



EARLY CHILDHOOD CONNECTION

Information and Resources for Parents of Young Children with Disabilities

Summer 2008

NATURAL ENVIRONMENTS PROMOTE LEARNING

Children with disabilities or developmental delays are, above all else, children. They need love, family, friends, support, new experiences, education, and fun just like any other child in order to grow into their full potential. As they go about their playing and learning and striving and growing, they belong in the same places all children do—parks, playgrounds, pools, stores, libraries, museums, birthday parties, and more.

It's no different when a young child is receiving early intervention services. Speech, occupational, and physical therapy, for example, often can be provided in the natural flow of a child's life.

Think Creatively!

Opportunities to help your child with early intervention skills are everywhere you go. Social interactions, motor skills, speech, and other abilities can be practiced anywhere. Try them out during these times:

- Brushing teeth
- Diapering
- Mealtimes, naptime, or bedtime
- Watching TV
- Folding laundry
- Reading stories

In fact, the Individuals with Disabilities Education Act (IDEA) says that early intervention services must be provided in natural environments to the maximum extent appropriate. "Natural environments" are any place your family and child live, learn, and play—including your home and community settings where children without disabilities would typically be found. In other words, depending on your child's needs,

services can take place at the park, in child care, or splashing in the community pool.

Your Individualized Family Service Plan (IFSP) team can help you identify natural environments, tailor services to you and

your family, and make sure those choices support the goals and outcomes you have identified in the IFSP. You play a key role in helping the team understand the locations and activities that are important in your family's life.

One way to start is by realizing how many places are considered natural environments. Your home, of course, is an obvious one. Did you know that the homes of nearby relatives also are natural environments? So are your backyard, the grocery store, and public places such as the library.

Natural environments aren't just places. They also include the objects your child finds in everyday life, from toys, rocks, books, and swings to grass, spoons, a hairbrush, or a wagon. All can be teaching tools that support IFSP goals.



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COMMUNICATION

How Do You TALK TO OTHERS ABOUT YOUR CHILD's DISABILITY?

Experience is the best teacher, as the saying goes—and one of its big lessons is how to communicate about your child's disability. For Kathy Graves, the learning began when her son Sam, then 1, was diagnosed with cerebral palsy (CP). "He was born on his due date and was healthy," she recalls. "Then he contracted meningitis when he was a week old." At the time, Sam seemed to recover and was reaching all his developmental milestones. "But at six months, he didn't crawl," Kathy remembers. Eventually, doctors discovered that the motor part of Sam's brain had been affected.

"I remember well getting that diagnosis and thinking, now what? I remember not knowing who to call, who to tell, or how to tell it. There's not a road map for you," Kathy says.

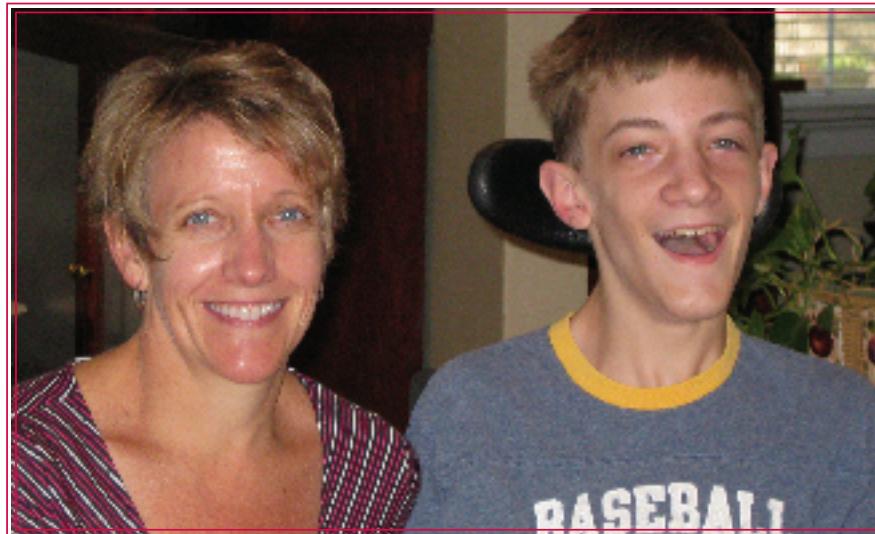
Sam is now 14. Over the years, experience has taught Kathy some important lessons about communicating with others about her son's disability. As a result, she has developed a philosophy about whom, what, and how much to tell, as well as how much energy to expend on it. Here's what she's learned.

