

Learn More About Outcomes and Goals

If you have a young child with a disability, you’ve probably heard the terms “family outcomes” or “child goals.” But do you really know what they mean? Many parents don’t, even though they encounter the phrases in their Individual Family Service Plan (IFSP) or Individualized Education Program (IEP) meetings.

Tammy Hausken, whose 14-month-old son, Nathan, has Down syndrome, was one of those parents. “I had no idea what family outcomes meant,” she admits. In fact, in the beginning, “I had no idea what his IFSP plan really meant or how to use it.” It’s a common situation for parents new to the world of disability.

“Then, as I got to know Nathan better, a light bulb went on,” she says. She realized that Nathan had things *he* wanted to accomplish. Family outcomes, she realized, were simply things that she wanted her family to be able to do to enhance Nathan’s development and help him achieve those things.

“Nathan is a delightful child and a lot of fun,” Tammy explains. “He likes to be mobile because he’s social, and he showed signs he wanted to climb stairs. I thought his legs were too short, but his physical therapist showed

me how to position his legs on the steps. He figured it out in a day.” Now he can crawl up the stairs himself at naptime, bedtime, and for diaper changes. “He learned not only a skill, but a daily living skill,” Tammy says.



A social child, Nathan Hausken has his heart set on learning to walk and communicate. His family is receiving information and support to help make it happen for him.

Receiving such information and support to help a child develop is what family outcomes are all about for people with children from birth to age 3. Families can learn to use the child’s everyday activities and routines to enhance developmental skills such as crawling, walking, eating, and talking. For the Hauskens, climbing stairs is just the beginning. “Nathan really wants to walk,” Tammy says. “He shows more and more signs of that. I also believe he truly wants to communicate. He tries very hard. He doesn’t have the fine motor skills to sign yet, but he’ll move *my* fingers to indicate ‘more.’”

Like Tammy, Beth Praska understands how perplexing early childhood special education terminology can be. She also realizes how valuable everyday routines can be in helping her child develop. As a mother of a 5-year-old with disabilities and as a kindergarten teacher, she sees the issue of “outcomes” and “goals” from a personal and a professional perspective.

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When Jake was born, he seemed to be developing typically. By the time he was 18 months old, however, his parents noticed a drop in his growth. After some tests, they learned he had an addition on his seventh chromosome that was affecting several areas of development. “It was all very shocking, and we didn’t know what to expect. We just went day to day,” Beth says.

Besides his delayed growth, Jake has delayed speech, fine and gross motor challenges, and “lots of sensory problems,” Beth says. When he was about 2, they contacted the school, had him tested, and received an IFSP.

Family outcomes focused on things “like helping him learn to move, use words, feed himself. Simple things that many people take for

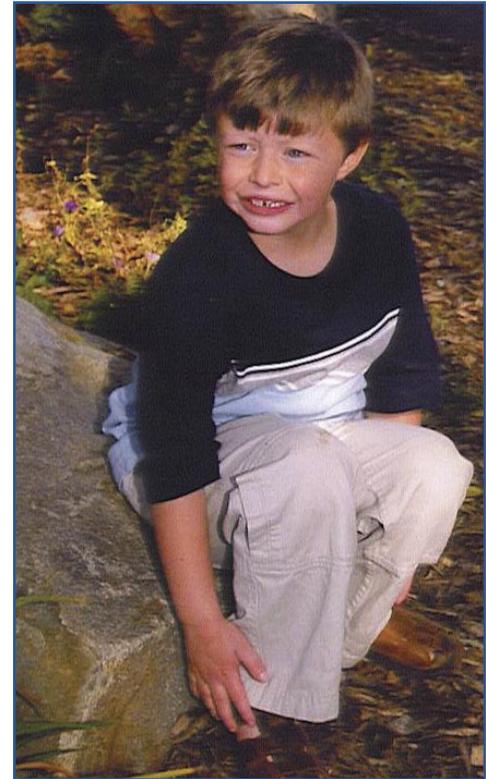
granted,” Beth says. When he turned 3, “there was a smooth transition from his IFSP to his IEP,” she says. The focus then shifted to “child goals.”

“I didn’t know what that meant,” Beth acknowledges. Now, however, she is developing a clearer vision.

“Jake now has more specific goals,” Beth explains, and they are about helping him gain skills that lead to more independence. “His goals have a lot to do with separating from me. We also have goals that he can communicate with other people. He learned sign language for ‘more,’ and then the word came. He now speaks in complete sentences and is working on conversational skills. He also has goals

to do simple things like putting his coat away in his cubby, so he can take care of himself.”

