

Early Childhood Connection

A Newsletter for Minnesota Families of Young Children with Disabilities

Spring 2002

Grandparents expand their roles:

Offer love, time and crucial support



By Beth Wohlberg

Many families of children with disabilities count on extended family for support. Parents may wish to share the following story with their parents.

When the Greemans' granddaughter Haven was eight months old, a neighbor asked her age, smiled knowingly and said, "She must be getting ready to walk."

The innocent statement brought Don Greeman to tears. He knew Haven wouldn't be walking in the near future.

Even though Haven's doctors haven't been able to diagnose her specific disability, they know she is developmentally delayed. Now at 4 years old, she speaks about 15 words, and she is just now gaining a sense of control over

her body—she loses her balance sometimes. She sees an occupational and speech therapist every week.

It hasn't been easy for Don

and Dianne Greeman, who wish they had the power to erase Haven's frustrations and ease their daughter's pain. But that hasn't stopped them from playing a crucial role in Haven's life. The Greemans, along with many others who have young grandchildren with disabilities, are expanding their roles as grandparents.

"Grandparents are a part of a grandchild's support system," said Jane Johnson, a PACER advocate and coordinator of PACER's Grandparent-to-Grandparent program. "They are the extended family."

Johnson said grandparents play important roles.

"We helped Haven learn to ride a bike—a Big Wheel—this summer, and she'll graduate to a bigger bike soon," Dianne said. "We give a lot of time and love, and we offer a little bit of foundation and stability."

The Greemans' support is evident in the way they talk about Haven, but also in their presence at PACER's grandparents group monthly meeting. Each grandparent in the group has a grandchild with a disability. They attend the support group to learn from other grandparents in similar situations and to share things they have learned. They meet to discuss anything from their grandchild's progress in school to the struggles they have communicating with their children. They also come to pass around pictures of their grandchildren and unabashedly praise them—something they say is hard to do around



Dianne and Don Greeman pose with Haven at holiday time.

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Grandparents provide vital support, love

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grandparents with grandchildren without disabilities.

“Grandparents often don’t have a place to brag about their grandchild with a disability,” said Johnson. “This is a place to sing their praises. But it is also a safe place for them to talk about their fears and share their frustrations—a place where everybody recognizes what they are going through.”

Arlene and Glenn Hyde, who attend the group regularly, found out their daughter was pregnant with twins four years ago in October. They laughed about the work involved in caring for two newborns, but they happily prepared for double-duty as grandparents.

A month later, they learned that their granddaughters had twin-to-twin transfusion syndrome, which is a disease of the placenta where blood passes disproportionately from one baby to the other.

Kianna and Malia were born prematurely, needed intensive care and remained in the hospital for three months. Kianna, who was born with severe brain damage, needed several surgeries.

Arlene and Glenn never skipped a beat.

They visited the hospital all the time to learn how to care for the girls. Once the babies were home, they babysat whenever their daughter and son-in-law needed it. They tried to support their children without offering unwanted opinions. They sometimes just sat and listened. Arlene returned to school to receive a certificate to become a personal care assistant and now works at least 20 hours a week at her daughter’s home.

It hasn’t been easy. Arlene and Glenn said they felt a great deal of pain when they learned of Kianna’s disabilities. They knew very early that Kianna would always seem like a two-month-old baby.



Kianna’s laughs and smiles and giggles delight Arlene and Glenn Hyde.



Arlene and Glenn Hyde hold their granddaughters Kianna (left) and Malia.

“I cried all the time at first,” Arlene said. “I released a lot of my anger by crying. As a grandparent, I watched my daughter go through so much pain and I wanted to take away all that pain.”

PACER’s Jane Johnson said that often grandparents are hit hard when their grandchild is born or diagnosed with disabilities. They feel a loss of dreams for themselves, their adult child, and their grandchild.

“The grief ebbs and flows,” Jane said, “but never truly goes away.”

To stem the pain, these grandparents focus on their grandchild’s abilities and successes. The Hydes smile when they talk about how Kianna recognizes them when they see her—with smiles and giggles—and beams from ear to ear when her daddy comes home from work. The Greemans tell stories about Haven’s affection—shaking everyone’s hand that she meets and running to greet her friends at daycare—and her high energy level that keeps her exploring new things every day.

“She never says more than two words at a time,” Don said. “But one day I told her she couldn’t bring her bike in the house because it was already too crowded. She said, ‘No it ain’t.’”

“I couldn’t believe it,” Don said, laughing. “It was beautiful to hear her say that.”

Grandparents need to know how to help

Parents may wish to share or adapt these tips for grandparents who want to help.