Lesson 1: Find People You Trust

"My husband and I started slowly by calling people we could really trust and talk to without having to make them feel good," she says. "My sister-in-law and brother-in-law both work in special education, and they felt like the right people to talk to."

"We also learned early on that you need people outside the family. Find three or four people who are always there for you, without judgment; people you want to go through this with," she says. "Stage one for us was having someone listen and not try to fix it or say 'everything will be fine,'" she says.

As time went on, they also found friends who have kids with disabilities. "There's nothing better than that. You can call them on days when you're really down. They understand."



Kathy & Sam Graves

Lesson 2: Learn and Share—But Set Limits

"Stage two was educating ourselves about the disability," Kathy says. That paved the way for communicating with professionals. "You get further with teachers and doctors," she says, if you're knowledgeable about the disability.

"Help those closest to you understand, too" she adds, but let them know you're still learning. "When people ask questions, it can feel like pressure. Tell them, 'Hang in there with us. We'll tell you what we know as time goes along.' Plus, it's not what we wanted to talk about first all the time. It wasn't helpful for us."

What was useful was a question someone asked early on: "Well, what's the future likely to look like?"

"It was so helpful because it had hope

in it," Kathy says. "Ask me questions about what you think our future will be like. Have it be forward looking, with hope, not grief."

Lesson 3: Be Prepared for Questions and Stares

"In the beginning you think you have to explain the disability to everyone," Kathy says. "You get exhausted telling your story that much. It helps to have short, medium, and long answers, depending on who you're talking to," Kathy says.

"If kids ask, they're okay with a two-sentence reply," she says. "Adults will ask 'how did it happen?' It's like a defense mechanism; they want to know how to stop it from happening to them. They're not trying to hurt you; they may just be fearful. I try to remember that in responding to them, but the honest answer, which I believe is the best, is that sometimes things just happen. It's as simple as that."

Then there are people who stare and ask inappropriate questions. "One doctor told us if people stare, just stare back until they quit looking," Kathy says. "If an adult says, 'what's wrong with him,' I feel it's my job to say 'nothing is wrong. He has CP.' Their insensitivity is wrong. You don't have to tell them anything."

"You constantly have to help people understand," she adds. When someone talks down to Sam or treats him like he's a little child, Kathy finds that gentle reminders about Sam's teen activities and interests help to change the interaction.

Lesson 4: Talk about Strengths

"In one of my very first [Individualized Education Program] IEP meetings, there was a physical education teacher who said, 'Let's talk about what Sam can do.' That was the best advice. A lot of this world focuses on what he can't do. We just started to focus immediately on Sam's assets and what he could do. It's an amazingly powerful way to refocus yourself and your kid's future," Kathy says.

"There are so many things people will try to pin on your child's disability," she adds. He might not be great at geometry—"but neither is his mom," Kathy says. "Not everything is about the disability." He's a person with strengths who also has CP, Kathy says. The disability doesn't define him, and that's a message she always communicates.

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Even the people in your child's world are defined as part of the natural environment. That might include you, siblings, grandparents, aunts, uncles, cousins, friends, neighbors, or elders.

Activities and routines are also considered part of the natural environment. Eating, bathing, dressing, playing, reading, walking, camping, swimming, going to the grocery store, riding in different forms of transportation, celebrating, and participating in other cultural practices are all opportunities to learn. These routine activities can easily be incorporated into early intervention services.

