

Early Childhood Connection

A Newsletter for Minnesota Families of Young Children with Disabilities

Fall 2001

Teddy's disability:

For his sisters, it's part of normal family life



By Susan Shogren Smith

When Teddy Spencer was born in 1989, 5-year-old Katie and 3-year-old Alison were thrilled. Their parents Ed and Val had prepared them for a new baby in the family, and the girls were ready to be big sisters.

The Spencers did not anticipate, however, that Teddy would have Down syndrome.

While Ed and Val processed the information after the birth of their son, Katie and Alison merely looked forward to Teddy coming home from the hospital. The terms "Down syndrome" or "disability" had meant nothing to them, said Katie and Alison 12 years later. To them, Teddy was like any other baby; they did not realize that their brother's special needs could affect their lives.

Their parents' honesty and candor about Teddy's health helped Katie and Alison understand and accept his needs, said the sisters.

Like many children with Down syndrome, Teddy had frequent chest colds and

coughing spells. Both girls remember Teddy struggling to breathe and their fears about his health.

"I didn't think of him as being sick because he had Down syndrome," Katie explained. "He was just my little brother who had problems breathing."

"Our parents knew it was scary for us so they made sure they always told us he was going to be okay. We learned about his medicine and the treatments he needed to get better," Alison added.

Throughout Teddy's life, the entire family has been involved in his care and development.

Katie and Alison remember the hours they

spent helping to teach Teddy to sit up and walk. They learned sign language to help him communicate.

"Our family took a sign class together, because Teddy had trouble talking," Katie explained. "We all had fun helping him learn to sign. He still uses his sign



To Katie and Alison Spencer, Teddy is simply their little brother. His disability, however, has taught them patience and understanding.

Tips for parents from siblings—
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Teddy's disability: For his sisters,

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language sometimes, but he doesn't need it anymore."

Their parents made sure the girls learned about Down syndrome and disability issues at a young age.

Alison, for example, attended a preschool that included children with disabilities. "When we were little, we always watched *Life Goes On*

because one of the [children] on the show had Down syndrome," she added.

The Spencers continue to participate as a family in activities that help Teddy. Now they are involved in Special Olympics, said Katie.

Alison and Katie agree that having a brother with a disability helped them become better people. They believe Teddy teaches them patience and understanding. Knowing they are important role models for him helps them be more responsible.

Teddy also teaches them about acceptance. "Teddy never cares what people look like. He wants everyone to get along," Alison explained. "I think about how he looks at life and wish I could be more like him."

Having a sibling with a dis-

ability sometimes affects their relationships with peers, the girls said. For example, they have learned to be sensitive to other people's feelings.

"Our mom really taught us to think about what we say and how our words affect people," said Alison.

"I think that was really important," Katie continued. "Sometimes kids will say things about people who have disabilities, not realizing I have a brother with Down syndrome. Even though their words are hurtful, I try to remember most kids don't think about the meaning of words they use. It's just slang to them. Teddy helps us know who is a really good friend. If it weren't for Teddy, most of them [the friends] would never know a person with a disability. Our close friends are great with Teddy. They accept Teddy, and he loves them."

In addition to teaching his sisters to be patient and understanding, Teddy has also taught them to have fun. Teddy loves people, and he loves doing silly things, they said.

On the other hand, Katie and Alison have learned to be careful of what they teach Teddy. They gave an example. One evening at home the three had a burping contest. The girls thought it was funny—until Teddy continued the contest at school. He sometimes does not un-

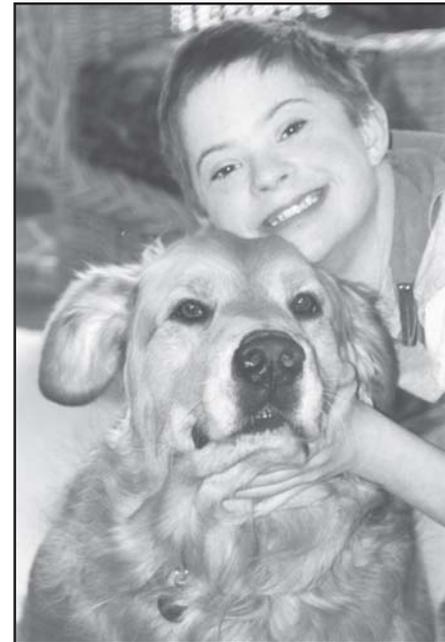


Katie and Alison apply the sensitivity they've learned to their relationships with peers.

Young children accept disabilities

Early childhood experts say that because young children often have limited experience with any babies and typically have no preconceptions about disabilities, they often will be very accepting and matter-of-fact about a baby's special needs.

