

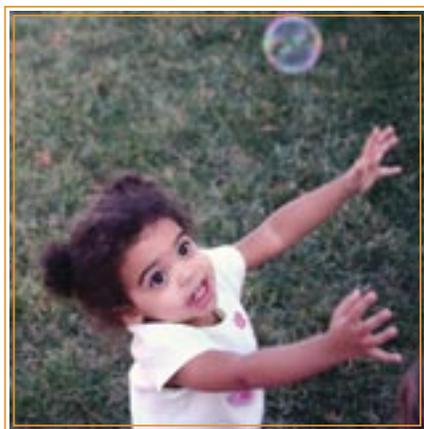


EARLY CHILDHOOD CONNECTION

New Eligibility Criteria May Affect Transition Planning for Your Child

When a child with disabilities turns 3, early intervention services end and preschool special education services may begin – if the child is eligible for them. Planning for this transition and determining whether your child will qualify for services is an important milestone in your child’s life. By learning all you can about these issues and working with your Individualized Family Service Plan (IFSP) team, you can help chart the brightest future possible for your child.

You and your IFSP team will begin transition planning as early as nine months before your child’s third birthday. When you do, you should be aware of a change in Minnesota law that may affect your child’s eligibility for special education preschool services.



Here’s a look at what the new law says and how it may affect your family.

What the Law Says

The federal Individuals with Disabilities Education Act

(IDEA) defines the services that states must make available to children with disabilities. Part C of IDEA addresses early intervention, which includes such services as occupational, physical, and speech therapy as well as supports for the

family. Part B of IDEA defines preschool services and focuses on the child’s academic needs.

Minnesota’s new law has broadened eligibility criteria for Part C. It now says that children from birth to age 3 qualify if they have a delay in *one* area of development or have “a diagnosed medical, physical, or mental condition or disorder that has a high probability of resulting in developmental delay *regardless of whether the child has a demonstrated need or delay.*” (Emphasis added.)

The new law does not, however, broaden eligibility criteria for Part B preschool services. Children qualify if they have a delay in at least two areas of development or “a diagnosed physical or mental condition or disorder that has a high probability of resulting in developmental delay *and a demonstrated need for special education.*” (Emphasis added.)

The more stringent Part B eligibility requirements may mean that some children who qualified for early childhood services will not qualify for preschool special education services at age 3. Your IFSP team will help you determine your child’s eligibility at your transition planning meeting.

Work with Your IFSP Team for a Smooth Transition

As early as nine months before your child turns 3, your service coordinator or other early intervention staff will call an IFSP team meeting. The agenda will be to discuss

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your child's transition needs and write a transition plan that addresses the end of early intervention services.

Part of the discussion will focus on your child's eligibility for Part B services. The team will let you know if additional information such as updated medical records or further testing is needed in order to evaluate your child. The meeting also will address your child's transition to a new program, services, and community resources. Your written permission will be required for testing and for referral to a new program.

The transition meeting is an opportunity for you to share your hopes for your child's future and your concern about your child's learning. Be prepared to share ideas and methods that work for your child at home.

During the meeting, be sure to ask questions about anything that is unclear to you. For example, you may want to ask:

- How will the school district decide if my child is eligible for special education?
- What kind of testing will be needed?
- What is the difference between an IFSP and an Individualized Education Program (IEP)?
- What are our options for services if my child is eligible?
- Whom do we contact if we want to visit a program or classroom?
- How long is the school day or class?
- What is the daily routine of the class or program?
- How will my child participate with children who do not have a disability?
- How many children will be in the classroom?
- How will my child be transported to the new program?
- Whom do we contact if we have questions?

After the transition meeting and before your child turns 3, you may want to visit the program site proposed for your child. Doing so will allow you and your child to become familiar with the new setting and ask questions such as:

- How could this program match my child's learning style?
- What is the ratio of adults to children in the program?
- How is communication encouraged?
- How are families involved?
- Is the travel time from home to the program reasonable for my child?