In other words, the natural environment is everywhere your child goes, everyone your child knows, and everything your child does. All of it can be brought into play when early intervention services are provided. By

Experience—both good and bad—has shaped Kathy's philosophy about communicating with others about Sam's disability. Time, too, has played a role. "In the early days, I spent a lot of energy on it. I tried to learn everything about CP and interpret it to the world. I do that less now. Most days, I think about getting lunches packed, getting the kids off to school, getting to lessons and games—just regular, plain old life. The effort is less as time goes by, at least for us," she says.

For others, she offers this simple advice. "You have to carve out your own philosophy. Every kid is different, and you need to honor who that child is. Focus on their strengths, and let people know that to you they're no different than any other child. A diagnosis of a disability is the start of something, not the end of something."

And remember, Kathy adds, "you don't have to figure out everything at once. One day at a time is a beautiful thing."



working with early childhood professionals and learning how to integrate services into your child's everyday life, you help promote his or her development, learning, and

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Be an Advocate for Your Child

Receiving early intervention services in natural environments benefits both your child and your family. To make sure your child has every opportunity to learn at home and in the community, you may need to speak up for your child's needs.

Make sure your Individualized Family Service Plan (IFSP) team knows you want services delivered in natural environments. Does your son spend time in child care? Ask the physical therapist to work with him there. Want to partici-

pate in the library's story hour? Ask the speech pathologist to come along. Are mealtimes a struggle? Ask the occupational therapist to come at lunchtime rather than between meals when your child isn't hungry.

You also may want to take opportunities in your community to advocate for accessible, inclusive access. If your local playground doesn't accommodate wheelchairs, for example, you could ask the park to add inclusive equipment next time they upgrade.

EARLY INTERVENTION HELPS CHILDREN AND FAMILIES

If you have a young child with disabilities or developmental delays, you probably already know that challenges can meet you at every turn. Maybe your baby doesn't eat well and mealtimes are a problem. Or maybe your toddler can't climb stairs and throws tantrums in frustration. Perhaps your child is almost 3 and still isn't speaking. Such issues can lead to even more problems. Your child's growing, learning, and developing may be slowed, for example, or your family's participation in social or community activities may be limited. The situation can feel overwhelming to any family.

"The good news is that help is available," says Judy Swett, an early childhood parent advocate for PACER Center. "Through Part C of the Individuals with Disabilities Education Act (IDEA), early intervention services can meet the developmental needs of eligible children up to age 3 and provide supports to their families. Services may include anything from speech therapy for your child to information on helpful community resources for you. Your strengths, resources, needs, priorities, wishes, and concerns as they relate to the development of your child are of prime importance to those working with your child and family."

The benefits don't stop there. All families who receive early intervention services also have a service coordinator who can help make services work across agencies. Additional supports and services may include parent training as well as counseling and social work services.

To find out if your child qualifies for early intervention services, you can ask your school district for an evaluation. If you prefer, your doctor, child care provider, or other family member may make the request for you. A team that includes you will be formed to learn about your concerns and create an evaluation plan that will consider all areas of your child's development. Once you give your written

permission, the evaluation can begin.

If your child qualifies, you'll participate in a family assessment so the team can learn about what's working and what isn't as you parent your child with a disability or developmental delay. These areas of concern will then be written into an Individualized Family Service Plan (IFSP), a document that maps out goals for your child and family for one year. Depending on your child's needs, goals will focus on developing basic skills such as communication, mobility, cognition, social interaction, and self-care. Your family goals might include such things as learning more about your child's disability, accessing child care, participating in community activities, or meeting other parents.

With the goals clearly defined, the team will then consider what services are needed. If your infant daughter has trouble eating, for example, the IFSP team might write a goal that involves your child being able to suck and swallow. They'll also discuss what services she will need and who will provide them. Family goals that you have identified, such as finding caregivers, also will be written into your IFSP. The team will support you in achieving them as well.

"Children grow, develop, and learn in the context of relationships with their families and other caregivers in everyday routines and activities," Swett says. "As a parent, you are essential to the decision-making process in early intervention. You are the expert about the needs of your child and your family. You also are a key member of IFSP team, and your involvement is necessary if your child and family are to be served well."

"Having a child with disabilities or developmental delays can be challenging," Swett adds. "Fortunately, early intervention services are family centered and can give you the supports and services you need to help your child grow,

learn, and develop. Those services also can teach you how to advocate for your child and support your participation in your community to the extent that you desire."

