

Early Childhood Connection

A Newsletter for Minnesota Families of Young Children with Disabilities

Spring 2000

Building support for families is vital

By Karen Chappell

When a child is born with a disability, parents face complicated challenges, including where to find adequate support for their child and themselves.

Some families can count on help from extended family and long-time friends, but others discover they need to build a new support system. In either case, parents must define the support they want and need.

The Williams-Mersereau and the Kimlinger families, profiled below, have done that. They receive support from very different sources, but they address the task of finding support similarly: with creativity, honesty, and appreciation.



Miles's family

The Williams-Mersereau household is an active one—Curtis and Michelle have three young sons. Six-year-old Miles, the middle child, had spinal meningitis as an infant, resulting in multiple disabilities that include deaf-blindness and cerebral palsy.

Miles's communication difficulties and frustration lead to behavior challenges, so a familiar person must attend him in his waking hours. Curtis and Michelle are his primary caregivers, and Mary Jordheim, a neighbor who also has a six-year-old son, is their reliable and appreciated backup.

Mary and Michelle met two years ago when Curtis and Michelle moved to their South Minneapolis neighborhood. The women discovered that in addition to having children close in age, they share similar beliefs and values. A friendship blossomed. Now, Michelle and Mary do what all friends do—they share resources and support each other. Michelle helped Mary with her first garage sale, and Mary's husband, Steve, loaned Michelle computer equipment to help her use Internet resources. The families swap baby-sitting for their typical children.

A nurse, Mary is not intimidated by Miles' special needs, and she has offered to watch him, too.

Mary's ease with Miles is an exception, according to Michelle. "Sometimes it's hard for people, even family members, to cope with the child with special needs. But, what they *can* do is help with the other kids," said Michelle. "The only reason I have had time to myself is because Mary has taken my other two kids, especially on weekends

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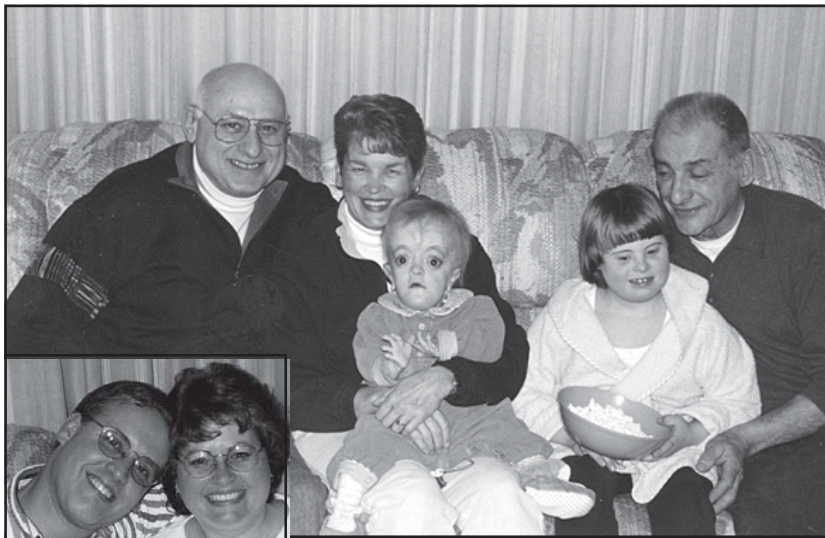


Miles Williams (above left) shares a moment of affection with his dad, Curtis. The family appreciates the support of their neighbor, Mary Jordheim. Inset: Miles's mom, Michelle (left) and Mary (right) are close friends and share many resources.



Photos by Susan Shogren Smith

Varied sources offer vital support to families



Ashley and Amber Kimlinger, enjoy time with their grandparents above. From left are Gabe and Leslie Giancola (holding Amber) and Joe Kimlinger (holding Ashley). Tom and Lisa Kimlinger (inset) appreciate the support.

Photos by Susan Shogren Smith

**“You are always a mother,”
—Leslie Giancola,
Lisa’s parent**

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when Miles is in respite care.”

Mary is “on call” for emergencies. For example, she is designated to pick up Michelle’s and Curtis’s youngest son at day care, if his parents cannot. Her support also helped Michelle to return to college to complete a degree in social work.