If, after visiting a program, you have questions about the appropriateness of the placement for your child, discuss your concerns with your IFSP team.

Assuming your child qualifies for preschool services, an IEP must be in place by his or her third birthday. The IFSP team will be replaced by an IEP team, which will develop the initial IEP for your child. You may ask to have the Part C service coordinator or others from the IFSP team invited to the transition meeting. The IEP team will consider the services and information contained in your child's IFSP.

The IEP will look different from your IFSP. Designed to meet the unique needs of your child, the IEP describes:

- Your child's strengths and needs (present levels of performance)
- What your child will be working on during the coming year (annual goals and short-term objectives)
- What special services will be provided for identified areas (specially designed instruction and related services)
- What special supports (modifications and adaptations), supplementary aids, and services your child will need to function in a preschool program
- When services will begin and how long they will last
- How and when the team will measure your child's progress and share this information with you.

If your child does not qualify for special education preschool services, the team can tell you about resources that might be available in your community. These resources may include such options as community-based preschool programs, Head Start, Early Childhood Family Education (ECFE), private child-care centers or preschools, family child-care settings, or school district pre-kindergarten programs.

Now That's a Switch!

If your young child's disabilities interfere with his or her playtime, communication, or interactions with others, it may be time to switch things up—literally. An accessible electronic switch can be attached to toys, computers, communication devices, lights, radios, and other equipment to help young children learn, play, participate, socialize, and communicate more fully. Available in various shapes, sizes, colors, methods of activation, and placement options, a switch may be just the solution if your child is unable to use direct touch, a mouse, or a keyboard to activate toys and tools.

When introducing switches to toddlers and preschoolers, it's best to start with a simple activity, such as making a toy move, light up, or make noise. You can help your child understand the cause-and-effect relationship between the switch and the toy by keeping the main focus on the activity rather than the switch.

Once your child understands that cause-and-effect relationship, switch-access software programs for early learners can teach literacy skills, such as letter and number recognition. In most of these software programs, the child presses the switch and the image on the screen changes, moves, makes noise, or sings a song. This can be a very rewarding experience for children who need visual or auditory stimulation. Switches also can be used to activate communication devices, which

An accessible electronic switch can be attached to toys and other equipment to help young children learn, play, participate, socialize, and communicate more fully.



can help a child with limited language skills to socialize and be included with peers.

In all cases, the switch should be placed in the most accessible position for your child. For example, a preschooler who uses an adapted chair may be able to access the switch connected to his communication device more

accurately if it is placed near his elbow rather than directly in front of him. Switches can be placed wherever they are most useful—whether it's by your child's head, arm, hand, leg, or foot.

Keep in mind that switches can be used in many places beyond the home. In an early childhood environment, for example, switch-activated toys, software programs, and communication devices can help your child participate with peers in activities that all the children find enjoyable. In fact, children without disabilities also may want to use the switch to join in the fun.

For more information about switches and other switch-accessible ideas that can help young children with disabilities play, learn, and communicate, contact Tenley McDonald at PACER's Simon Technology Center, 952-838-9000 or tenley.mcdonald@PACER.org.



Letting Help In

Having a child inevitably brings changes to a family. When the child has disabilities or special health care needs, those changes can mean inviting professional help into the home. Nurses, service coordinators, therapists, and personal care attendants (PCAs) can play a critical role in helping families address the challenges of having a child with disabilities. The presence of these professionals, however, also requires families to adjust to having a stranger in their midst. There is less privacy, more dependency on others, and the need to define how and to what degree the professionals will blend into family life.

Amy Dawson, PACER's health information and advocacy coordinator, and Julie Hertzog, PACER's bullying prevention coordinator, understand those issues intimately. They share their stories of coping with both the gratitude and ambivalence of letting help into their homes.

When Amy's twins were born prematurely in 2003, she and her husband learned that one of them, Mac, had severe health problems. Due to lung problems, he was on oxygen for 18 months. When he came home from the hospital at six months old, he had very low muscle tone, required many medications, and was fed through a tube. Eventually they discovered that he had congenital defects in his spine, heart, and central nervous system. By the time he was 3, he also had an autism diagnosis.