For more information about early intervention services in Minnesota, call PACER Center at 952-838-9000 and ask to speak with an early childhood parent advocate.

Information in this article applies to families who live in Minnesota. Each state has its own policies under the federal law.

PARENTS HELP PROMOTE GOOD EMOTIONAL HEALTH IN YOUNG CHILDREN

From the moment they are born, babies are social, emotional beings. Every coo and cry is an attempt to express needs and feelings and communicate with the world around them. By responding with unconditional love and consistency, parents can help their babies and young children develop healthy social and emotional patterns that will serve them well throughout life.

That's not always easy to do—especially when your infant is wailing through the night or your toddler is having a tantrum in the grocery store. Yet through every interaction you have with your child throughout the day, you have the opportunity to support your child's social and emotional development. You are helping your child build trust in others and the ability to form meaningful relationships, says Christopher Watson, co-director of the Infant and Early Childhood Mental Health Certificate Program at the University of Minnesota.

"Children need adult emotional partners to help them interpret what they're feeling and manage their emotions," Watson explains. "For example, a toddler who is suddenly afraid of something will look to Mom or Dad to see if they should be scared. They need an adult to help them know what's okay, what's not, and how to respond to the world."

Watson offers these tips on how you can promote social and emotional health in your young children, with or without disabilities.

Provide unconditional love

Children need to know that they are loved even if they misbehave, make mistakes, or experience failures.

Provide appropriate discipline

Children need to explore and experiment, and they also need to know where the limits of acceptable behavior are. When rules are broken, criticize the behavior, not your child. Be firm but kind. Help your child understand why the behavior was not okay and what he or she can do instead.



When Should You Seek Help?

Did you know that infants and preschoolers can become depressed, suffer from traumatic events, or have a tendency to develop mental health problems? It can happen to any child—regardless of age, race, ethnicity, religion, or family situation, says Christopher Watson, co-director of the Infant and Early Childhood Mental Health Certificate Program at the University of Minnesota.

Symptoms of mental health issues vary but may be suspected if a young child regularly:

- Lacks emotion
- Rejects affection
- Is unable to calm himself or herself
- Is extremely fearful
- Acts withdrawn
- Is often inconsolable
- Acts violent, defiant, or aggressive
- Has significant sleeping or feeding problems
- Is extremely clingy, sad, or out of control

All children go through challenging phases, but that doesn't mean they have mental health issues, he adds. When a child's behavior repeatedly seems too extreme, intense, or unusual, however, it may be a sign that something is amiss.

Remember, no one knows your child better than you. If you are concerned about your child's mental health, call your pediatrician or county public health office and request a social/emotional screening. An infant or toddler with a diagnosed physical or mental condition that's likely to result in developmental delay may qualify for early intervention services even if the delay isn't apparent at the time. Early intervention can help turn problems around before they become more severe or long lasting.



Foster self-esteem

Children develop feelings of self worth when they are praised, encouraged, respected, reassured, and treated fairly.

Encourage play

Play helps children learn how to relate to others, handle challenges, gain a sense of belonging, and learn social skills.

Express feelings appropriately

Children learn from imitation. They will learn to express their own feelings and develop empathy by watching how you deal with emotions.

Provide a safe home

Stability, consistency, and predictability help a child feel safe. Protect your child from violence in the home—including violence on TV.

Interpret the world and develop emotional literacy

Children begin to understand other people by learning about their own feelings first. Build emotional vocabulary through your day-to-day actions together. For example, if your son has fears about monsters under the bed, reading books about scary things may give him a safe way to explore

that feeling, gain perspective, and understand that everyone has fears.

Name and affirm your child's emotional experiences

Your child will learn to trust emotions and relationships if you name and affirm what your child is feeling and provide assurances that you can help your child deal with them. For example, if your daughter is upset because you limit before-meal treats, saying, "Yes, I see you are angry because I won't let you have a cookie before dinner," helps her identify the feeling she is having, affirms the feeling, and demonstrates that you understand (even though she still can't have a cookie). "The goal," Watson says, "is to create an environment where a child feels held emotionally."