While parents may react to the child's disability—or even struggle with the possibility that the baby could die—young children just want to see the baby or have their new sibling home to hold.



Katie and Alison help Teddy learn "the rules" and that what is okay in one setting may not be in another.

it's part of normal family life

derstand that what is “okay” in one place may not be in another, they explained. Increasingly, Alison and Katie realize that throughout their lives they will help Teddy learn the rules.

Disability experts note that siblings often take responsibility for protecting a child with a disability. The Spencer girls are no exception. As they grow older, both Katie and Alison think about the future.

“It scares me sometimes—to think about what Teddy will do. He’ll say ‘I’m going to drive when I get older,’ or [he will] talk

about living on his own, and I wonder if he’ll be able to do these things,” said Katie. The girls also are concerned about how people will treat Teddy.

Whatever their questions or concerns, Alison and Katie rely on the precedent their parents set when Teddy was a baby.

“We are glad we can talk openly with our parents about the issues,” they said. —*Susan Shogren Smith was employed by the Spencer family when the children were younger. Former PACER staff member; she is now in law school.*

Questions
on sibling
relationships?
Call PACER at
(952) 838-9000

Tips for parents from siblings’ viewpoints

1. Provide honest communication about the disability and issues related to it.

“I’m really glad our parents were so open with us about things that happened to Teddy,” Katie said.

“They explained why he was sick or why he couldn’t do things other kids his age did. They didn’t just say he has Down syndrome. They gave us real information in words we could understand.”

2. Include the child in activities at home and in the community.

The Spencers include Teddy in their activities as they would any family member, and they participate as a family in events, such as Special Olympics, that pertain to him.

“When I think about Teddy, I don’t think about him having Down syndrome,” said Alison. He is just my brother. Teddy has Down syndrome, but that doesn’t change how he fits in our family.”

3. Teach your children to accept their sibling with a disability, but encourage them to help the child to reach his or her potential.

The Spencer family expects Teddy to accomplish things within his ability—as soon as he is able to do them.

“Having Down syndrome isn’t an excuse for Teddy to not have any responsibilities,” Katie explained. Alison added: “Our parents taught us about Teddy’s disability but always made sure that Teddy was expected to do everything he could.”

4. Remember that as parents, you are the model for how others will treat your child with disabilities.

Katie and Alison said they have deep respect for how their parents handle issues related to their brother’s disabilities. The sisters’ love and respect for Teddy reflects that of Ed and Val.

Watching their parents seek services for Teddy has helped Alison and Katie understand the need for advocacy, they said. The Spencers have taught the girls to have high expectations for the people who work with Teddy, as well as for Teddy, himself.

As a family, the Spencers work together to ensure that Teddy has as many choices and opportunities as possible to be independent.

The early intervention framework: c

Parents and advocates from other states often tell PACER Center staff that they envy Minnesota's interagency early childhood intervention system, which helps young children with disabilities or delays. Many say the Minnesota system is excellent because parents and state and local professionals work together to develop policy and plan services.

Although the local Interagency Early Childhood Intervention Committee (IEIC) is the part of the system most familiar to Minnesota families, it may be helpful for parents to see how IEICs fit into the overall picture.

Following is a look at how Minnesota's interagency early childhood intervention system is organized, including contacts for Minnesota parents who wish to share their ideas. For more information about Minnesota early childhood intervention and links to other organizations and government offices, visit the PACER's Web site at www.pacer.org or the Children, Families & Learning (CFL) site at <http://children.state.mn.us/ecfi/partc.htm>.

U.S. Congress

Federal law provides a free, appropriate, public education for children with disabilities through the Individuals with Disabilities Education Act (IDEA). The IDEA has a section (Part C) that focuses on young children, under age 3, and their families. Parents may contact their U.S. senators and representatives about early intervention and special education policy issues.

U.S. Department of Education

The U.S. Department of Education puts the IDEA into action, and it funds related programs, including those affecting young children with disabilities or delays. The Office of Special Education and Rehabilitative Services (OSERS) and one of its divisions, the Office of Special Education Programs (OSEP), work directly with states on special education. Information about OSERS and OSEP is on the Internet at www.ed.gov/offices/OSERS/.

Minnesota's Early Intervention System

Appointed groups oversee the system that serves Minnesota's young children (birth to age 5) with disabilities and their families. CFL is the lead state agency that administers, supervises, and monitors early childhood intervention programs.

State Agency Committee (SAC)

The commissioners of the Minnesota agencies of Health, Human Services, and CFL appoint representatives of their respective departments to serve on the SAC. The SAC determines the policy, direction, and leadership for the state's interagency early childhood intervention system.

