

Information and Resources for Parents of Young Children with Disabilities

Summer 2012

Measuring Outcomes Helps to Track Your Child's Progress

As a parent, you want your child with developmental delays or disabilities to be an active, thriving participant at home, in childcare or school programs, and in the community. That's also the purpose of early childhood intervention services. Your partnership with early intervention and preschool special education professionals is vital in helping your child succeed.

From the time your child is first evaluated until he or she goes to preschool, early intervention providers will work with you to evaluate your child, create an Individual Family Service Plan (IFSP) that guides his or her development, and choose specific desired "outcomes." Outcomes are the positive results you'd like your child to achieve and the benefits of early intervention services your child and family will receive.

You and these service providers will work together to enhance your child's development and learning and help achieve the outcomes you set together. You'll work with the service providers to measure the progress your child makes towards the desired outcomes.

By taking an active role in observing your child and defining outcomes, you will become an informed, effective advocate. You'll also be prepared to play a major role in developing your child's future education.

Choosing outcomes

The process begins when early intervention specialists evaluate your child to establish his or her strengths and needs and determine your family's needs and concerns.



The Yerkes family

You'll work with the specialists to write the IFSP, which establishes a baseline for your child's development and learning. It also defines desired outcomes — the benefits to be gained by your child and family as a result of the services provided.

The early intervention provider will visit your home regularly to share practical, effective strategies you can use — advice on bathing, feeding, and dressing, for example. Along the way, those strategies will be tweaked as needed. This approach has worked well for Tanya and Bruce Yerkes of Burnsville, Minn., whose son Ben has been diagnosed with cerebral palsy.

Measuring Outcomes continued on next page

In This Issue

FAQs4	FAMILY LIFE6
TECHNOLOGY5	Resources7



"The person from the early intervention program came every week and she knew Ben well," Tanya says. "We set goals and then we followed up and adjusted the goals every six months or so. We started with what he could do — he could roll over, he could get up on his hands and knees. We would see how well he did and we would adjust if needed."

What outcomes are measured?

While the desired outcomes written in the IFSP are specific to your child, there are also big picture outcomes that have been established for all children who receive early intervention services. The U.S. Department of Education Office of Special Education Programs (OSEP) measures three main outcome areas:

- 1. **Children have positive social relationships.** How well do children relate to those around them? For his or her age, is the child able to:
 - Build and maintain relationships with children and adults?
 - Regulate his or her emotions?
 - Understand and follow rules?
 - Communicate wants and needs effectively?
- 2. **Children acquire and use knowledge and skills.** This refers to thinking, learning, reasoning, memory, and problem-solving skills. For his or her age, can the child:
 - Engage in thinking, reasoning, remembering, and problem solving?
 - Show an eagerness for learning?
 - Explore his or her environment and engage in daily learning opportunities?

- Show imagination and creativity in play?
- Understand and communicate thoughts and ideas?
- 3. Children take action to meet their needs. Are children able to take care of themselves and use appropriate ways to have their needs met? For his or her age, is the child able to:
 - Move from place to place to participate in everyday activities and routines?
 - Meet his or her self-care needs such as feeding, dressing, or toileting?
 - Seek help when needed to move from place to place?
 - Use objects such as spoons, crayons, and switches as tools?

When and why are outcomes measured?

Progress towards these three outcome areas is measured throughout the early intervention process. You know your child better than anyone and you can provide important information about how your child behaves with different people and in different settings.

The early intervention provider will ask you to share your observations of the skills and abilities your child uses daily. You'll be asked about your child's emotions and behaviors, how he or she relates to adults and other children, what activities he or she enjoys, and how your child communicates wants and needs. If formal testing is needed to obtain more information, your early intervention provider will ask for your written consent to conduct evaluations. Other caregivers who are involved



PACER CAN HELP

It can be a difficult time when your child is first diagnosed with a developmental delay or disability. There is a lot to learn and there are many obstacles to overcome. Fortunately, you are not alone. PACER Center provides a variety of workshops and services to parents of young children with developmental delays and disabilities.

Tanya Yerkes learned about PACER through a friend. She attended workshops and read everything she could. "I was so overwhelmed at first, and I am still learning. I found the workshops to be very helpful, and I don't know what I would have done if I had not come to PACER," she says. "I tell people to take in as much information and be as informed as you can be."

in your child's life will also be asked for input, as will the professionals who have observed your child.

All of this information is combined with the provider's assessment to create an accurate measure of outcomes, both during and after the delivery of early intervention services. This information is used to determine how much progress your child is making and to improve services nationally for children with disabilities and their families in the future.