Michelle said she believes some people may be afraid to help a family because they fear they will be overwhelmed. “The family doesn’t need you all the time,” she explained. “It just helps them to know that they could call you if they needed to,” she continued.

They can rely on Mary for assistance, and that is a greatly appreciated relief for her and Curtis, Michelle said.

Ashley’s and Amber’s family

Tom and Lisa Kimlinger have two young daughters, Ashley and Amber. Both have disabilities. Eight-year-old Ashley has Down syndrome. Three-and-a-half-year old Amber was born with complications.

Eventually she was diagnosed with Lenz-Majewski Hyperostosis Syndrome, an extremely rare condition.

Amber spent her first three weeks in intensive care on oxygen and numerous medications.

While Amber was in the hospital, Tom or Lisa alternated spending the nights with her. Leslie and Gabe Giancola, Lisa’s parents, stayed at the Kimlinger home with Ashley.

Lisa said she remembers how relieved she felt knowing that someone was caring for Ashley, not to mention helping with laundry and other household needs, such as grocery shopping. The grandparents also fielded a multitude of telephone calls from the Kimlinger’s concerned friends.

Following the crisis at Amber’s birth, the grandparents continued their dependable support. They need it, Lisa and Tom acknowledge. The first three years of Amber’s life have been filled with medical appointments, therapies, surgeries, and uncertainty. While Amber has had a gastrostomy tube for most of her life, Lisa and Leslie recently discovered that Amber has severe food allergies. Now, to ensure Amber receives all of the nutrition necessary, Lisa must finely grind fruits, vegetables, and chicken to be administered through her gastrostomy tube every half hour. Lisa’s parents and Tom’s father Joe all feel comfortable helping with Amber’s feedings and jump in to help whenever necessary. Other time-consuming demands include coordinating appointments among 20 therapists for both children.

Tom and Lisa’s parents attend Individual Family Support Plan (IFSP) meetings, doctor appointments, and other activities with the Kimlingers. For example, when Tom and Lisa learned that Amber may lose much of her hearing and vision, they enrolled in sign language classes. Leslie and Gabe feel that communication is important

of children with disabilities

to Amber, so they joined the class too.

The grandparents also share in happy times and traditions. Ashley will soon participate in a first communion ceremony at the family's church, and all the proud grandparents will attend.

Joe, Leslie and Gabe provide a sense of security to her family, said Lisa. They are reliable. Tom and Lisa know their parents will be there when they are needed, even in the middle of the night.

Tom once telephoned his father at 2 a.m. "I can call at any time, and he listens," Tom said. Lisa said she experiences the same kind of support from her parents. She and her mother telephone or see each

other in person nearly daily.

As a break from their responsibilities at home, Tom and Lisa attend church and community activities. Being able to rely on child-care by the children's grandparents makes it possible, they said.

Joe, Leslie, and Gabe wouldn't have it any other way. Leslie repeats a lesson in support she learned from Gabe's mother. It is: "You are always a mother, no matter how old your children are."

For many families of children with disabilities, the adage may enjoy a twist: "No matter how old you are, you are your parents' child, and they are a source of support."

It's a relief to know there is someone on whom you can rely

Can friends and relatives help your family?

When friends and relatives ask how they can help, it is sometimes difficult for families to come up with a precise list. Michelle, Tom, and Lisa offered ideas:

1. Remember, little things mean a lot.

Michelle gratefully recalled that many neighbors have assisted her family. There is the person who cleared their sidewalk of snow; the neighbor who gave them plants and gardening tips when Michelle landscaped the home; and those who constructed a ramp for Miles's wheelchair.

Gifts of used items and equipment may also be welcome. Mary and Steve gave Michelle a computer when they purchased a newer model. Michelle also gladly accepted a neighbor's former set of dishes.

"You never know what may help the family," Michelle said.

2. Let the family give back, if they can.

Michelle says that her friendship with Mary works well because it is mutually beneficial.