State Early Intervention Team (SEIT)

The State Early Intervention Team (SEIT) carries out the plans made by the SAC. The SEIT includes staff from the Minnesota Departments of Health, Human Services, and CFL. Members of the SEIT, with direction from the SAC, develop policy and provide technical assistance to local IEICs to assure appropriate early childhood intervention services.

For information...

For information about Minnesota's early childhood intervention system, parents can call:

Minnesota's Early Childhood Intervention Information and Referral at (651) 215-8956 (Metro area) or (800) 728-5420 (Greater Minnesota);

PACER Center at (952) 838-9000 (Metro area), or (800) 537-2237 (Greater Minnesota).

The Governor's Interagency Coordinating Council (ICC)

All states receiving federal funds under Part C of IDEA, including Minnesota, must have an Interagency Coordinating Council (ICC) appointed by the governor. The ICC makes recommendations to the governor, the legislature, and the state agencies serv-

Coordinated to serve families

ing infants and toddlers with disabilities and their families. The recommendations are made to ensure a coordinated state and local early childhood intervention system. At least 20 percent of the council's members must be parents who have children with disabilities ages birth to 12 years.

Interagency Early Intervention Committees (IEICs)

Interagency Early Intervention Committees (IEICs) are local coordinating councils made up of parents and representatives of the school district, other agencies, service providers, and county government. They plan and coordinate their community's system of early intervention services. There are 96 IEICs across Minnesota.

IEICs were established in 1985, when the Minnesota Legislature mandated that local communities work together to better address the needs of children with disabilities, ages 3 to 5 years, and their families.

State law now provides for children from birth to age 5 and their families.

IEIC responsibilities are broad. They include identifying infants and young children with (and at risk for) disabilities in the community, creating plans to serve them and their families, developing policy, allocating funds, and other tasks.

Parents are invited to participate in their local IEICs. The IEICs offer parents an opportunity to learn about and affect Minnesota's early intervention system. Each IEIC has a family support subcommittee of which most of the members are parents. The family support subcommittees plan activities, such as individual parent support, support groups, family events, newsletters, and resource libraries.

For information about how to contact their local IEIC, parents may call Minnesota's Early Childhood Intervention Information and Referral (see page 4), PACER Center, or the local school district's special education director.

Here's who to call:

The Governor's Interagency Coordinating Council (ICC)

Chair: Wes Mattsfield, Esko
Parent Rep.
(218) 879-3321

Vice chair: Judy Swett, St. Paul
Parent/Advocacy Rep.
(651) 645-2291

Rep. Jim Abeler, Dist. 49A,
Minnesota House Rep.
(651) 296-1729

Lois Engstrom, Early Childhood and Family
Initiatives
CFL Rep.
(651) 582-8345

James R. Huber, Continuing Care
Dept. of Human Services Rep.
(651) 582-1806

Mary Jungwirth, Countryside Public Health,
Benson
Public Health Rep.
(320) 843-4546

Diane Landwehr, Janesville-Waldorf
Pemberton Schools
Public Provider Rep.
(507) 234-6360

Veneta Lykken, Minneapolis
Parent Rep.
(612) 822-9399

Mary McEvoy, University of Minnesota
Institute of Higher Learning Rep.
(612) 626-7819

Linda Nelson, Early Childhood Services
Center, Maple Grove
Public Provider Rep.
(763) 315-7402

Deb Niedfeldt, Arc Olmsted, Rochester
Parent Rep.
(507) 287-2032

Barbara O Sullivan, CFL
Child Care Rep.
(651) 582-8422

Sen. Julie Sabo, Dist. 62
Minnesota Senate Rep.
(651) 296-4274

David Sanders, Hennepin Children and
Family Services Rep.
(612) 348-2102

Sandy Simar, CFL
Head Start Rep.
(651) 634-2203

Sarah Thorson, MN Children with Special
Health Needs
Dept. of Health Rep.
(651) 281-9992

Barbara Troolin, South Washington County
Special Education
MN Association of Special Education Rep.
(651) 458-6670

State Early Intervention Team (SEIT)

Department of CFL

Lisa Backer – (651) 582-8473
Michael Eastman – (651) 582-8343
Jan Rubenstein – (651) 582-8436

Department of Health

Alice Engelhardt – (651) 281-9989
Lois Harrison – (651) 281-9896
Lola Jahnke – (651) 281-9999

Department of Human Services

Sue Benolken – (651) 582-1886

Interagency Early Childhood Intervention Support Staff

Dorie Dahlberg, CFL – (651) 582-8438

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

Part C of IDEA to be reauthorized

Congress plans to reauthorize, or update, parts of the Individuals with Disabilities Education Act (IDEA) in 2002. The IDEA provides special education services to children with disabilities.