When your child is about to exit the early intervention program at age 3, you'll be asked to complete the Family Outcomes Survey. The survey is designed to measure the impact of early intervention services for parents. It asks you to respond to questions about how effective early intervention services have been in helping you know your rights, in helping you communicate your child's needs, and in helping your child develop and learn. "The survey wasn't hard at all," Tanya says.

Why are outcomes important?

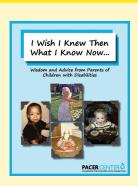
Parents want feedback on how their child is functioning. By knowing what outcomes are measured — and being an active participant in the process — you'll be able to track your child's development and celebrate progress. You'll also be prepared to be an active participant in your child's education plans from preschool through grade 12! This will be much easier if you are used to providing accurate, detailed information on your child's development and learning.

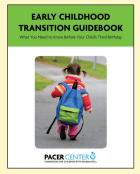
Tanya has kept detailed records on Ben's progress from the time he entered early intervention. When Ben was evaluated by special education professionals from their local school district prior to preschool, Tanya was ready to be an effective advocate for her son.

"I was the one who knew what he could do," she says. "For example, they wanted him to walk with a gait trainer all the time, but he can't do that. I was able to tell them."

New! I WISH I KNEW THEN WHAT I KNOW NOW

The insights from parents who have raised a child with a disability can be helpful to parents who are just beginning that process. This publication includes advice from more than 20 parents who share what they have learned while navigating health care, education, and social support systems, and what they would do differently if they could do it all again. Books are \$8 each, or one copy free to Minnesota parents of children with disabilities. Call PACER at (952) 838-9000 or (800) 537-2237 and order item PHP-a42.





PACER'S EARLY CHILDHOOD TRANSITION GUIDEBOOK

Now available in Somali and Spanish! Learn everything you need to know about your child's transition from infant and toddler intervention services to preschool in PACER Center's new publication, "Early Childhood Transition Guidebook: Everything You Need to Know Before Your Child's Third Birthday." The guidebook explains what transition is, how and when to plan for it, how to implement a transition plan, and what to do if your child is not eligible for special education services. Download the book online at PACER.org/publications/earlychildhood.asp, or request a copy by calling PACER at (952) 838-9000. Free to Minnesota parents of children with disabilities.

CONNECT WITH PACER CENTER ON FACEBOOK AND TWITTER

Want to stay informed of all the latest PACER news and happenings, including updates on PACER's Early Childhood Project? Find us on Facebook (PACER Center) or follow us on Twitter @PACERCenter. Be the first to hear about PACER news, information, and events, no matter where you are!



EDUCATION

PACER Answers Frequently Asked Questions



Judy Swett, PACER's early childhood advocate, has answers for your questions on child and family outcomes.

Q: How is information on child outcomes collected?

A: Multiple sources of information are used to assign a rating for your child in each of the three outcome areas as defined by the U.S. Department of Education Office of Special Education Programs (OSEP). Most of this information is already collected as part of determining the child's eligibility for the program, and in developing his or her Individualized Family Service Plan (IFSP) or Individualized Education Program (IEP). Progress is measured by comparing the child's performance from the time he or she begins an early childhood or early intervention program to the time the child leaves that program. The process is simple, but it provides valuable information for you, your child's teachers, and other caregivers. Parents should work together with the teacher (or a member of the early intervention team) to rate the child's progress on the Child Outcome Summary Form.

Q: How is this information used?

A: This information is required by the federal Individuals with Disabilities Education Improvement Act of 2004. It

is used to make improvements to local and state services, and measure the impact of government investment in early intervention. Each state is required to report on the success of early intervention programs in improving outcomes for children with disabilities and their families. In Minnesota, the Department of Education collects this information. Results are reported annually to OSEP and to local programs. The surveys are anonymous.

Q: What is the difference between the OSEP child outcomes and the outcomes on my child's IFSP or IEP?

A: The outcomes on a child's IFSP are developed based on the unique needs of the child and the priorities established by the family during the

assessment process. In contrast, the three OSEP outcomes are the same for every child. These three functional child outcomes can serve as a framework or lens for viewing a child's functioning, and can provide valuable insight into a child's needs that should be addressed in an IFSP or IEP. For instance, if parents have a concern regarding a delay in their child's speech, an outcome could be written into the IFSP regarding speech development. Progress on this outcome could also be used to measure progress on Outcome 1 (children have positive social relationships). In other words, speech development is important not just for the sake of the child's ability to talk, but also as a tool to be used in forming relationships, participating in activities, and communicating wants and needs.

The goals on a child's IEP should reflect the child's specific educational, functional, and developmental needs. All of these needs are also reflected in the three OSEP child outcomes. While the outcomes may be worded differently, tracking progress on IEP goals should provide information on progress toward the OSEP outcomes. This progress should lead to active and successful participation at home, in preschool, and in the community.