3. Adjust your offer to meet the needs.

Relatives or friends may offer to watch the family's children so the parents can go out. For some parents, the offer can be a lifesaver. For others, however, leaving their child is stressful. Tom noted that, for a long time, he and Lisa were uncomfortable leaving Amber; they worried while they were away. Other options for

helping with childcare may include attending to the children while the mother reads a book or the parents indulge in a backyard ball game with their other children. Parents receive a break on such occasions, yet they are available to take care of emergencies.

4. Know the children and learn about their needs.

Now that Grandpa Joe Kimlinger is retired, he baby-sits for all nine of his grandchildren. He plays with Ashley for hours, even donning various hats and costumes for her entertainment. Leslie, Gabe, and Joe are comfortable caring for Amber and Ashley, because they took time to know the children's personalities and learn about their physical needs. The familiarity pays off if there are emergencies while baby-sitting, such as when Amber's feeding pump broke or the gastrostomy tube came loose. "When you have a child with special needs, you have to know what to do," Leslie said.

5. Be aware of services and support them.

Many families rely on government-funded services such as respite care and personal care attendants. Even with friends or relatives to help, the services are critical to families of children with disabilities. Tell legislators that you care about issues affecting children with disabilities.

Nurturing, belonging lead children v

By Susan Shogren Smith and Patricia Bill

The community, friends, and family sometimes see a child's disability rather than his or her many abilities. Attitudes of others affect how children view themselves, how they interact with others, and, ultimately, their expectations for success. It is important for parents to understand how general perceptions about disability affect their child so they can avoid or correct situations that may be negative.

Regardless of their specific needs, children with disabilities usually benefit when others treat them as much like typical children as possible. *All children need*

- nurturing and
- a feeling of belonging.

Knowing how to provide them for your child with a disability will go a long way toward helping him or her become a well-adjusted, successful adult.

Nurturing

Most children enjoy affection, such as hugs and hearing "I love you," from family and friends. The desire for trustworthy relationships begins in infancy. Dependable nurturing fuels a child's self-confidence and leads to independence and autonomy.

It is easy to be affectionate with a child who responds appreciatively. Some children with disabilities, however, do not have the physical ability to return smiles, embraces, or compliments. Others, with mental or emotional disabilities, may seem to discourage interaction. Despite behaviors resulting from their disabilities, the children need nurturing.

Frequent, positive communication is one way to nurture. When families and friends are patient and encouraging, they motivate the child to try to communicate. Enjoyable exchanges help children develop social skills and create mutually satisfying relationships with others. On the other hand, children sense others' frustration when attempts to communicate are not immediately successful. The result: they quit trying.

Going places? Here are travel tips for fam

By Susan Shogren Smith

Traveling with young children, whether they do or do not have a disability, can be challenging. When traveling long distances, planning ahead will help prevent frustration for all riders in the car. Consider the following tips as you plan your travels:

- 1. Consider the length of time your child tolerates being in the same position.** Children in car seats, especially if they are molded to a particular child, can become uncomfortable. If a child typically gets frustrated after being in the seat for an hour, don't expect their tolerance to suddenly increase for the trip. Remember your child expects you to anticipate his or her every need and respond accordingly.
- 2. Consider the time of day your child will be most likely to travel well.**

If you need to drive two hours, and your child normally takes a two-hour nap from 1 p.m. to 3 p.m., planning to travel during that time may make sense if your child will sleep in the car. Think about your child's dietary needs: Can she or he snack while riding or will you need to pull over regularly? (You may have better luck always pulling over for meals. Use these stops as an opportunity to stretch, change diapers, and use the bathroom to freshen up.)

- 3. Identify your child's favorite toys or activities.** At the beginning of the trip, try to let your child entertain him or herself and always save the best toys for last. If your child becomes bored with their options too soon, you may be in for some rough riding. Sometimes borrowing different toys from a friend may help also. The "new" toys may help ease the tedium of the trip.

with disabilities toward independence

Nurturing some children with disabilities takes time, a precious commodity for their families. Often, however, it is simple activities, such as reading a short story, singing a song, chatting in the kitchen, or taking a brief walk, that involve a child and satisfy a need for nurturing.

Belonging

When parents and others learn that a child has a disability, each person reacts differently. If the reaction is disappointment or dismay, it must be overcome to support the child and one another.