"Mac also had pain and needed medication to sleep," Amy adds, "but even with that, he didn't sleep very well." Neither did his parents. "By the time Mac had been home from the hospital two or three months, I was exhausted," Amy recalls. "I'd quit my job as an attorney to take care of him. Because of the worry of infections, we were pretty isolated."

Julie can relate to the challenges. "David was born with Down syndrome and significant medical issues," she says, recalling the 1996 birth of her second child. "By the time

he was six months, he'd had two open heart surgeries and had received a tracheotomy and was vented, which required constant oxygen. He also had a pacemaker and a feeding tube. He had significant medical complications that required near-hospital-level care."

For six months, the Hertzogs managed David's care on their own. The toll on the family, however, was high. David didn't sleep well, so Julie and her husband alternated nights sitting up with him. That schedule, plus the fact that they both worked and were also raising a 2-year-old daughter, was too much. They were exhausted. And they were isolated. "We had no interaction with friends," Julie recalls. "It was too complex for family members to help. Plus, they were scared."

Isolated, exhausted, and stressed, both families came to the same conclusion: They needed outside help. Finding it, managing it, and making it work with family life, however, was a journey marked by successes, frustrations, and adjustments unique to each household.

For Amy, "our introduction to medical assistance and PCAs was really quite serendipitous." A nurse suggested that they apply for Supplemental Security Income (SSI), a federal program that Mac qualified

for because he was a resident of the hospital. Once enrolled, Mac qualified for Medical Assistance (MA)—and 12 ½ hours of PCA services a day. When Mac finally came home, his SSI eligibility ended and the family learned that he could continue on MA through a state program called TEFRA. The program enables eligible children with disabilities and special health care needs to receive MA; parents may pay a fee, depending on their income.

"We had really good luck finding terrific PCAs," Amy says. "They helped us make sure Mac was safe and comfortable. They helped work on his different therapy goals—trying to sit up or doing the simple things other babies do, like shaking a rattle."

To find a PCA, she recommends using an agency. For people on MA, there's also a program called PCA Choice that lets families choose and train a PCA. "We also tried



Mac Dawson, age 3

Consumer Directed Community Supports (CDCS). It's an option for some children with disabilities on MA that provides flexibility in how you spend your support dollars. Instead of using PCA services, for example, parents can choose to be paid to take care of their child, spend the money on respite, or seek caregiver training."

Julie now uses CDCS, but for seven years the family used agency services. During David's first two years, for example, his condition required intense services. "We needed at minimum a licensed practical nurse, and we preferred a registered nurse," she says, noting that they were eligible for 18 hours of care a day.

"It wasn't always easy. It felt chaotic all the time," Julie recalls. "You relied on the nurses emotionally and logistically. There was a real dependency. If they didn't show up, then it was just you."

Eventually, David's medical conditions improved and his care needs subsided. "When David got his trach out at 2½, we came to the world of PCAs," she says.

Both families discovered that finding, training, and managing caregivers can be a job in itself. Despite the families' best efforts, some people just didn't work out. They would cancel frequently, not show up, fail to do what was asked of them, or not meet the families' standards for keeping the child safe.

Both families also realized that having an outsider in their homes presented challenges and tradeoffs.

"You need to negotiate your terms with the PCA," Amy says. For example, would caregivers join the family at mealtimes? For Amy, "it was really just easier to make enough food to include them. We started treating them more like family. That model has worked well for us." For Julie, the answer was no. "It's a professional relationship," she says. "They're not a guest." She expected staff to bring their own meals.

Having outsiders in the house also affected family relationships. "They're there," Amy says. "If you want to talk to your husband about something, they're there. It can be a little much to have someone in your house all the time."

"We are very private people," Julie adds. "We took longer to access services because we didn't want people in our house. Having someone in the house means that sometimes you have to temper your reaction and act like you would in a public setting."

