



AUTISM: EARLY DIAGNOSIS BRINGS BETTER OUTCOMES

At 18 months, Ben Mattson was a healthy and active boy who liked playing with his Matchbox cars and figuring out how things worked. He was eating and sleeping well, and he was meeting most of his developmental milestones.

His mom, Jessica, wasn't too concerned that he had limited speech. After all, he wasn't even 2, and children develop at their own rates. She was concerned, however, that he was hitting other children and even his parents. "He would do it without warning if he was frustrated or another child had a toy he wanted," she says. In her Early Childhood Family Education (ECFE) group, "my son was the only child of 16 who would not sit in his parent's lap during circle time," Jessica says. "He was the only one hitting other children and who had a speech delay. My child was the only one who would say 'hi' to everyone in the classroom and then find a toy to play with alone. He would not interact with other children."

Although other moms in the group assured her that such behavior was typical, "I was always on edge," she recalls. Despite the support, Jessica couldn't shake the nagging feeling that something more was at work.

Eventually, she contacted her school district and requested a full evaluation for her son. She was surprised to learn that Ben needed speech therapy. Weekly services in her home soon began, with the expectation that increased language



Ben and Jessica Mattson

skills would reduce Ben's frustration and result in improved behavior. As they continued in their ECFE group, however, Jessica still had concerns about Ben's social interactions.

In the summer of 2009, Ben's speech therapist told Jessica her son was making good progress, but she saw some "red flags" in his behavior, including frequent meltdowns and

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difficulty making transitions from one task to the next. She asked Jessica if she would consent to additional testing, and Jessica agreed. After the school district completed formal testing, Ben was evaluated as having autism spectrum disorder (ASD) and a speech-language impairment called articulation disorder.

It's a story that's played out across Minnesota and the nation. According to the 2009 autism prevalence report from the Centers for Disease Control and Prevention (CDC), 1 percent of U.S. children have autism, and the prevalence appears to be increasing.

A complex developmental disability that affects a person's ability to communicate and relate socially, autism can

manifest differently and to varying degrees. Children typically show symptoms, including loss of skills, between one and three years. No single cause has been identified.

What's Typical, What's Not?

Before you can know what behaviors—or lack of them—might be signs of autism, it's helpful to know what typical developmental milestones are. Although children develop at their own pace, the CDC suggests some general guidelines for the ages at which most children develop important skills.

According to the CDC, you might expect to see the following skills at these ages (see chart below):

3 months		7 months	
	begins to smile		enjoys social play
	watches faces intently		responds to own name
	begins to babble		babbles chains of sounds
	turns head toward direction of sound		says "mama" or "dada"
	raises head and chest while lying on stomach		rolls both ways (front to back and back to front)
			reaches with one hand
12 months		18 months	
	cries when mom or dad leaves		walks without help
	is shy or anxious with strangers		says 10 to 20 words
	repeats sounds or gestures		imitates others
	tries to imitate words		laughs out loud
	answers to name when called		is curious and likes to explore
	feeds self with fingers and cup		shows interest in other children
	babbles with changes in tone		shows different emotions, such as happiness, fear, sympathy
	crawls forward on belly; may pull to stand and walk holding on to furniture		
24 months		3 years	
	shows increasing independence		imitates adults and playmates
	begins to say "no" and do the opposite of what's asked		expresses affection openly
	tries new things and explores new places		expresses a wide range of emotions
	begins make-believe play		separates easily from parents
	uses two- to four-word sentences		plays make-believe with dolls, animals, and people
	follows simple directions		uses the toilet during the day
	shows affection by returning a hug or kiss		pays attention longer
	refers to self by name		names six body parts
	enjoys books and simple games		uses four- to five-word sentences
	likes people and company of other children		talks and usually can be understood

When Should You Seek Help?

If your child is not meeting milestones, it could be for any number of reasons. He or she could simply be a late bloomer or perhaps have developmental delays that could benefit from early intervention services. If you see a pattern of characteristics that continue over time, however, it could be a sign of autism.