Have more questions? Call PACER at (952) 838-9000 and ask to speak with an early childhood advocate.

CHECK OUT THIS GREAT IDEA FOR SUMMER COMMUNICATION

Heading to the beach or pool this summer? Don't let a little water stop your child from being able to communicate. Check out this easy technology tip from "EZ AT 2"* and "Ideas to Share."

A Floating Communication Board

Sharise loves bath time. It is one of her favorite activities of the day, and she enjoys splashing in the water and playing with her bath toys. Because bath time is going so well, Sharise's mom would like to incorporate opportunities to communicate into the routine. Sharise already uses a communication board at home, but it would be ruined if it were used in the bathtub. To solve the problem, Sharise's early intervention provider suggested using a floating communication board. The waterproof board can be used in the bath, at the pool, or on the beach.

Goal

The child will participate in bath time by communicating simple words (e.g., "all done," "stop," "towel," or "bath toy") to her caregiver by using the floating communication board.

Subject Area and Skills Addressed

Communication, life skills/daily activities

Technology Used

Picture communication symbol software, computer, printer, laminator (optional)

Other Materials Used

Foam garden kneeler, card stock paper, large Ziploc bag, two Velcro strips

Preparation

- 1. Create the communication board using picture communication symbol software.
- 2. Laminate the communication board (optional).
- 3. Put the communication board in the Ziploc bag, pushing out excess air so that the bag lies flat.
- 4. Place Velcro (loop side) on the garden kneeler.
- 5. Place Velcro (hook side) on the back of the Ziploc bag. Communication symbols should face upward.
- 6. Attach the Ziploc bag to the kneeler.



Ways to Adapt this Activity

Use the floating communication board at the community pool or beach. Include symbols such as swimsuit, beach ball, goggles, sand castle, or swim.

*"EZ AT 2" is a guide for parents and professionals who want to help infants and toddlers with disabilities participate more fully in daily activities with the use of assistive technology. Books are available for \$5 each. Call PACER at (952) 838-9000 or (800) 537-2237 to order publication STC-24 or visit PACER.org/publications/stc.asp.

RECEIVE EARLY CHILDHOOD UPDATES VIA TEXT MESSAGE

Always on the go? Now parents of young children with disabilities can receive updates and information from PACER via text message. This new service provides families of children ages birth to 5 with updates from PACER's Early Childhood Family Information and Resources Project, including notice of upcoming workshops, reminders, short tips and ideas, and new resources. Text "ECSE" to 27138 to receive updates from PACER on your mobile device. Standard text messaging rates will apply.

FAMILY LIFE

Make Life Easier with These Tips for Bedtime

Many families find bedtime and naptime challenging. It is estimated that 43 percent of all children, and 86 percent of children with developmental delays, experience some type of sleep difficulty. Sleep problems can impact learning and make infants and young children moody, short tempered, and unable to interact well with others. As a young child sleeps, her body develops new brain cells needed for physical, mental, and emotional development. Parents need to feel rested, too, in order to be nurturing and responsive to their child's needs. Here are some tips to make bedtime and naptime easier.

TIP: ESTABLISH GOOD SLEEP HABITS

- Develop a regular bedtime, naptime, and time to wake up. Young children need 10 to12 hours of sleep daily including naps.
- Make time for physical activity and time outside but not within an hour of naptime or bedtime
- Give your undivided, unrushed attention as you prepare him for bed or a nap to calm him, and let him know how important this time is for both of you.
- Develop calm, relaxing routines. Young children thrive on predictability and learn from repetition.
- Establish steps in routines to help her understand and predict what will happen next. "Sara, it's time to take a nap. First, let's find teddy. Then we can cuddle."
- Tell your child what might happen when she wakes up. Talk with her or show her a picture.
 "First, sleep. Then you will wake up and go to the park."
- Carry a favorite transition object to bed. A teddy bear, blanket, or book becomes a signal that it's bedtime.
- Provide your child with calming activities, sounds, or objects. Avoid rough-housing, tickling, DVDs, or computer games before bed.
- Put your child down for sleep while he's still awake. Say "good night" and leave the room so he'll learn to go to sleep on his own.
- Avoid certain foods and drinks six hours before sleep.
 Anything sugary, caffeinated, or fatty can keep a child awake.
- Try breast feeding or a warm bottle before bed. Milk can induce deep sleep, but avoid it three hours before

- sleep if your child is being potty trained.
- Provide choices when possible. This is a powerful strategy to prevent challenging behaviors. Ask what toy or story your child wants or if a night light should be on or off.
- Reduce noise and distractions nearby. The quieter the better in or near the child's room.
- Reduce light. A dark room is best, but your child might want a small light or hallway light on.
 - Make sure your child is comfortable.
 Comfortable for you might be chilly or warm for your child.

