



# EARLY CHILDHOOD CONNECTION

## LITERACY OPENS THE WORLD TO A CHILD WITH DISABILITIES

When Maddie Lewis was born full term and healthy six years ago, everything seemed storybook perfect. By the time she was nine months old, however, the tale began to take an unexpected twist. Maddie wasn't crawling, and her language abilities, along with other skills, were slowing. Concerned, her mother, Kelly, had her evaluated, and Maddie began receiving early intervention services. Shortly thereafter, in January 2003, Kelly received the news that her first-born child had epilepsy and global developmental delay.

The news came as a shock, but Kelly was determined to rewrite the story into something with a better ending than was foreshadowed. She's doing it in part by focusing on literacy. "Literacy is universal," she says. More than just being able to read or write, it is a key component of learning, development, communication, and a richer life. "It's not only about being understood, it's about being able to comprehend your world," Kelly explains.

For Maddie, the oldest of three children, both diagnoses influence her ability to learn. Global developmental delay affects her fine and gross motor skills, social-emotional development, daily skills, and cognitive abilities. Her epilepsy manifests as absence seizures—short, subtle slowdowns in her brain. Kelly describes the seizures as

like a "pause/play" button that slows Maddie's processing and learning.

"Focusing long enough to absorb a letter or sight word has been hard for her," Kelly explains. "The seizures slow her cognition, and she processes at a slower pace."

To compensate, Kelly uses several approaches to help Maddie learn. One way is by focusing on multiple learning styles—visual, auditory, tactile, musical, kinesthetic, and more. "Maybe looking at an apple isn't enough," Kelly says. "Maybe she needs to hold an apple, bite it, do an apple puzzle. She needs to wake her body up.

"There's more than one intelligence," Kelly adds, "so I might put clay on a plate and have her write her name in it. She sees it and feels it; she moves and controls it with her finger. You look at your child's primary way of learning, but that's not all you use. You raise the bar so they don't feel intimidated but challenged."

Another approach is to help her look at picture books and talk about what she sees. It improves Maddie's "ability to recognize pictures, what's happening in it, and generalize it into her environment," Kelly says. "If you can't understand the picture and what's happening, you can't associate it with the label or the letter."



**Maddie Lewis**

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## BASE DECISIONS ON A VISION FOR YOUR CHILD'S FUTURE

When you first discover that your young child has a disability, it can feel overwhelming. Eventually, however, you find your bearings, see the long view, and begin to ask the questions: Where do we go from here—and how do we get there?

The specific answers, of course, depend on your particular situation. Certain principles, however, can guide you as you discover that decisions made now have long-term implications for your child later in life.

For Judy Swett, one of PACER's early childhood parent advocates, the journey began 23 years ago when her daughter Joanna was born 10 weeks premature. With developmental delays and developmental ataxia, a brain abnormality that affected her balance and coordination, Joanna faced an uncertain future. "The only thing the neurologist knew for sure was that he could not tell us how this would impact her life," Swett says.

That was when Swett realized it was critical to have a vision for her child and to make every decision based on it. "I decided to treat her as if she'd be able to do everything," Swett says. "I was determined that she would learn to walk and run and do all those things other kids did."

That realization led to her first insight. "**Decisions you make along the way will support or detract from the vision you have for your child. Don't settle for less.** Even not knowing your child's potential, maintain high expectations," Swett says.

The path wasn't always easy, but Swett didn't walk it alone. Guiding her was her second insight: **Seek inclusion and enlist the support of the community.**

"I assumed Joanna would benefit from being involved in activities that other children in our neighborhood were involved in," Swett says. That meant T-ball and softball, as well as swimming and gymnastics lessons. From age 2 until she went to kindergarten, it meant attending an Early Childhood Special Education (ECSE) classroom program and finding supplemental support. "The primary goals on her Individualized Education Program (IEP) were in the areas of speech-language, yet ironically, she was the only child in the classroom who had any language skills," Swett recalls. "In order to give her time with typically developing peers who



**Joanna Swett is an assistant teacher.**

could encourage her communication skills, I enrolled her in our church preschool program one day a week."