The CDC has identified behaviors common to young children with ASD. A child with autism may:

- avoid eye contact
- prefer not to be cuddled or held
- have extreme trouble adapting when the routine changes
- not smile by five months or laugh by six months
- have trouble expressing needs using typical words or motions
- repeat or echo words or phrases others say, or repeat words or phrases in place of typical language
- show no interest in games or peek-a-boo by eight months
- have other language delays, such as not using words such as “mama” or “dada”
- not play “pretend” games, such as feeding a doll, by 24 months
- not point to objects to show interest by age 24 months

If you see these patterns in your young child, the CDC recommends taking action right away so your child can

receive needed services as early as possible. You can:

- Ask your pediatrician to determine if your child’s behaviors stem from autism or some other cause.
- Contact your local school district for an evaluation to see if your child qualifies for early childhood special education services that could help with delays in development or learning. You can do this with or without a medical diagnosis of autism.
- Check out Help Me Grow, the state of Minnesota’s early childhood special education program. Call 1-866-693-GROW (4769) or visit parentsknow.state.mn.us/parentsknow/newborn/HelpMeGrow_SpecialNeeds/index.html, where you’ll find brief videos that discuss typical development and information on how to make a referral to your local Help Me Grow program.
- Call PACER. An early childhood advocate can talk with you about your concerns and refer you to programs and resources that can help.
- Visit the CDC’s Web site at cdc.gov/ncbddd/autism/index.html for information and resources on autism.

If your child already has a diagnosis of autism, you may wish to contact the Autism Society of Minnesota, an organization of families, educators, caregivers, and professionals committed to supporting individuals with ASD. You can learn more by calling 651-647-1083 or visiting ausm.org.

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PACER Works with Somali Community on Autism

The rate of autism in Minneapolis’s Somali community is significantly higher than it is in other populations.



Hassan Samantar

Although experts have yet to determine the reason, PACER and others are helping the families deal with the situation.

PACER’s multicultural advocates, for example, sit on the Minnesota Department of Health’s Cultural Influences Workgroup

to explore the prevalence of autism spectrum disorder (ASD) in Somali children. They are investigating how cultural differences can affect both identification of autism in preschoolers and families’ use of ASD special education services.

PACER also has received a McKnight grant to teach Somali parents of children with ASD and other disabilities how to work with school and county staff, and how to locate necessary educational resources. Hassan Samantar, PACER’s Somali Parents Project coordinator, oversees the project. As part of the project, Samantar will help a small group of parents learn to become effective parent leaders. These parent leaders will help other parents understand how to advocate for their children in school and locate needed services.

PACER ANSWERS FREQUENTLY ASKED QUESTIONS

Whether your young child has an Individualized Family Service Plan (IFSP) or an Individualized Education Program (IEP), you may have questions about qualifying for and receiving services. Is 40 minutes of services a week enough? Do charter schools have to provide special education services? Do children who move to Minnesota from another state qualify for services? Judy Swett, one of PACER's early childhood parent advocates, answers those questions.

Q. My son has turned 3 and is going to attend an inclusive preschool. According to his IEP, he'll receive services from a special education teacher only twice a week for 20 minutes each time. How can he possibly make progress on his goals with such a limited amount of service?

A. In an inclusive preschool classroom, all staff members should be informed of a child's IEP goals and any modifications or accommodations that may be needed. They most likely will create opportunities for your child to work on his goals throughout the day. If your son has an IEP goal related to expressing his wants and needs, for



example, staff may set up a drive-up window in the dramatic play area to encourage him to order his favorite food. By using your son's interests and activities, the staff can provide many opportunities for him to work on the goal, beyond the 40 minutes of direct service he receives each week. Since your son enjoys the activities, he is likely to stay engaged with them and make progress on his IEP goals.

If, however, you disagree with the special education services proposed by the school, you can indicate on the IEP that you disagree and ask for an IEP meeting to discuss your concerns. If you're unable to reach an agreement on appropriate services for your child, you can call PACER to discuss ways to resolve your disagreement in the special education process.

Q. I am considering enrolling my daughter in a charter school for kindergarten. She is on an IEP. Does the charter school have to provide special education services?