Finding the balance between obtaining help and maintaining privacy is as individual as each family. "If you start to feel the 'ick,' maybe it isn't fitting what the family needs," Julie says. "Trust your instincts."

"Some PCAs are just wonderful to have in your house," Amy adds. "They're a big help and a delight. But others can get on my nerves—especially if they start at 7 a.m. So it's me; I'm just cranky then. You just have to remember that they're helping you help your child. Go have another cup of coffee.



David Hertzog, age 11

"The whole situation has given me more patience with everything and everybody," she adds. "The important thing is my son is not going to die. He can breathe. He's even walking and running. He's moved from using sign language to talking.

"He asks his twin sister to dance with him," Amy says, "and he loves to sing and tell jokes. If someone gets on my nerves a little, but they're teaching my son a valuable skill, most of the time it's not a chore."

Julie agrees. "Without the system in place, we would have never survived. We could have never done this on our own.

"I remember our hesitancy at first to accept help," she adds, "but you come to realize that there's a reason these services are in place and it's beneficial to the family as a whole."

If you would like more information on Consumer Directed Community Supports, Medical Assistance, PCA Choice, Supplemental Security Income, TEFRA, or other programs for children with disabilities or special health care needs, call PACER Center at 952-838-9000 and ask to speak with someone in the Health Information and Advocacy Center.

Try These Tips for a Smooth Transition to Kindergarten

Entering kindergarten can be an exciting time. There's a new classroom, a new teacher, new kids, new things to learn. As with any new endeavor, however, the move to kindergarten also can make parents anxious — especially when the child has a disability. Parents may question whether their child is ready for kindergarten. They also may wonder if the new staff will understand their child's needs.

Those and other concerns can be addressed during the year before your child begins kindergarten. Here are some tips that can help you assess your child's readiness, make sure that needed supports are in place, and prepare your child for an exciting year.

If you think your child needs to develop skills for kindergarten, ask your Individualized Education Program (IEP) team to identify what your 4-year-old should be working on in order to be ready for a successful transition. For example, your child could be practicing how to follow directions, take turns, and recognize his or her written name.

Ask, too, about the supports and services the school will provide to help your child succeed. The IEP team is required by the Individuals with Disabilities Education Act (IDEA) to create a plan that will allow your child to participate in the kindergarten curriculum — even if it means providing support or modifying academic expectations. All those needs and supports are to be identified in your child's evaluation and must be documented in the IEP.

In the spring before your child starts kindergarten, begin looking at specific school choices. Your IEP team can tell you about the options available in your area. Many districts have “kindergarten round-up” events so families can check out programs at different schools. Other districts assign children to a kindergarten in a specific school. Take advantage of the learning opportunities your district offers to parents of children entering kindergarten.

By late spring, when you know which school your child will be attending, you can request a meeting with the current IEP team and a kindergarten teacher or other staff from the new school to discuss your child's needs.

At this meeting, you can talk about any necessary changes to the IEP, including revisions to your child's goals. If your child has medical needs, tell the IEP team so that all the necessary people can be included as a plan is written for the new school. Be sure to share any updated medical information at this time.



At this meeting, you may want to address such topics as:

- Your major priorities for your child's program for the coming school year
- Your child's strengths and needs
- Areas of your child's functioning at home and school that you can work on in a coordinated way (toileting, self-help skills, or communication, for example)
- Opportunities for you to be involved in your child's new school

You also may want to ask the following questions:

- Will my child go to school for a half day or a full day?
- What type of setting does the school propose for my child?
- Will my child receive extended school year services?
- Will my child ride the regular school bus? If so, will an aide be on the bus?

This meeting also is a good time to discuss ways that you and the IEP team can prepare your child for the transition. For example, the team may be able to set up a time for you and your child to visit the classroom and meet the teacher. The team members also may provide you with summer activities to better prepare your child for kindergarten.

Finally, remember to help your child become comfortable with the idea of kindergarten. One way is to familiarize your child with the new people and settings he or she will be discovering. You could, for example, take photos of the new school and spend time over the summer reviewing the pictures and talking about going to kindergarten.