When family members and friends work together to help the child, they create an environment that tells the child he or she is loved, valued, and included. Inclusion (or belonging) is the safe foundation from which children eventually launch their independence.

Friends and relatives may inadvertently exclude children with disabilities by treating them differently than they do the other children in the family. Most children notice if an aunt has a pat on the shoulder

for the child in a wheelchair but hugs for the others. If grandparents take some siblings, but not others, on an outing, those who stay home feel left out.

Inclusion or belonging usually results when others are accustomed to a child with disabilities. Frequent contact and interaction with the child improves comfort levels and communication for both parties. For example, becoming familiar with a child's speech pattern may help friends and relatives better understand the communication efforts of a child with speech and language difficulties. Children with behavior challenges may relax and respond more positively toward people with whom they feel familiar and accepted.

Helping a child with a disability become part of the family circle, or the wider community, may seem to be a daunting task for parents. Nurturing and providing a sense of belonging, however, are simple and effective first steps toward the goal. Furthermore, there is a bonus: successful results last a lifetime.

Families of children with disabilities

4. Determine locations to stop along the route.

Plan your itinerary and stick with it. Look at a map and choose stop points for snacks, meals, bathroom breaks and stretching. You may need to pull off the road sooner, but try not to skip scheduled stops when things are going well. Once a child is frustrated, things can quickly go from bad to worse. If more than one child is along for the ride, one's problem will often escalate the frustration of another.

5. Identify who will sit closest to the child.

If your child needs a lot of interaction to remain entertained, plan on having an adult in the back seat, next to the child. An older sibling may be able to help out as well. Regardless of who sits by the child, if the helper begins to become frustrated or irritable, the younger child will surely sense it and be more likely to become upset as well. If possible, avoid

having two small children sit right next to each other. Listening to "I want that" or "He's touching me or my things" can become very upsetting very quickly.

6. Preparation is the key.

Plan to double your driving time: If it would take three hours without children, plan on six. If you arrive in four, you will be very happy.

7. Remember, the trip home may be difficult.

Everyone will be tired and the anticipation of going home is not always as motivating as a vacation or seeing friends and relatives.

Planning a trip or an outing may require extra effort from parents, but it may be worth it. Someday your child is likely to remember the event with fondness and nostalgia.

Want a repeat?

Past *Early Childhood* articles are available

Articles on varied topics of interest to parents of young children have appeared in Early Childhood Connection over the years. Some past articles may be of help to families of young children with disabilities who are new to early intervention services.

Parents wanting copies of articles (or handouts based on the articles) from the past four years are asked to call PACER Center.

Please state the name of the article and the issue that carried it.

“Choices: Opportunities for Life” (Book Review) - Fall 1996
Communication Techniques and Devices – Spring 1999
Computers Can Help Young Children – Winter 1999
Establishing Rapport with Physicians – Fall 1997
“Facilitating Hearing and Listening in Young Children” (Book Review) – Spring 1997
“Families are Important” (Book Review) – Fall 1997
Father’s Involvement is Important – Summer 1999
Financial Planning for Child’s Future – Summer 1998
Grandparents Can Help Families – Fall 1996
Grandparent Group; How to Join – Summer 1999
Hearing Screening for Newborns – Fall 1997
IDEA Part B regulations – Spring 1999
Interagency Coordinating Council Members – Fall 1997
Is Your Young Child Developing at a Normal Rate? – Summer 1997
Introducing Your Child to the Community – Spring 1997
Knowing the Disability Helps Your Child – Summer 1998

Minnesota Early Intervention Seeks Parent Involvement – Summer 1999
Parents are Welcome on IEICs – Spring 1998
Parents Can Influence Legislation – Summer 1998
Parents Find Support in Local Groups of Statewide System – Fall 1996
Planning Early Childhood Transition – Summer 1996
Precautions for Cold and Flu Season – Winter 1999
Reduced Stress Leads to Happier Families – Spring 1998
Simple, Inexpensive Devices Can Assist in Communication – Summer 1997
Speech Augmentative Devices – Spring 1999
SSI Appeal Rate Lower Than Expected – Fall 1997
State System for Intervention – Fall 1996
Summer Activities for Families – Spring 1999
Surviving a Child’s Death – Summer 1997
Take the ‘Scary’ Out of Hospitalization, Testing – Spring 1997
Talking the Talk: Learning the ABCs of Special Education – Spring 1998
Vulnerable Children (Abuse Prevention) – Summer 1996
Wheel Helps Mark Development – Summer 1999