A. Charter schools are public schools, so they must comply with state and federal special education laws. Like all public schools, they must have a system to evaluate children and determine eligibility for special education services, and they must provide those services. The charter school can either accept your daughter's current IEP or do its own evaluation and write a new IEP. In the latter case, it would have to provide the services noted in the IEP or propose comparable services to which you agree. These services would be in effect until the evaluation is completed, a new IEP is written, and you have signed an agreement.

Q. I have just moved to Minnesota from another state. My son was on an IFSP there, but when I contacted the school district here, they told me he may not necessarily qualify for services. How can that be?

A. Your son may have qualified under the category of developmental delay. The Individuals with Disabilities Education Act (IDEA) allows each state to determine its own definition of developmental delay, so a child may qualify in one state but not another. You have a right to request that that your son be evaluated to determine eligibility in Minnesota.

If you have questions regarding any aspect of early childhood services or resources, please call PACER Center and ask to speak with a parent advocate.

DEVICES AND SOFTWARE CAN HELP YOUNG CHILDREN COMMUNICATE

It's no secret that children have feelings, opinions, and desires they want to express. If your child has autism, developmental delays, or any other disability that makes communication difficult, you already know how frustrating that can be for you and your child.

What you may not know is that an array of communication devices and software can help. Known as augmentative and alternative communication (AAC), these tools can help even very young children express their wants, develop stronger relationships with peers, and find inclusion in the classroom and elsewhere.

Here are two popular types of AAC you may want to consider for your child.

Picture Communication Symbols

Often the first form of AAC used by young children, picture communication symbols (PCS) consist of simple images showing objects, actions, and feelings. By pointing to a given symbol—a picture of a favorite toy, for example—your child can make choices and communicate his or her wants and needs. PCS software programs such as Boardmaker by Mayer-Johnson or Picture It by Slater Software allow you to create customized communication materials for your child. They usually contain a searchable graphics database to help you find specific symbols, such as images associated with a birthday party or your child's morning routines. You also can use digital photos and images to create simple communication symbols and schedules.



Mid-tech Devices

If your child needs more support when communicating, a device that incorporates PCS and voice output may be a good option. This type of device features a recorded voice that “speaks” when the corresponding button or picture is activated. You may want to start with a simple one-message device such as the BigMack by AbleNet or Partner Plus Communicator by AMDI.

Once your child becomes familiar with how the device works, you may want a more advanced version that can expand his or her choices. A device with four message buttons and five levels, for example, would hold 20



pre-recorded messages. This feature provides a much broader vocabulary without additional programming and without overwhelming your child with more-complicated technology. The Go Talk 4+ by Attainment and SuperTalker by AbleNet, for example, have multiple buttons and levels.

As you explore which device might be best, look for one that motivates your child, is appropriate for his or her abilities, and offers more advanced capabilities your child could use as his or her skills develop. Depending on the situation, funding for such devices may come from you, your insurance, or your child's school. Mid-tech devices can range from \$10 to \$2,500, so it's worthwhile to try out a few before making a purchase. Many assistive technology companies and centers offer “try before you buy” loan programs. PACER's Simon Technology Center has helpful information about funding sources, as well as a number of AAC devices you can look at and borrow.

All people need to communicate. For young children whose disabilities interfere with their ability to share their ideas, feelings, needs, and wants, AAC can offer a solution.

To learn more about AAC software and devices, contact the Simon Technology Center at 952-838-9000 or stc@PACER.org. You may also want to check out the AAC publications at PACER.org/publications/stc.asp.

NEW! Assistive Technology (AT) Booklet for Infants and Toddlers

“Discover How Assistive Technology Can Help Your Infant or Toddler Learn and Grow” explains how parents and professionals can utilize AT in the home and through early intervention services. This helpful booklet was produced through a partnership between PACER Center and Tots-n-Tech, a federally funded project that is conducting a series of national policy studies regarding AT with infants and toddlers.

To receive this free booklet, contact PACER Center at 952-838-9000 or PACER@PACER.org. For more information about Tots-n-Tech, visit <http://tnt.asu.edu>.