Even though she is a kindergarten teacher, “special education was very new to me,” Beth says. She’s learning more about it, however. This past year she had one student in her class who had an IEP. “He needed a lot of reminders to stay on task—just like Jake,” she says. “Having him in the class has helped when I’ve gone to Jake’s IEP meetings. I can talk about how he’ll be able to function in the classroom.”



Jake Praska’s goals include gaining skills that lead to more independence. His IEP is helping him improve his conversational skills and other abilities.

For both families, understanding family outcomes and child goals didn’t come intuitively. It came by seeking information from PACER and other resources. “You can’t be afraid to call an organization or other parents and say, ‘Tell me what you know,’” Tammy says. “PACER helped me understand what we were entitled to in our plan and services,” she adds. “We learned how to create the plan and what should be in it.”

Gaining that kind of knowledge and understanding of the language of early childhood special education allows you to work more effectively with the team to accomplish better outcomes for your child. It’s a good result for everyone.

What Are They?

Family outcomes

are benefits you experience as a result of the services and supports that your family receives. They include such things as understanding your child’s strengths, abilities, and special needs; helping your child learn and develop; having confidence in your ability to make decisions about your child’s services; having support systems; and receiving desired services, programs, and activities in your community.

Child goals

refer to your child’s progress in gaining specific developmental or pre-academic skills. These proficiencies may include such things as walking, talking, effective social and interpersonal abilities, and preliteracy skills.

Are Extended School Year Services Right for Your Young Child?

Summer is a time for fun and sun. For some young children with disabilities, however, it can also be a time when important skills gained during the school year are lost. The three-month break from special education instruction and related services can mean that by September, some children have lost significant ground from their achievements in May.

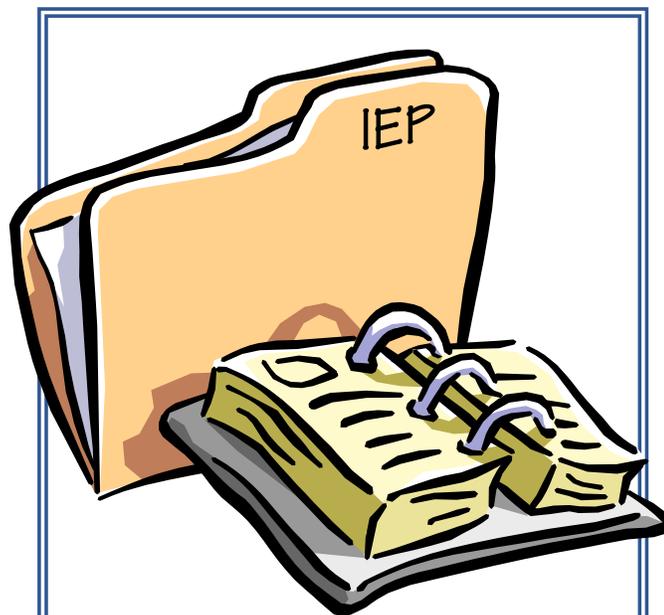
For them, extended school year services may be a solution. Unlike summer school, extended school year services are tailored to the needs of the child and support goals established in the child's Individualized Education Program (IEP). Designed to help children maintain their skill or development levels during long breaks, these services are provided at no cost to the family. They are for children with disabilities who are 3 to 21 years old and who have demonstrated the need for them.

Each year, your IEP team must discuss whether your child needs extended school year services. The team will look at several factors and compare them to the goals specified in your child's IEP to determine if your child qualifies.

One factor the team will consider is called regression. "It means that when there's a break in services, your child falls back to a significantly earlier skill level," says Judy Swett, PACER's early childhood advocate. "For example, before winter break, your child showed progress on a speech goal, such as using longer sentences. After winter break, he was back to using two-word sentences." Such changes should be documented

by the team throughout the year, Swett adds. "This data is essential to determining if your child qualifies for extended school year services."

A related consideration is called recoupment. It refers to how long it takes your child to regain the pre-break skill level. "It should not take longer to regain skills than the length of the break," Swett says. Your child's recoupment time should be documented as well.



"The decision about extended school year services is based on data, not opinions."

—Judy Swett,
PACER early childhood advocate

Other factors will be considered, too. For example, would the break prevent your child from attaining or maintaining self-sufficiency skills that allow for personal independence? These skills typically are identified in your child's IEP and may include such things as toileting, eating, dressing, manipulating objects, having impulse control, maintaining stable relationships with adults and children, and being able to communicate wants and needs.

As the team looks at your child's potential need for extended school year services, they also will evaluate such things as:

- Rate of progress on a goal
- Impact of the break in service on emerging skills
- Goals on the child's IEP that need continuous attention

After weighing all the data, the team will determine if your child qualifies for extended school year services. If so, the team will consider what services and settings

Skill Development: When Should You Worry?

