagement of the child in learning opportunities within a family's routines and activities;
- Reflects both the Birth to 3 Program mission and research-based recommendations by the National Research Council on *Educating Children with Autism* (2001) and a NECTAC-sponsored forum on "Areas of Agreement about Effective Practices among Programs Serving Young Children with Autism Spectrum Disorders", published in *Infants and Young Children* (1999). These recommendations underscore; and
- Underscores the importance of developing individualized, child and family outcomes through the Individualized Family Service Plan (IFSP) process.

# SERVICES & RESOURCES

## Wisconsin Birth to 3 Program, continued

**Information, Resources and Supports:** After diagnosis, early intervention providers help the family learn about options for support and services for children with autism. One of those resources is the **Children's Long Term Care Waiver for Intensive In-Home Intervention**. The Birth to 3 Program is a primary way for families to access timely and accurate information about this benefit. (See below. )Because there are numerous programs and approaches designed for children with autism spectrum disorders, it is essential that early intervention staff provide unbiased information about various intervention approaches and options. This includes access to current research about treatments and interventions for autism spectrum disorders. Since the science is evolving, families may need guidance in interpreting the findings relative to their child. Other sources of information and support include: Wisconsin First Step (1-800-642-STEP), the Regional Centers for Children and Youth with Special Health Care Needs, and the Autism Society.

**Coordination between Birth to 3 Programs and Intensive In-Home Intervention Programs (Children's Long Term Care Waiver):** If a child with a diagnosis on the autism spectrum is enrolled in the Intensive In-Home Intervention program and participates in a Birth to 3 Program, it is essential that communication and coordination occur between the two programs to best support the family. The Work Group recommended a number of strategies to build upon the strengths and priorities of each program that could be addressed in a collaborative agreement or memo. Topics to consider within such an agreement include: communication with staff across programs (including service coordinators and providers), provision of and billing for targeted case management, coordination of intervention strategies and approaches, and communication with families. In some counties, the Birth to 3 Program and the Waiver Program are operated out of the same county office which naturally leads to opportunities for excellent coordination.

## Wisconsin Children's Autism Waiver: Intensive In-Home Treatment for Children with Autism, Asperger's and Pervasive Developmental Disorders

Through the Wisconsin Children's Long Term Care Waiver Program, the Department of Health and Family Services supports the provision of intensive in-home treatment for children with Autism, Asperger's and PDD-NOS under the age of 8 years old. This benefit is funded by the Wisconsin Medicaid Program. Service consists of a variety of therapeutic approaches that can be implemented with the intent to enhance behavior, communication and social skills. The services must be provided by a qualified provider to children who meet eligibility criteria for the program. The intent of the treatment is to improve the health, welfare and effective functioning in the home and community.

Each county has a contact agency to assist families in applying for the services and to provide ongoing service coordination, if a child is eligible for and accepted into the program. County staff is supported by regional children's section staff. The amount of services is individually determined for each child ranging from 20-35 hours per week of face-to-face contact for up to three years. There are a limited number of slots for the program statewide, and some children are waiting for services. There are exceptions that may be considered for time extensions on an individual child basis according to established criteria. After completion of the three years, children may transition to other home and community-based waiver supports and services. The service coordinator plays an essential role in assisting and supporting families through all aspects of the program.

For additional information about the waiver program, visit:

<http://dhfs.wisconsin.gov/bdds/clts/autism/index.htm>

## Trainings on Autism for Early Childhood Professionals

Northeast Wisconsin Technical College, Green Bay

- Physical Aspects      October 9 or 13
- Communication      October 23 or 27
- Behavior Workshop    November 6 or 10
- School Resources     November 20 or December 11

Contact: To register, call 1-800-422-6982, ext. 5444 or [www.nwtc.edu](http://www.nwtc.edu) (click on my.NW )

# SERVICES & RESOURCES

## Early Childhood Special Education

Eligible preschool children, ages 3 through 5 with or suspected of having autism spectrum disorders are served by early childhood special education services through public school districts.