PROMOTE YOUR PRESCHOOLER'S LITERACY WITH THESE FUN ACTIVITIES

Literacy skills are important at every age, and they are critical for establishing a foundation for learning in young children. You can use everyday activities to encourage your young child to develop those important abilities. How? Try out the free practice guides from the Center for Early Literacy Learning (CELL). They help parents and professionals promote the building blocks of early literacy with infants, toddlers, and preschoolers. You can learn more about CELL practice guides at earlyliteracylearning.org/pgparents.php.

Here is an excerpt* from one of CELL's preschooler guides.

ALPHA FUN

Letters and Spelling

Preschoolers can recognize and identify letters—especially familiar letters like those in their names. When you join your child with enthusiasm in his play with alphabet toys, you help him build skills and encourage his interest in learning.

What is the Practice?

Playing, talking, and asking questions as your child enjoys alphabet toys makes letter-learning fun and exciting. Letter blocks, magnetic letters, and alphabet puzzles are the kinds of toys that can spark parent-child talks about letters and let children become familiar with the ABCs. Such toys also help preschoolers begin to form words without the added pressure of writing.

What Does the Practice Look Like?

Let your child play with letter-shaped cookie cutters in cornmeal, play dough, or real biscuit dough. Cut letter



shapes from sponges for her to play with in the bathtub or use as stamps to make designs with washable paint. Talk to her about what she's doing as she plays. As your child lines up magnetic letters on the refrigerator door, stacks alphabet blocks, or strings alphabet beads, talk with her about what she is doing and encourage her interest and curiosity about letter sounds.

How Do You Do the Practice?

When your child plays with alphabet toys, add to the fun by providing a variety of such toys, praising his efforts, and following his lead.

- Ask your child to tell you the letters in his name by pointing out the blocks, stamps, or other toys that have those letters. Show him how to use them to form his name. Help him discover that even though letters may be different colors or sizes on different toys, their names and sounds stay the same.
- Show your child how the letters on her alphabet toys are paired with sounds. For example, when your child hands you the block with T on it, help her name the

letter and its sound. Together try to think of words that start with the Ttt sound.

- Try to avoid making alphabet toys seem too “hard” or too much like work. Most preschoolers are beginning to understand that we use letters to make words, but they are often unsure about their exact sounds and shapes. Showing interest and pleasure in his attempts at learning through play is more important than expecting your child to remember all the letters right away.

How Do You Know the Practice Worked?

- Does your child play eagerly with alphabet toys?
- Does your child point out familiar letters on his toys and other places he sees them?
- Does your child name sounds and letters when you are playing with alphabet toys together?

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PACER'S GRANDPARENT SUPPORT GROUP TO MEET SEPT. 21

PACER's Grandparent to Grandparent Program offers people with grandchildren of any age and any disability a chance to meet others; share concerns, joys, and interests; discover resources; and learn how they can provide support to their children and grandchildren.

Through monthly meetings during the school year, the group offers grandparents opportunities to discuss the impact of the child's disability on the entire family and receive information pertaining to special education, relevant laws, and other issues that may be of concern. Pam and Bill Telleen, who have a young granddaughter with Down syndrome, lead the group.

The next meeting is Sept. 21. For more information, call PACER at 952-838-9000 or visit PACER.org/grandparent.

Left: Sharon Stoebner and her granddaughter Skylar

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PACER is a coalition of organizations founded on the concept of parents helping parents. PACER strives to improve and expand opportunities that enhance the quality of life for children and young adults with disabilities and their families. This Early Childhood Project is partially funded with training funds provided by the Minnesota Department of Education.

(Alternate format is available upon request.)

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A Brighter Future

The earlier children are diagnosed and receive help, the sooner they can make progress and the more easily they will be able to learn when they enter school.

As Jessica knows, taking that first step can be hard. She well remembers those initial feelings of disbelief and guilt, but these days she's smiling. "Ben is now 3 ½ and he's doing fantastic," she says. "He's in a special ASD program four days a week, he has occupational therapy once a week, and speech two times a week. He's in a smaller group setting with less stimulation, and it has been amazing for him. His speech and social interaction have increased beyond my expectations.

"I can't say enough about early intervention," she adds. "Ben's everyday routines and living are enhanced by being in a social setting I never would have known about. With early intervention, every child is looked upon as an individual, and that helps both him and me. Our district made the transition from early intervention to the classroom very positive for Ben and our family."