Maybe it starts as a gut feeling that something is wrong, or perhaps relatives have suggested that your child isn't developing skills as quickly as other children of the same age. Some might say things like, "Shouldn't Megan be feeding herself by now?" or "When Ethan was Josh's age, he was already walking."

"But he's healthy and fine otherwise," you tell them. In the back of your mind, however, you wonder.

If you have concerns about your child's development, the most important thing to do is seek an expert opinion as soon as possible. You can do that by asking your local early intervention program for a screening. If you are not sure how to contact the program in your area,

ask your child's pediatrician, your local public health department, school district, special education director, county human services agency, or PACER Center.

If the screening indicates that your child has delays, the facilitator and a team of local health, human services, and education professionals may assess your child's development. The assessment determines whether your child qualifies for free services.

If your child is not eligible, you may be referred to other resources for information, services, and support. The team may also suggest follow-up to determine if your child qualifies for services later.

Your Guideline to Childhood Skills

Children develop at different paces. Don't worry if your child doesn't have all of these age-appropriate skills. If, however, your child can perform none or only a few of the skills, you may want to have your child screened.

3 mos

By 3 months a child usually can

- look toward bright colors and lights
- move eyes in the same direction together
- react to bottle or breast
- react to loud noises or voices
- make a fist with either hand
- grasp hair or toy
- wiggle and kick
- lift head and chest when on his or her stomach
- smile in social interaction
- vocalize and coo

6 mos

By 6 months, a child usually can

- turn over from stomach to back
- follow moving objects with eyes
- distinguish mother from others
- turn toward source of normal sound
- pick up toy with one hand
- transfer objects from one hand to the other
- play with toes
- help hold bottle during feeding
- recognize familiar persons
- babble

9 mos

By 9 months, a child usually can

- sit without support
- feed self cracker or cookie
- push away things not wanted
- reach for familiar persons
- roll from back to stomach
- make wide range of vocalizations
- react when called by name

12 mos

By 12 months

- crawl on hands and knees
- pull to standing
- walk around holding on
- drink from a cup
- wave bye-bye
- and patty cake
- pick up small objects with index finger
- hold out arm when dressed
- put objects in container
- stack two blocks
- use five to ten words

18mos

By 18 months, a child usually can

- walk without support
- enjoy pulling, pushing, and dumping things
- follow simple directions
- pull off shoes, socks, mittens
- enjoy looking at pictures
- keep balance when stepping off low objects
- hold cup by self to drink
- give kisses and hugs
- feed self with spoon
- pick up two small toys in one hand
- speak in single words
- scribble with crayon

24mos

By 24 months, a child usually can

- climb stairs and knees
- stand on tiptoes
- pull furniture or crib while walking
- hold cup
- play peek-a-boo
- pick up small objects with thumb and index finger
- pull pants and legs while being dressed
- put objects into container
- build a tower of two blocks
- speak six words

2yrs

By 2 years, a child usually can

- use two- to three-word sentences
- recognize familiar pictures
- play independently
- sometimes say "no" when interfered with
- enjoy imitating parents
- identify hair, eyes, ears, and nose by pointing
- build a tower of four blocks
- show affection
- kick a ball forward
- show sympathy to other children
- run well
- respond to correction
- take off open coat or shirt without help
- walk up and down stairs alone
- turn pages of picture book one at a time
- follow two-part instructions

3yrs

At 3 years, a child usually can

- ride a tricycle
- repeat common rhymes
- name at least one color correctly
- use toilet
- help with simple household tasks
- open door by turning knob
- climb on play equipment, ladders, slide
- scribble with circular motion
- play with other children
- stand on one foot without support
- draw or copy vertical lines
- speak and be understood most of the time
- dress self with help
- walk up and down stairs alternating feet

PACER offers early childhood development materials. To order, contact PACER at 952-838-9000 or 800-537-2237 (toll free), or visit www.pacer.org.



Let's Talk Activity Cards Build Skills

PACER's *Let's Talk* activity cards help you improve your child's vocabulary and speaking skills—one fun activity at a time. Designed for children ages 2 to 6, the easy-to-read, illustrated cards include simple directions. One set is free to Minnesota parents of young children with disabilities. Additional sets are \$4. (Discounts apply for orders of 10+.)



Wheel Helps Parents Identify Developmental Milestones

Here's a handy gizmo. *The Guide to Your Child's First Five Years* is a wheel that shows developmental milestones by age. Each age describes what a child ought to be able to do at that point, as well as what families can do to support their child's development. It's free!