When it came time to choose a kindergarten program, it also meant looking for a school that valued inclusion. "As it became more apparent that she was struggling with math and reading, we added some time in a resource room so she could get some one-to-one instruction," Swett says. "I learned to work with her IEP team to modify her goals and services as the academic expectations became more challenging."

**"Because we had set high goals from early on and had not set any limits on Joanna, she had no limits on herself."**

*- Judy Swett*

In junior high, Joanna's need for additional educational support became even more apparent—and Swett discovered a third principle: **Find other adults to play a role in her development.** "Joanna was very firm in her desire to be included in challenging classes. She had a great case manager who helped us to see the need for Joanna to learn how to advocate for

herself with teachers. This was great training for her high school years and eventually for when she went to college," Swett says.

"As Joanna entered high school, we had to work a little harder to include her in the advanced curriculum so she could take international baccalaureate classes," Swett says.



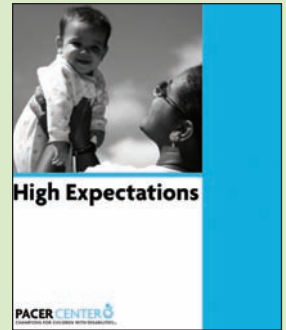
“I learned the value of hiring tutors,” she adds, noting that the vision she’d had for her daughter was coming true. “Because we had set high goals from early on and had not set any limits on Joanna, she had no limits on herself,” Swett says. Her next goal was college and a career in child care.

It all paid off. From a tiny preemie, to a toddler with a diagnosis of developmental ataxia and later pervasive development disorder, to a family and community that never gave up, Joanna graduated from St. Paul College in December 2008 with an associate degree in child development and a 3.95 GPA. Joanna is now an assistant teacher at the child-care center where she worked in college.

“Joanna has been successful because she learned to see herself as having different abilities rather than a disability,” Swett says. Many people—from school, the community, and the college—were involved and supported Joanna along the way. “Together we created a positive vision for her future and took the steps needed to fulfill that vision.”

### Have “High Expectations” for Your Child

“High Expectations” is a new 10-page booklet for parents who have just learned their child has a disability. Written by PACER parent advocate Carolyn Anderson, it explains that “having high expectations when raising a child with a disability requires challenging yourself, your child, and others to do more than simply assume that a disability limits a child.” One copy is free to Minnesota families of children with disabilities. Additional copies are \$3 each; \$2 for orders of 10 or more. Order php-a34 by visiting [PACER.org/publications](http://PACER.org/publications) or calling 952-838-9000.



## Webinar Addresses Ways to Serve Diverse Families of Young Children with Disabilities

PACER’s free, online training, “Serving Diverse Families: Strategies for Early Childhood Service Providers,” is now available as an archived Webinar on PACER’s Web site. Geared for early childhood intervention or early childhood special education professionals who work with parents from a culture different from their own, the comprehensive training shows how to help the family determine outcomes based on their own concerns, needs, and priorities. It also includes “Practical Tips for Successful Interactions,” a panel presentation and Q&A by PACER’s multicultural parent advocates. You’ll find it at [PACER.org/pacerwebinars](http://PACER.org/pacerwebinars).



## Free Multicultural Parent Outreach Publications Available to Minnesota School Districts, Community Organizations, and Agencies



PACER Center has published a series of free brochures for outreach to families from diverse cultures who may have concerns about their child’s development. The materials are in Hmong, Spanish, Somali, and Russian. English versions are directed to American Indian and African American parents and also accompany each order of translated materials. The eye-catching brochures feature culture-specific photographs and family-friendly language. There is space to affix a label providing local contact information on the back page of the brochure. Funding for the project is provided by the Minnesota Department of Education through the federal State Personnel Development Grant. For more information about ordering hard copies, please contact Barb Ziemke at [bziemke@PACER.org](mailto:bziemke@PACER.org) or at 952-838-9000.

## PROJECT KITE PROMOTES INCLUSION

For Thomas Collom, preschool was a fun yet disappointing experience. While other kids were running around to play, he was in his wheelchair. With his speech significantly affected by his cerebral palsy, he had trouble communicating with his peers and they didn't always understand that Thomas was the same age they were. Frustrated by that situation, the effort it took to communicate, and his limited mobility, the 4-year-old would often have tantrums and tended to play independently instead of with classmates.