TIP: TRY KEEPING A SLEEP DIARY FOR A WEEK

It might be helpful to keep a written log of when your child falls asleep and wakes up, along with a daily total of hours slept.

TIP: LOOK FOR SIGNS OF SLEEPINESS

Learn the signs when your child is getting tired, and share these with others who help put her to sleep.

TIP: TALK WITH YOUR CHILD ABOUT FEARS

For a young child, there really are monsters under the bed! In the dark, shadows of toys or furniture may be frightening, but your child might not be able to tell you he's scared. If your child expresses fear, let him know you understand and then provide comfort. A soft toy can help, too.

TIP: CELEBRATE LITTLE SUCCESSES!

Congratulate your child: "You're such a big girl sleeping in your bed with your teddy!" Remember, restful sleep for your child also means rest for you, so you'll both be ready for shared days of family fun and learning.

*Adapted from the Making Life Easier Tip Sheet series developed by The Technical Assistance Center on Social Emotional Intervention for Young Children (TACSEI), a federally funded center that translates extensive research into everyday practice to improve the social-emotional outcomes for children with, or at risk for, delays and disabilities. Learn more at challengingbehavior.org/communities/families.



HELP YOUR YOUNG CHILD GROW WITH THESE RESOURCES

These resources can provide you with information and support to help your child grow in important ways — and in the three outcome areas outlined by the U.S. Department of Education: building positive social relationships, acquiring and using knowledge and skills, and taking action to meet their needs. For more information on early childhood resources, call PACER at (952) 838-9000 and ask to speak with a parent advocate.

Parenting Counts | parentingcounts.org

Explore the many ways your child will develop from birth to age 5 with the free Developmental Timeline on this website. Parenting Counts is the research-based family of products developed by Talaris Institute to support parents and caregivers in raising socially and emotionally healthy children.

Center on the Social Emotional Foundations of Early Learning (CSEFEL) | csefel.vanderbilt.edu/index.html

Look for the "Family Tools" tip sheets on the CSEFEL website covering topics such as "Supporting Your Child's Communication Skills." This national resource center promotes the social emotional development and school readiness of young children from birth to age 5.

Minnesota Parents Know | parentsknow.state.mn.us

This state program offers trusted parenting information and resources to help your child grow, develop, and learn from birth through high school. Hosted by the Minnesota Department of Education, the website provides up-to-date, research-based information, strategies to support children's learning, expert tips, an interactive early childhood and child care search, connections to Minnesota services and resources, and videos.

Center for Early Learning and Literacy (CELL) | earlyliteracylearning.org

Want to encourage literacy skills in your infant, toddler, or preschooler? "Practice Guides Especially for Parents" from CELL show you how everyday home and community activities encourage your young child to listen, talk, and

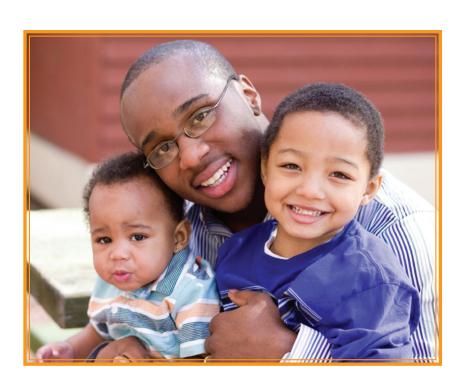
learn the building blocks of early literacy. The website has free resources for early childhood intervention practitioners, parents, and other caregivers of children (birth to age 5) with identified disabilities or developmental delays.

Help Me Grow | parentsknow.state.mn.us/ parentsknow/Newborn/HelpMeGrow_ SpecialNeeds/

Minnesota's Early Intervention Services for eligible infants and toddlers are designed to meet the unique developmental needs of each child and their family. Preschool Special Education Services for eligible children ages 3 to 5 provide special instruction and related services which are delivered at no cost to families.

NECTAC | nectac.org

NECTAC is the national early childhood technical assistance center supported by the U.S. Department of Education's Office of Special Education Programs (OSEP) under the provisions of the Individuals with Disabilities Education Act (IDEA). NECTAC serves Part C-Infant and Toddlers with Disabilities Programs and Part B-Section 619 Preschool Programs for Children with Disabilities in all 50 states and 10 jurisdictions to improve service systems and outcomes for children and families.





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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 funds provided by the Minnesota Department of Education.

(Alternate format is available upon request.)









CELEBRATE YOUR CHILD ON PACER'S WALL OF CHAMPIONS!

Celebrate your young champions (birth to age five) by submitting their photos to PACER's "Wall of Champions" on PACER's Facebook page. The photos will be posted with first names only. E-mail photos to Judy Swett, Early Childhood Coordinator, at jswett@PACER.org.