Developed by the Early Childhood Intervention Program of Minnesota, a joint initiative of the Minnesota Departments of Education, Health, Human Services, and local Interagency Early Intervention Committees, the wheel also includes information about whom to contact if you have questions or concerns.



You Can Promote Inclusion at Family Gatherings

The picnic basket is ready, the Frisbee® is in the car, the camera is loaded...you're off to the family reunion. Before you go, however, you might also want to bring along some tips on including children with disabilities at family events.

Amid all the fun and love when relatives gather, there sometimes can be tension when a child with disabilities is part of the clan. Some family members may not understand your child's special needs and what kinds of accommodations are needed. Others may have questions about the disability but be uncomfortable asking them. Still others may even be afraid. The result can be unintentional hurtfulness.

Carolyn Anderson, Virginia Richardson, and Dao Xiong know firsthand what it's like. All three PACER advocates have grown children with disabilities and remember well the challenges they faced in the early years when family would gather. If you would like a three-step plan for creating an inclusive family environment for your child, take a CUE from them: Communicate, Understand, Educate.

Communicate

No matter how much they love you and your child, relatives are not mind readers. They need you to share information about your child's skills and interests, his or her disability, accommodations you may need, realistic expectations for what your child can do, and your

expectations for the family. They also need to know whether it's okay to ask questions about your child's disability.

Virginia puts it this way: "I expect my family to be supportive. But I have to give them enough information to be supportive in the way I want them to be." For her, that meant letting people know that her daughter Deborah's seizures weren't life threatening. "I didn't want them to be afraid of her or to think that she was so fragile that every seizure was a Code Blue," she recalls.

She also made sure that they knew who Deborah was as a person. "I let people know what she was doing in school, that Deborah was participating in gymnastics," she says.

"I was still crying my way through the world at that time," she adds, so she enlisted her sister, Jessie, to be her spokesperson. "I wanted to give factual information about Deborah's disability, and I wanted people to know what we were working on at the moment so they could ask," she explains. "I was interested in the right information being conveyed. I wanted them to ask the family and not be afraid they were going to hurt anyone's feelings."

Dao, whose daughter Tsai has cognitive delays, notes that when it comes to talking about a child's disability, keep in mind that there may be cultural differences in

how and when such communication occurs. “In the Hmong community, for example, even though the parent is open to discussion, people aren’t likely to come forward publicly and ask a direct question about the child,” Dao says. “Instead, they might indirectly ask how the child is doing. That might lead to a more direct private conversation.”

Understand

Even in the most loving, well-intentioned families, there are bound to be times when someone does or says something insensitive to your child. Carolyn remembers family gatherings where no one communicated with her son Matthew, who is deaf. If people learned any sign language, it was for words like “no” or “stop”—negative things.

“You do the best you can,” she says, noting that she tried to teach family members some sign language and show them how to speak to Matthew so he could read their lips. “Just try not to be judgmental,” she says. “Remember, if it wasn’t your child, you might be acting the same way. You have the opportunity to know better.”

Educate

Family members won’t automatically know the right ways to interact with your child with a disability. You, however, can help them learn skills and attitudes by modeling them yourself.



“We talked about Matthew’s deafness openly,” Carolyn explains. “We had a positive attitude toward the disability. We also modeled good communication rather than just telling people what to do. For example, we would tap Matthew on the shoulder to catch his attention before we talked with him. We also tried to teach some sign language to the people who were open to it.”



Carolyn Anderson (left) and Dao Xiong, PACER advocates, and Virginia Richardson, parent training manager, know from personal experience that family gatherings are a great time to promote inclusion of children with disabilities.

Dao encourages parents to help other family members to find ways for the child with disabilities to participate. “Parents may need to say, ‘I want my child to play. Let her join.’ They might need to point out specific things the child needs in order to participate, like asking the other children not to chase her too fast in a running game.”

At the heart of all these CUEs is a philosophy of belonging. As Dao says with a smile, “Any family gathering is a time to include the children.”



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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.)

EDUCATION

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would be best. Recommendations can range anywhere from a structured program at a school to community activities and suggestions of things the family can do at home. Some of the choices may include support from staff.

If your child does not qualify for services, you have other alternatives. You could, for example, ask your IEP team for suggestion of activities you can do with your child to maintain skills. If you can afford it, you also could hire a private therapist to provide services over the summer to work on individual skills.

Summer is indeed a time for fun and sun. For some children, it can also be a perfect time to keep skills sharp and give learning a great start in the fall.



Visit PACER's Web sites at www.pacer.org, www.taalliance.org, and www.pacerkidsagainstbullying.org.