■ **Offer support, but don't hover:** By doing so, your child will know you trust their decisions about medication, therapy, education, etc.

■ **Provide support in practical ways:** Open communication is important. Ask what you can do to help. You can attend doctors' appointments for moral support and an extra set of ears and notes, or babysit to allow your children to relax one evening a week. Even if you live far away, you can help by locating therapists in your grandchild's city and finding useful books or other information.

■ **Offer opinions only if asked:** Some parents might be sensitive about suggestions for raising their child. Try to understand that raising a child with a disability is difficult and give advice only when your child asks for it. "Sometimes my parents say things that sound as if they think we aren't doing things right," said a mother. "For example, my child has difficulty eating. But my mother has said, 'She does just fine when she's with me.' That might have been Mom trying to reassure me, but that's not how I heard it."

■ **Find out what you need to know about the disability:** If you become informed about a child's disability, it indicates that you really want to be involved. However, follow the lead of your children—they have gathered plenty of information, and they have the information they need to raise their child. Before you offer new information, wait until they ask.

■ **Accept your grandchild as he or she is:** Treat the child with a disability as you would any grandchild. Acknowledge the disability, but recognize the talents and abilities of your grandchild.

■ **Give yourself time to grieve:** Many grandparents say their grief is magnified because they watch their child grieving also. Let yourself grieve and take care of yourself during difficult times.

■ **Enjoy your grandchild:** If you enjoy reading to your grandchild, sit on the couch and read a book—even if the doctor says the child can't hear. Rock your grandchild in your favorite rocking chair. Bring pictures of your grandchild to your friends. Spend time together—you will quickly learn all of the talents and abilities your grandchild has and the important place you have in his or her life.

Sign up for the grandparent-to-grandparent support group

PACER Center's Grandparent-to-Grandparent group provides education and support for any Minnesota grandparents of grandchildren with disabilities.

The group meets monthly September-May at PACER in the Twin Cities.

For information, complete this form and mail it to PACER (see page 8), or call (952) 838-9000 or (800) 537-2237 (Greater Minn.).

Name: _____

Address: _____

City: _____ State, Zip: _____

Phone: (Home) _____ (Work) _____

Grandchild's disability and year of birth: _____

E-mail: _____

- | | |
|--|--|
| <input type="checkbox"/> Add my name to the mailing list | <input type="checkbox"/> I wish to talk to another grandparent |
| <input type="checkbox"/> I wish to attend a support group | <input type="checkbox"/> I wish to attend a workshop |
| <input type="checkbox"/> I wish to start a support group in Greater Minnesota or another state | |

Meet the staff: Sharon Young helps children with disabilities

By Beth Wohlberg

“Assistive technology can change lives,” says Sharon Young, early childhood technology trainer at PACER’s Simon Technology Center. “I have seen parents become overwhelmed with tears of joy after seeing their child’s first experience with a communication tool or a program that connects their child with a good book.”

Research shows that assistive technology, such as computers and software programs, can help young children improve their communication skills, attention span, fine and gross motor skills, self-confidence, independence, and social skills.

Sharon Young is one of PACER’s assistive technology specialists—helping families find the right kinds of assistive technologies. The following is a recent interview with her:

Q: How does the Simon Technology Center help young children?

A: Families can schedule a free, personalized consultation with staff at the Simon Technology Center (STC) to explore software programs and assistive technology that can help young children communicate, learn, and play.

Parents determine the goal of the consultation, which can be anything from finding an easy-to-use keyboard to discovering a program that helps children learn to read. STC staff gathers information from parents, teachers, and service providers of the child prior to the meeting so that appropriate software and devices are selected and demonstrated. At the consultation, the child, their parents and professionals try computer software programs that are developmentally

appropriate, educational, and fun. A typical consultation is 1 to 2 hours.

A child may use a trackball, touch window, or alternative keyboard for easier access to the computer. A child who is nonverbal may explore various communication devices that have recorded phrases paired with pictures so they can communicate with their friends and family.

Families and professionals can also join the

Software Lending Library to borrow materials and try them at home or school before making a purchase.



Sharon Young works with 4-year-old Keith Pierce to explore a program with the trackball.

Q: Why is access to the computer important for young children with disabilities?

A: Technology is for *all* children. For children with disabilities, computers offer assistance by removing barriers to reading and writing, creating new ways to communicate thoughts and feelings, and allowing children

to participate in group activities. Computers also can offer repetition and consistency—making it easier for children to learn difficult concepts.

Q: What surprises parents when they come to the Simon Technology Center?