"He's very social, so he had a hard time with not being able to play the same as other kids," says his mom, Holly. "He's the all-American boy," she adds, noting with a smile that he loves "old cars, trucks, dirt, and getting into trouble. And he has the *best* sense of humor."

At preschool, his teachers recognized that Thomas's tantrums were expressions of his frustration at not having another way to interact or communicate. They began searching for new ways to help Thomas express himself in a healthy way and interact more successfully.

That search led them to a PACER Center training called Project KITE (Kids Included through Technology are Enriched). A team-based curriculum for parents and teach-

ers of young children with disabilities, it promotes inclusion for children with disabilities through the use of technology. Its focus is on integrating technology into early childhood classrooms and homes.

When Thomas's teacher asked Holly if she'd be interested in joining the effort, she agreed, eager to keep options open for her son and be knowledgeable about resources that might help him. Last spring, she, Thomas's teacher, and his speech therapist took the KITE training to find ways to help Thomas participate and communicate with the other children.

"When I first started, I didn't know what to expect, but the trainers were wonderful about explaining things," Holly says. "It was easy to pick up. I loved the packets they handed out. They were simple and wonderful. We all had our own separate goals," she says of her team, "but we shared the main goal of helping Thomas communicate better."

As a result of the KITE training, that's exactly what happened. At school, Thomas's teacher began making the classroom more accessible by putting more Boardmaker labels at Thomas's level to give him more options. She introduced a communication device called BIGMack that let him participate in circle time by counting his classmates. She also put simple Boardmaker symbols on a key chain that Thomas can use when he wants to ask for something.

"Mostly, the adaptations make sure Thomas can get at everything he wants," Holly says. More important, they allow Thomas to bypass his physical disabilities and become more interactive with his classmates. The communication barriers started coming down.

The result? "His tantrums are pretty much gone as long as he has a way to communicate," Holly says. "I've gotten feedback from the teacher and volunteer parents that he's communicating and interacting much better."

It's a similar success story at home. Through KITE, Holly learned how switches could give Thomas access to toys, computers, and simple communication devices. "We've used the mini mouse for the computer; he loves to play games," Holly says. "We've done switch-activated toys—including a kangaroo that flips over," she says, "and we're working on a switch for the TV so he can turn it on and a communication device that, among other things, will open doors."

Proving that technology promotes inclusion, Thomas and his 3-year-old sister, Kaitlyn, play together and argue hap-



Holly & Thomas Collom



pily over who gets to use the switch. The benefits of inclusion are about more than just playing together. “Kaitlyn talks nonstop,” Holly says, “but now Thomas is able to fit a few words in, too.

“Through all the different things we’ve added,” she says, “Thomas’s speech has become more enunciated. His favorite thing to tell me is, ‘Mom, I’m a hard worker.’”

Thanks to KITE and assistive technology, his hard work is paying off. “Thomas has always been very smart, but being

able to convey that to people has been almost impossible,” she says. “Now, milestones are being met because he can let his needs be known.”

For the future, “I hope he can use whatever devices let him live as independently as he wants to and pursue whatever makes him happy,” Holly says. “PACER showed us what options are open to us. The whole KITE experience was really wonderful.”

*KITE is funded in part by the Minnesota Department of Education.*

#### Literacy, continued from page 1

Predicting what’s going to happen next in a story is also part of learning and literacy. “A child has to be able to sequence—to listen to a story and know what’s coming,” Kelly says. “She needs to learn how to anticipate and be able to describe what she sees. One of the tools we use is taking pictures out of a magazine and focusing on the subject, the noun, and verb. I say, ‘tell me a story.’ It gets her to think about what she sees—are the children in the picture happy or sad? Are they running?” When she can do that, she has increased her attention, and that means she can better focus and learn. By looking at people’s faces and body language in a story, Maddie also learns nonverbal cues of communication.