**Eligibility:** Autism is a special education eligibility criteria for the Wisconsin Department of Public Instruction. The current eligibility criteria under state law is found at PI.11.36(8) Wisconsin Administrative Code. If a student is found to have an impairment, the IEP team must also determine the need for special education services (PI 11.35). The *Autism Evaluation Guide*, drafted August 2007 is an excellent resource for IEP teams.

If a child has a medical diagnosis of autism based on the DSM-IV criteria, a child still needs to be found eligible for special education by the school district. Furthermore, if a child with characteristics on the autism spectrum has not had a medical diagnosis or does not meet the educational criteria for autism, the child may be eligible for early childhood special education services and supports under other eligibility criteria.


On the right of this page is the Wisconsin Department of Public Instruction checklist to assist teams in determining if a child meets the educational criteria for eligibility in the area of autism.

**Programming:** A child who has been evaluated and found to meet the eligibility criteria and needs special education and related services has an individual education program (IEP) developed. The IEP is based on the individual needs of a particular student and the placement for the child is developed to implement the IEP in the least restrictive environment.

**Information and Assistance:** School district personnel are in an excellent position to assist families in accessing information about autism and other supports and resources in the community. This would include information about resources for obtaining a medical diagnosis and related health care services, as well as accurate and timely information about the Intensive In-Home Intervention Waiver Program. For children who have not transitioned from a Birth to 3 Program, school may be the only source of additional information that a family may have.

For access to the information summarized above, visit <http://dpi.state.wi.us/sped/autism.html>

## Early Childhood Community Programs

Children with autism spectrum disorders also receive supports and services through community programs available to all children. Some children with or suspected of having autism are enrolled in Early Head Start/Head Start Programs where they receive individualized program plans in coordination with other programs such as Birth to 3 or schools. Children with autism also attend child care and other early education programs. When children are enrolled in community programs as well as special programs such as Birth to 3 or early childhood special education, it is important for providers to coordinate their services to promote the success of children with autism in all environments. 

Criteria for impairment in the area of autism can be documented as follows:

Section I. (Both must be checked Yes.)	
<input type="checkbox"/> Yes <input type="checkbox"/> No	The child displays difficulties or differences or both in interacting with people and events. The child may be unable to establish and maintain reciprocal relationships with people. The child may seek consistency in environmental events to the point of exhibiting rigidity in routines.
<input type="checkbox"/> Yes <input type="checkbox"/> No	The child displays problems which extend beyond speech and language to other aspects of social communication, both receptively and expressively. The child's verbal language may be absent or, if present, lacks the usual communicative form which may involve deviance or delay or both. The child may have a speech or language disorder or both in addition to communication difficulties associated with autism.
Section II. (At least one must be checked Yes.)	
<input type="checkbox"/> Yes <input type="checkbox"/> No	The child exhibits delays, arrests, or regressions in motor, sensory, social or learning skills. The child may exhibit precocious or advanced skill development, while other skills may develop at normal or extremely depressed rates. The child may not follow developmental patterns in the acquisition of skills.
<input type="checkbox"/> Yes <input type="checkbox"/> No	The child exhibits abnormalities in the thinking process and in generalizing. The child exhibits strengths in concrete thinking while difficulties are demonstrated in abstract thinking, awareness and judgment. Perseverant thinking and impaired ability to process symbolic information may be present.
<input type="checkbox"/> Yes <input type="checkbox"/> No	The child exhibits unusual, inconsistent, repetitive or unconventional responses to sounds, sights, smells, tastes, touch or movement. The child may have a visual or hearing impairment or both in addition to sensory processing difficulties associated with autism.
<input type="checkbox"/> Yes <input type="checkbox"/> No	The child displays marked distress over changes, insistence on following routines, and a persistent preoccupation with or attachment to objects. The child's capacity to use objects in an age-appropriate or functional manner may be absent, arrested or delayed. The child may have difficulty displaying a range of interests or imaginative activities or both. The child may exhibit stereotyped body movements.