Ask the Experts:

Accessibility – Spring 1999
Difference Between IEPs and IFSPs – Spring 1998
Therapy, But No Insurance – Summer 1999
Members of IFSP Team – Spring 1999
Scheduling IFSP Sooner – Summer 1998
Transition from IFSP to IEP – Winter 1999
Well-written Goals – Summer 1999

If you are not on the mailing list and would like to receive *Early Childhood Connection*, please call PACER at (612) 827-2966 or (800) 53-PACER. E-mail to pacer@pacer.org

Ask the experts:

A forum for parents of young children

Parents of young children with disabilities often have questions about the early intervention system. With help from PACER staff, Early Childhood Connection answers some of the questions.

My former spouse and I have joint legal custody of our son. We disagree, however, about appropriate services for our child. What are my rights?

When parents are divorced and have *joint legal custody* of a child who requires special education services, each parent retains the right to be informed of and to participate in meetings regarding special education.

The school district should provide both parents, at the same time, with a copy of the proposed Individualized Family Service Plan (IFSP) or Individual Education Program (IEP).

If parents agree with the proposed services, they should put their consent to proceed in writing within 10 days, and the district should implement the new IEP or IFSP as soon as possible.

If the parents disagree, but one parent is in agreement with the school district, the parent who agrees with the school can provide written consent to proceed with services. If the parent who disagrees with the proposal does not respond in writing, the district may proceed with the proposed program of services.

If one parent disagrees with proposed services and notifies the school district of their disagreement in writing, the child's current IFSP or IEP would remain in effect until the dispute is resolved. This is frequently referred to as "Stay Put".

At any point in the IEP or IFSP process, either parent or the school district may begin conflict resolution procedures. This includes conciliation, mediation, or due process.

I have an Individualized Family Service Plan (IFSP) team meeting coming up. May I bring a friend with me to the meeting?

Parents have the right to bring additional people to their child's IFSP or Individualized Education Program (IEP) meetings. Minnesota law says that when parents are notified of a meeting to develop, review or revise their child's plan, "the district shall inform the parents of their right to bring anyone of their choosing to accompany them to the meeting."

Parents should feel comfortable and confident at the team meetings, because they make important decisions about their child's future there. Examples of people who may be invited include a family member or friend, doctor or nurse practitioner, community therapists or a child care provider. These people can often provide insight into a child's development. It is common and appropriate for parents to bring other adults to their child's meeting.

To help maintain courteous, open communication, parents should always notify their service coordinator or case manager if they plan to bring additional persons to the meeting.

**Want info?
Visit PACER's
Web site at
www.pacer.org**

**To speak to
an advocate,
call Susan
Shogren Smith
(early childhood)
at PACER**

What is PACER?

PACER is a parent center for families of children with all disabilities: physical, mental, learning, and emotional. Based on a parents-helping-parents philosophy, PACER provides resources to help families make decisions about education and other services for their child with disabilities.



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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.

Workshops address families' questions

Among PACER's many services for families of children with disabilities or delayed development are workshops that feature experts speaking and exchanging ideas with parents about issues affecting young children.

The workshops are free to families and offers insight on varied topics.

To register for a workshop, call PACER at (612) 827-2966.

Upcoming workshops are:

- Dr. Lauren Wills addresses challenging behaviors in young children, May 11, from 6:30 to 9:30 p.m. at Hope Presbyterian Church, Richfield
- "Preparing Young Children for Transitions," May 23, from 6:30 to 9:30 p.m., at Hope Presbyterian Church, Richfield

Parents: Want a specific workshop?

PACER Center considers designing workshops, such as one on assistive technology or other topics, for families of young children with disabilities.

If you have a suggestion for a workshop topic, please contact Susan Shogren Smith, early childhood coordinator at (612) 827-2966 or (800) 537-2237 (in Minnesota).