At school, Kelly has worked closely with staff to identify ways to reach specific literacy goals for Maddie. They made her a classroom helper to help her attend and learn sequencing. They changed her speech and occupational therapy to focus on letters and are using computer-based literacy games to support reading and literacy skills. They’re also finding library books on audio so she can pace herself.

Literacy also helps Maddie learn about herself and her feelings. One book she loves is “Today I Feel Silly & Other Moods That Make My Day,” by Jamie Lee Curtis. A fun rhyming book about emotions, it ends with the question “how do you feel today?” and includes a mood wheel where readers can manipulate a character’s eyes and mouth to show their own emotions. “The most important thing I can give my child is self-love,” Kelly says. “I want her to know her feelings.” When Maddie reaches that last page, “she now actively says, ‘Here give me the page, I’ll tell you,’” Kelly says. “We end our day with it. She is able to self-reflect. If she can do that, she can get her needs met.”

Literacy is more than knowing letters and words and reading. It is the main character in a lifelong story about learning, communication, self-awareness, and fulfillment. By finding a variety of ways for Maddie to gain those literacy skills, “I’m creating her potential,” Kelly says. “You want the child to love learning like a dog to a bone,” she adds. “It’s a lifeline to maximize the child’s potential into the future.” “



#### Free Early Literacy Guides Combine Fun and Learning

Want to encourage literacy skills in your infant, toddler, or preschooler? Here are some free resources you’re sure to enjoy. “Practice Guides Especially for Parents” show you how everyday home and community activities encourage your young child to listen, talk, and learn the building blocks for early literacy. They’re from the Center for Early Literacy Learning (CELL). Funded by the U.S. Department of Education’s Office of Special Education Programs, CELL is a research-to-practice technical assistance center and a major initiative of the Center for Evidence-based Practices at the Orelena Hawks Puckett Institute. Learn more at [earlyliteracylearning.org/pgparents.php](http://earlyliteracylearning.org/pgparents.php) or at [PACER.org](http://PACER.org).

## PACER ANSWERS PARENTS' MOST FREQUENTLY ASKED QUESTIONS

As the parent of a young child with disabilities, you may already know that the federal Individuals with Disabilities Education Act (IDEA) requires states to provide early intervention services to eligible children from birth to age 3 (under Part C) and special education services for eligible children ages 3 to 21 (under Part B). But what does that mean for you and your child? Judy Swett, one of PACER's early childhood parent advocates, answers parents' most frequently asked questions.

### How do I access early intervention services?

The process begins with a request for evaluation. You can call your local elementary school or school district and make that request. If you prefer, a doctor or other person who works with your child can refer your child for an evaluation.

### What is an evaluation?

An evaluation is a process used to determine if your child has a disability or developmental delay as defined by IDEA and if he or she is eligible for services. It is provided at no cost to you.

With your written permission, a group of people looks at your child's developmental or educational strengths and needs. You play an important role by providing information about your concerns and priorities regarding your child's development. Other data—from doctor's reports, developmental tests, observations of your child at home or in a child-care or preschool setting, and developmental and behavioral checklists—round out the evaluation.

The evaluation must not discriminate against your child based on his or her disability. If your child does not speak English, the evaluation must be done in your child's native language.

### My daughter's Individualized Family Service Plan (IFSP) team keeps talking about "services in her natural environment." What does this mean?

A natural environment is anywhere infants and toddlers without disabilities would typically be found. It could be in the home, a child-care center, a community-based program such as Early Head Start, or even at the park. IDEA says early childhood services should be provided in such environments.

Your everyday activities with your child are also a natural environment. Feeding, bathing, changing, dressing, and playing with your child and participating in community activities are all great opportunities to implement strategies and interventions that allow your child to learn and practice new skills that will enhance growth and development.

### What is meant by the term "least restrictive environment"?

Least restrictive environment (LRE) means that children with disabilities should be educated with their peers in the regular classroom to the greatest extent possible. That's because most children learn by modeling the behavior of peers.

For children ages 3 to 5, LRE may be a community preschool program, child-care center, Head Start classroom, or other public or private preschool setting. For an older child who attends a preschool classroom, the service provider may show the teacher how to integrate interventions into the regular classroom routines.