## 2007-2008 Statewide Autism Training—Wisconsin Department of Public Instruction

- November 27-28, 2007: Basic Level Madison, WI
- January 30-31, 2008: Basic Level Green Bay, WI
- April 8-9, 2008: Advanced Level, Addressing Challenging Behavior Madison, WI

Contact: Jeanne Hook at [jeanne.hook@dpi.state.wi.us](mailto:jeanne.hook@dpi.state.wi.us) or 608-266-3928 or Lynn Boreson at [lynn.boreson@dpi.state.wi.us](mailto:lynn.boreson@dpi.state.wi.us) or 608-266-1218; <http://dpi.state.wi.us/sped/autism.html>

# OTHER RESOURCES

## Other Important Resources for Children with Autism and Their Families

### Wisconsin Autism Council

<http://dhfs.wisconsin.gov/bdds/clts/autism/council/index.htm>

In a February, 2005 letter (<http://dhfs.wisconsin.gov/bdds/clts/autism/autism2-7-05.pdf>) to then Department of Health and Family Services (DHFS) Secretary Helene Nelson, Governor Jim Doyle announced that he would appoint a Council on Autism to advise the Department on strategies for implementing statewide supports and services for children with autism and directing the Department to assist the Council with administrative and support services.

Governor Doyle specified that he wanted the Council to address some of the important issues identified by his earlier **Task Force on Autism** (<http://dhfs.wisconsin.gov/bdds/clts/autism/taskforc.htm>) :

- Provider staff training issues
- Provider and parent strategies to recruit and retain line staff.
- Provider outreach efforts to recruit parents to work as line staff.
- Alternative approaches to the current age restriction policy in the intensive phase

## National Resources

### First Signs

<http://www.firstsigns.org/>

First Signs aims to educate parents, healthcare providers, early childhood educators, and other professionals in order to ensure the best developmental outcome for every child. The First Signs Web site provides resources on typical development, developmental concerns, screening and referral processes, and treatments for autism spectrum disorders.

### CDC: Learn the Signs, Act Early

<http://www.cdc.gov/ncbddd/autism/ActEarly/default.htm>

Campaign to increase awareness of typical social and emotional development in children age birth to 5 years.

### “Manitas por autismo”

<http://www.manitasporautismo.com/index.html> Website in Spanish designed for parents and care givers of children with autism.

## Nutrition Fact Sheet

**Nutrition Fact Sheet:** (<http://www.waisman.wisc.edu/birthto3/Nutrition.pdf>)

Listing of Wisconsin Women, Infants and Children (WIC) Program Services for Infants and Children with Special Health Care Needs

### Picture Exchange Communication System (PECS)

November 5-6

Park Plaza Hotel, Oshkosh

Contact: Chris Deluliis, (902) 424-1129 or (800) 633-1442



### PECS Review, Practice and Problem Solving

November 7

Park Plaza Hotel, Oshkosh

Contact: Chris Deluliis, (902) 424-1129 or (800) 633-1442

# JOB POSTING

Easter Seals Kindcare, **Milwaukee County**, has immediate openings for Speech Language Pathologists and Physical Therapists in their **Birth to 3 Program**. CFY Supervision is available. Flexible schedules, competitive salaries, benefits packages, and sign-on bonuses are offered. Contact Carrie Cianciola at [carriec@eastersealskindcaresewi.com](mailto:carriec@eastersealskindcaresewi.com) or 414-449-4444 ext. 212

## **Birth to 6** EVENTS



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For additional information, call 608-890-0144, 1-800-532-3321, or email [keil@waisman.wisc.edu](mailto:keil@waisman.wisc.edu)

Deadline for submissions to next Birth to 6 EVENTS: December 21, 2007.