If you know who the teacher will be, ask permission to take his or her picture and include it as well.

You also may want to make sure your child will know other children in the new class. Arranging summer play dates with other students who will be in the new classroom or at the school can make the transition smoother.

Shortly before school begins, make sure that your child has an opportunity to meet the new teacher and spend some time walking through the new school. Show your child how to find the classroom, bathroom, cafeteria, and school office. If your son or daughter is going to ride the bus, point out the drop-off location.

You also might want to read books with your child about the transition to kindergarten. Here is a list of books to consider:

- “David Goes to School” by David Shannon (Scholastic)
- “Off to School, Baby Duck!” by Amy Hest (Candlewick Press)

- “Vera’s First Day of School” by Vera Rosenberry (Henry Holt)
- “Look Out Kindergarten, Here I Come” by Nancy Carlson (Viking)

Going to kindergarten is a major milestone. Your child will be expected to learn a new set of rules, adjust to a new peer group, interact with a new teacher, and perhaps eat in a cafeteria. A successful transition can provide your child with increased self-confidence, improved relationships with other children and adults, increased motivation, and openness to new experiences. When parents, teachers, and administrators work together, the transition to kindergarten can be a positive experience for you and your child.

***Note:** If you have questions about your child going to kindergarten, call PACER Center and ask to speak with a parent advocate.*

FAMILY LIFE

Winter Fun

If cabin fever has set in at your house, here are some family-friendly boredom busters that can put a smile on everyone’s face.

Come to PACER’s Creative Kids Workshops – Free!

Children with any disability can explore their creative side while they produce artwork that may be selected for the cover of PACER’s 2008 greeting cards. These Saturday workshops with well-known artist Anthony R. Whelihan and other local Minnesota artists are on Feb. 23 and March 1, 10 a.m. to noon. Call 952-838-9000 or visit www.PACER.org to register. Space is limited!

Check Out a Museum, Historic Site, or Zoo – Free!

Thanks to the Museum Adventure Pass, anyone with a valid MELSA library card can obtain free passes to 20

metro organizations—from the American Swedish Institute to zoos. Each pass is for two or four free admissions, depending on location. A full listing of participating sites and information on obtaining passes is available at www.melsa.org/MuseumAdventurePass/index.cfm or from your local library. Check with individual sites for accessibility information. (MELSA is an alliance of 103 public libraries in the seven-county Twin Cities metro area.)



8161 Normandale Blvd.
Minneapolis, MN 55437
952-838-9000 (Voice)
952-838-0190 (TTY)
800-53-PACER (Greater MN)
952-838-0199 (Fax)
PACER@PACER.org (E-mail)
www.PACER.org

PACER Executive Director:
Paula F. Goldberg

Senior Editor/Writer:
Julie Holmquist

Editor/Writer:
Marcia Kelly

Early Childhood Director:
Kim Kang

Early Childhood Coordinator:
Judy Swett

Masthead Design/Layout:
Elizabeth Ross

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(Alternate format is available upon request.)

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Whether your child will be receiving Part B preschool services or using community resources, the following tips can help make the transition to the new program easier for you and your child:

- Find out what the program offers for new families and attend these events such as open houses or program visits.
- Meet as many staff members as you can.
- Become acquainted with the teachers and arrange for your child to meet them before your child's first day in the program.
- Ask if your child can bring a comfort item such as a stuffed animal or another familiar item from home during the transition period.
- Find ways to communicate with the teachers on a regular basis (i.e., notebook system, phone calls, progress notes, home visits).
- Talk with other families of children who are already in a preschool program.

All children face transitions as they grow up. Under federal special education laws, children with disabilities face some specific transitions at particular ages. With new changes in eligibility criteria, your child's access to services may be affected. Your IFSP team can help you understand the impact of these changes on your family and how you can receive the most appropriate services for your child. If you have questions about transition issues, contact PACER Center at 952-838-9000 and ask to speak with an early childhood parent advocate.