A: One thing that surprises parents is that computers can offer socialization skills as well as knowledge. Some beginning computer users think computers are used primarily for drill and practice, such as teaching a child the alphabet or how to count. Others see the computer like a TV, and they worry about the lack of socialization.

But children benefit socially when a group works together on the computer. They learn to take turns, follow directions, and have fun with classmates.

We recommend placing at least two chairs at a computer, and we help teachers use the computer in

ilities use the computer, software programs



Keith Pierce, 4, works with a literacy program with the help of Simon Technology Center staff.

classroom activities, such as reading electronic storybooks together. Software programs are helping children become interested in reading and literacy because instead of a black-and-white page in a book, there are sounds, colors, and moving characters that engage a child and appeal to multiple senses.

We also recommend that families interact with their child while the child is working with a computer—contrary to what many people would imagine. For younger children, set up a computer in the living room or near the kitchen so that people are around—it’s similar to the caring and cuddling associated with reading a book. Children want to have a warm friendly person nearby.

Because we want parents to be playmates with their child with a disability, we want them to know of the technology available to access toys, games, and

The Simon Technology Center is available to professionals and families with children with disabilities. Consultations are usually offered during business hours. To schedule a consultation or find information, call (952) 838-9000, or (800) 537-2237 (Greater Minnesota), or (952) 838-0190 (TTY). A \$25 deposit is required to secure the consultation time—it is returned at the consultation.

The Software Lending Library, with more than 1,500 software programs and assistive technology devices, is open from noon to 8 p.m. on Tuesdays and 10 a.m. to 4 p.m. on Saturdays. Minnesota families with a child or adult with disabilities may borrow three items for three weeks. Membership is \$25 a year for a family. Membership fees may be waived for families who qualify.

learning that can be part of their playtime. These tools can help children build relationships with their parents and peers, as well as gain important life skills.

Q: Why do you want to help children access assistive technology?

A: I taught children with learning disabilities for 10 years before becoming an early childhood family educator. One year, my classroom was selected to receive technology training by PACER’s Project KITE (Kids Included through Technology are Enriched.)

I was so impressed and so excited that I wanted to show families what I learned. These two stories are great example of how assistive technology can help families of young *and* older children:

Scott, a 4-year-old who is nonverbal, learned how to use a communication device with four pictures and recordings for a choice of snacks. His five-year-old brother, Todd, was immensely impacted by his brother’s ability to communicate. The first time Scott used the device at home, his older brother shouted, “Mom, Scott said he wants a cracker!” Their mother was relieved that Scott could make his choices known to the entire family so they could understand and respond.

One teenager with a cognitive disorder used a picture-symbol writing program to write a thank-you note to his grandmother. He selected pictures on a computer screen, and the program placed both the pictures and the words on the page. When he was ready to print his thoughts, the pictures were removed so that there were only lovely words of thanks on his note. He smiled with pride. He continued the session by communicating with pictures and text to his parents, who were astounded by how the technology removed a communication barrier and gave him independence.

PACER staff member Sharon Young is a licensed Early Childhood Family Educator. She recently received a graduate certificate in teaching and technology at Hamline University. She has two adult children with disabilities.

Take note:

Federal and state legislation may impact families

By Beth Wohlberg

Parents have power.

When the forerunner of the Individuals with Disabilities Education Act (IDEA) was first drafted, it did not include services for children under age 5 years old.

The federal law was extended to serve children age 3 and over because parents pushed for those early intervention services. They were responding to research that showed early intervention was vital to help children achieve their highest potential throughout their lives.

When states were given the opportunity to serve children under age 3, Minnesota parents stepped up and advocated for early intervention services to extend to birth.

“There are times when parents need to follow legislation and participate in the policy-making process,” said Virginia Richardson, manager of PACER’s parent training and information project.

Special education advocates hope that parents stay informed about legislative issues so they can make a difference.

Federal legislation

Parents should be aware of two main pieces of federal legislation that will be reviewed and updated this year: the Individuals with Disabilities Education

Act (IDEA) and the Child Care Development Block Grant.

Part C of IDEA, which addresses services for families and children birth to three, is scheduled for reauthorization (or updating) this year. Part C is reauthorized every five years.

The Child Care Development Block Grant, which was enacted in 1990, is also due to be renewed by Congress this year. This program is one of two primary federal sources of funding for child care for eligible families. Under the program, parents can choose any legally operating child care provider that meets basic health and safety requirements. For more information, visit www.acf.dhhs.gov/programs/ccb/

State legislation

In early March, Minnesota legislators overturned Gov. Jesse Ventura’s veto on a state budget bill for 2002-03. Their action erased \$1.95 billion of the projected budget shortfall.