### When the professional comes to my home, she focuses on me rather than my child. Why?

The value of early intervention comes between visits, when you integrate the techniques you've learned into your child's daily routines and activities. By modeling these interven-



#### PACER Offers a Grandparent Support Group

PACER's Grandparent to Grandparent Program offers people with grandchildren of any age and any disability a chance to meet others; share concerns, joys, and interests; discover resources; and learn how they can provide support to their children and grandchildren. Through monthly meetings, the group offers grandparents opportunities to discuss the impact of the child's disability on the entire family and obtain up-to-date information about the child's special problems and needs. For more information, call PACER at 952-838-9000 or visit [PACER.org/grandparent](http://PACER.org/grandparent).



tions for you, the professional is increasing your confidence and ability to enhance your child's development every day.

### **I work full time, and my child spends most of his day in a child-care center. How can he receive early intervention services when I have to be at work?**

The special education staff can provide services for your child at the child-care center and provide your child's primary caregiver with some strategies to successfully include your child in the child-care program. The staff should also meet regularly with you to support you in carrying out activities during the time when you are with your child.

### **My IFSP team wants to discuss "transition." What does this mean?**

Early intervention services end on your child's third birthday. By the time your child is 2 years and nine months old, your IFSP team will meet with you to discuss your child's needs and write a plan to address transition to early childhood special education programs or other options if your child does not qualify for Part B preschool services. Together, you will address a variety of topics, such as goals, timelines, and team member responsibilities; your concerns; the need for any further evaluations; and your special education legal rights.

### **What is the difference between an IFSP and an IEP?**

An IFSP is written for a child from birth to age 3. It is based on an in-depth assessment of the child's strengths and needs and the concerns, priorities, and resources of the family. It is used to coordinate services from multiple agencies and must

contain the name of a service coordinator. Services on an IFSP must be delivered in the child's natural environment.

An Individualized Education Program (IEP) is an educational document for children ages 3 to 21. It focuses on special education and related services and describes how the child will receive a free, appropriate public education (FAPE). An IEP must be in place by a child's third birthday.

### **My child was not on an IFSP, but I think she might need early childhood special education services. What should I do?**

You can contact your school district or local elementary school and ask to speak with the person who knows about special education services for children ages 3 through 5. Share your concerns and ask for an evaluation to see if your child would qualify for special education services.

### **My son is on an IEP. Does the school district have to provide transportation?**

Yes. Also, if your son needs special accommodations in order to be safe on the bus, the IEP team should discuss this and write them into the IEP as a related service.

### **Is there a limit to how much time my child can spend on the bus?**

Though no specific amount of time is stated in law, the travel time must be "appropriate to the physical, mental and emotional well-being" of the child. You should discuss any concerns you have about the length of the bus ride with your child's IEP team.

*For more information on these or other early childhood topics, please visit [PACER.org/ec](http://PACER.org/ec) or call PACER Center at 952-838-9000 and ask to speak with an early childhood parent advocate.*

#### **Breaking PACER News? Don't Miss It!**

PACER uses e-mail to deliver time-sensitive messages:

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- Workshops
- Legislative updates
- Monthly PACER e-news

Go to [PACER.org/forms](http://PACER.org/forms) and complete the form to be on PACER's e-mail list.

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**PACER CENTER**   
CHAMPIONS FOR CHILDREN WITH DISABILITIES™

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)  
**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

**Design:**  
Jenna Hanson

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(Alternate format is available upon request.)

**Frankie Valli & the Four Seasons to Headline PACER's 2009 Benefit!**

“Oh, What a Night” it will be when Frankie Valli & the Four Seasons bring their soaring harmonies to PACER Center’s 27<sup>th</sup> Annual Benefit on Saturday, May 2, at the Minneapolis Convention Center. With smash hits like “Sherry” and “Big Girls Don’t Cry,” the group has sold more than 100 million records worldwide and has been inducted into the Rock and Roll Hall of Fame. Don’t miss this American pop icon! Reserve your tickets now! Call PACER at 952-838-9000 or visit [PACER.org/benefit](http://PACER.org/benefit).



**TICKETS ON SALE NOW!**