Set children up for success

Anticipate when your child is prone to emotional outbursts and avoid those times when scheduling activities. For example, if your son is demanding and whiny when he's tired, wait until after his nap before you take him grocery shopping. "If you know a child won't like something, think about what they do like and mix a reward with the activity," Watson suggests.

Be calm

When your child is agitated, upset, or out of control, "your only job is to bring them down from that state," Watson says. How? "Be present. Keep a calm tone of voice and repeat simple, comforting words, such as 'It's okay. I'm here,'" he says. "Don't add extra demands on the child. In fact, take away demands. If necessary, remove your child from the environment," he adds, noting that large stores and fluorescent lighting can be overstimulating to young children. Another approach is to try distracting the child. Finally, "if your child is getting physically distraught, you may want to hold him or her closely to provide a calming sense of safety. Adults play a crucial role in providing support to children as they learn to regulate their feelings," Watson says.

All children—with and without disabilities—need a secure base in order to develop into emotionally healthy adults. That foundation is built moment by moment, in the daily interactions between you and your child. By helping your child understand and express his or her emotions, you're promoting social and emotional health that will allow your child to face life's challenges in the best way possible.

For more information, visit PACER's Web site at www.PACER.org or call PACER at 952-838-9000 and ask to speak with an early childhood advocate.

MAKE THE MOST OF SUMMER WITH THESE FUN IDEAS

What's more fun than summer when you're a kid? Not much, especially if you're playing, exploring, and learning new skills while a soft breeze moves across your face on a warm, sunny day.

If your young child has a disability or developmental delay, there's no reason summer can't still be a blast. There are lots of toys and activities that support learning, fun, and inclusion—no matter what the disability is.

Here are a few ideas for fun activities and simple adaptations that can make summer super for young children:

For children birth to six months:

- Activity quilts laid out on a shady spot in the grass
- Cloth toys, soft dolls, stuffed animals
- Rattles

Simple adaptation:

- Place a rolled-up bath towel under your baby to prop him or her up.

For children six months to one year:

- Balls
- Push-pull or squeeze-and-squeak toys
- Activity box in the backyard

Simple adaptation:

- Add a connecting link to toys so they stay attached to the stroller when you take a walk around a lake or through the neighborhood.

For children one to two years:

- Ride-on toys, wagons
- Backyard gym equipment
- Sandbox and water toys

Simple adaptation:

- Add a phonebook or cans of food to your child's push or riding toy to prevent it from tipping over.

For children two to three years:

- Wading pool, sand toys
- Tricycle with helmet
- Art projects to do outdoors

Simple adaptation:

- Add foam grips to the handles of toys or crayons for a better grip.

For children three to six years:

- Construction toys
- Dress-up clothes and accessories
- Story books

Simple adaptation:

- Add page turners to books to make reading easier while your child sits under a favorite tree at the park.

All children need to play, and summer is a great time to encourage activities that promote learning, socializing, communicating, and self-expression. Want more ideas for fun?

Download a free copy of "Toys: Universal Tools for Learning, Communication, and Inclusion for Children with Disabilities" at www.PACER.org/stc. A printed copy is available by calling PACER at 952-838-9000 (one free to Minnesota families; others, \$3).





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(Alternate format is available upon request.)

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participation in family and community life.

Using natural environments has other benefits, too. For starters, it gives your child many chances every day to practice the new skills he or she is learning. It also promotes inclusion with others and means that your child is offered the same opportunities and activities as typically developing peers. What's more, you can feel more confident in your ability to meet your child's needs at home and within your community.

As you think about your child's natural environments, keep in mind that there's no "right" place or method for providing services. Every child, family, and community is unique, and what works for one may not work for another. You, your IFSP team, and your service providers can be flexible and creative when designing early intervention services for your child and family. Your service coordinator, for example, can suggest ways to involve your child in community activities that you may not have considered possible.

Keep your eyes open for opportunities to promote your child's learning and skills. Natural environments are everywhere your child and family are!