The plan cuts about \$15 million from the K-12 education fund—the cuts most directly affect the Minnesota Department of Children, Families and Learning.

Money cut from state child care programs was replenished with federal funds, so these programs remain intact.

New projections, however, show another \$439 million shortage this year with which legislators are currently grappling. In addition, the Governor is pushing legislators to immediately address projected budget shortfalls for 2004-2005.

As part of its plan, the House has proposed to cut \$1 million each year to 2005 from the basic sliding fee program for child care, which helps families pay for child care. The Senate’s proposal contains no cuts to early childhood programs or education, but it suggests tax increases on items such as tobacco.

Stay informed

PACER maintains lists of parents and others who wish to be informed about legislation that may affect their child with disabilities.

One list tells families about pending Minnesota legislation affecting special education and children’s mental health issues. People who are willing to contact policymakers can be added to the alert list. To do so, e-mail your name, address, home and work phone numbers, your child’s date of birth and disability to mnalert@pacер.org.

To be added to a list for information about the reauthorization of the federal Individuals with Disabilities Education Act (IDEA), e-mail your information to idea@pacер.org.

For up-to-date information about legislative issues, see PACER’s Web site at www.pacер.org

Ask the experts:

A forum for parents of young children

The following are three commonly asked questions from parents of young children with disabilities and the answers.

Q The person who provides Early Childhood Intervention services in my home has failed to show up for the last several scheduled visits. I am concerned that my child will not make progress if he does not get the services he needs. What can I do about this?

A Check your Individual Family Service Plan (IFSP) for the name and telephone number of your service coordinator. Call this person first and state your concerns. Be prepared and ready to name dates when service was not delivered.

You may want to request that the missed visits be rescheduled, and that the issue be discussed with the person who has not delivered services.

You can also contact your school district and ask to speak to the special education director.

Remember, it is important that you receive the services listed in your IFSP. It is also important that the early childhood staff help you learn to work with your child through normal routines, such as playtime, dressing and undressing, and mealtime, to increase the effectiveness of the intervention service.

Q My daughter is almost 2 years old. She just began walking, plays with only two to three of her toys, and doesn't respond when I call her name even though the pediatrician says her hearing is fine. I have been told my child may need Early Childhood Intervention services. Who can I call for information?

A Call your local special education director or your local school district and say you have a child who may need Early Intervention Services.

You should be given a number to contact or someone will take your information and a staff person will

contact you.

If you are unsure of who to call or you need more information, call PACER at (952) 838-9000 and ask to speak to someone in the early childhood program.

Q Based on a physical therapy evaluation performed at the hospital, my doctor says that my 18-month-old son needs physical therapy twice a week. But the school's early childhood program evaluation recommends a physical therapist once a month to show me how to work with my child. Why doesn't the school follow my doctor's advice? What can I do?

A The hospital evaluated your child from a medical standpoint while the school evaluated him from an educational standpoint. Therefore it is not surprising that their recommendations are different.

The school must consider the information from your doctor, but school staff is under no legal obligation to provide the services recommended by the hospital.

If your doctor made a recommendation for therapy, discuss any available options within the medical field through your insurance.

This may also be a good time to have a conversation with your service coordinator about the way services are delivered in your home.

The spirit and intent of the Infant and Toddlers with Disabilities Act (Part C of the Individuals with Disabilities Education Act), also known as Early Intervention, is to enable families to become active participants in the development of their child. In this role, families should be able to access all available resources within their community.

Parents can actively engage in sessions with a physical therapist and occupational therapist. Ask questions. Learn how to reinforce the training yourself. Find out where to receive more information. After all, families know what's best for their child, and they are the most important first teachers in a child's life.

PACER advocates are available to offer more detailed answers to these and any other questions. Please call (952) 838-9000 or toll-free at (800) 537-2237 (Greater Minnesota).



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Join the mailing list!

If you or anyone you know would like to receive **Early Childhood Connection**, please call PACER at (952) 838-9000; (800) 537-2237 (Greater Minnesota); or (952) 838-0190 (TTY), *or* please e-mail the following information to pacer@pacer.org, *or* mail the information to Early Childhood Connection, PACER Center, 8161 Normandale Blvd., Bloomington, MN 55437.

Name: _____ Organization: _____

Address: _____ City: _____ State: _____ Zip: _____

E-mail: _____

Parent Professional Other

If parent, child's disability: _____

Birthdate of child with disability: _____

Phone: (H) _____ (W) _____

Fax: _____



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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. Funding for this Early Childhood Project is provided by Minnesota Department of Children, Families & Learning.

Early Childhood Connection