In preparation, Robert Pasternack, assistant secretary of the U.S. Department of Education's Office of Special Education and Rehabilitation Services, conducted an October forum at PACER Center. Parents of children with disabilities, special education professionals, and other interested persons from across Minnesota and the Midwest shared their IDEA-related concerns and successes.

Comments from several parents of young children praised the services their children have received through the IDEA, Part C.

One parent said, "IDEA works." When her child was born, she and her husband were told their son would never walk or talk. With services she sought through the school district under IDEA, she has hope that her son, now 3 years, will do both.

In Minnesota, the IDEA serves children

from birth to age 22. Part C affects young children birth to 3, and Part B affects school-aged children. Part C is scheduled for reauthorization. Part B is permanently authorized, but it can be amended, which would affect children with disabilities covered by that section of the law in the future.

Some members of Congress want to change Part B in ways that parents and advocates believe would damage the education rights of children with disabilities. At issue is IDEA's discipline clause, which provides a free, appropriate public education to all children with disabilities, including those suspended or otherwise excluded from school. Parents and advocates say that to have children at home or on the streets without an education does not benefit children or society.

Other Part B issues of concern involve reimbursement of litigation fees to parents winning court cases related to the IDEA and public school obligation when a child transfers to a private school designed to serve children with disabilities.

Hoffman heads PACER's early childhood project



John Hoffman

John Hoffman has joined PACER Center as coordinator of its Early Childhood project. The project offers individual information, workshops, and publications to Minnesota families who have questions

about their child's development or are parents of infants, toddlers, and preschoolers with a disability.

"I'm delighted to be at PACER and to have the opportunity to help parents learn about resources for their young children

and themselves," said John, the father of a four-year-old daughter with spina bifida.

John, who grew up in Watertown, Minn., is experienced in serving young children with disabilities. At the Iowa Department of Human Services he provided technical assistance to Part C (affecting infants and toddlers) of the Individuals with Disabilities Education Act (IDEA). While at the Iowa department, John served on several statewide groups working on issues affecting children with disabilities. John has also worked in juvenile justice and residential services.

To contact John, call (952) 838-9000 (voice), (800) 537-2237 (toll-free in Greater Minnesota), or (952) 838-0190 (TTY).

A Book Review

You Will Dream New Dreams

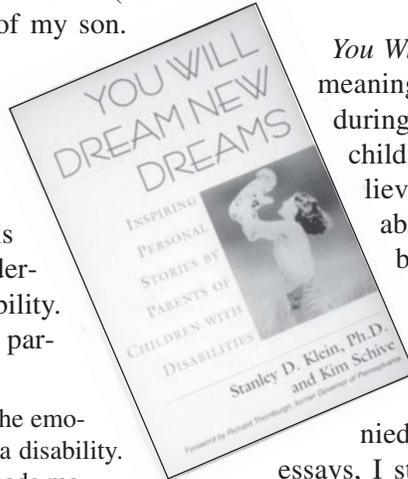
By Julie Hertzog

You Will Dream New Dreams, by Stanley D. Klein and Kim Schive, is exactly the kind of book I have wanted to read (and read again) since the birth of my son.

The book contains more than 60 brief essays written by parents of children with disabilities. The writings reflect the parents' emotions when their child is born or when they first understand their child has a disability.

The book is valuable for parents in many ways:

- The book focuses solely on the emotions of having a child with a disability. It made me sad, and it also made me smile.
- It is parents' perspectives—there is no “professional” judgment or advice.
- The writing is gritty and real; the stories are authentic.
- The content stresses the importance of parents trusting their instincts and understanding that they know their child better than anyone else.
- Many of the authors emphasize the importance of connecting with other parents.
- Parents can read one or all of the essays. The



book is a quick and easy read. In each story, a parent can see part of his or her own life.

- There are many wonderful quips and quotes that I will remember and use.

You Will Dream New Dreams will be meaningful to parents at any time during their journey of rearing a child with a disability, but I believe it would be especially valuable a year or two after the birth or diagnosis. Time provides experiences. The book evokes memories of those experiences and validates the feelings that accompanied them. While reading the essays, I stopped often to reflect, “Yes, that’s the way it was.”

You Will Dream New Dream is published by Kensington Books, 850 Third Ave., New York, NY 10022 (www.kensington.com). PACER has some copies for sale at \$13, plus postage and handling. To order, parents may call PACER at (952) 838-9000 (metro area) or (800) 537-2237 (Greater Minnesota).

Julie Hertzog, publications coordinator at PACER, is the mother of 5-year-old David, who has Down syndrome.

To contact
PACER, call
(952) 838-9000
(metro)
or
(800) 537-2237
(Greater Minn.)

PACER has a group for grandparents

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

The group meets monthly September-May at PACER in the Twin Cities. The meetings include informative programs and an opportunity to meet others who have grandchildren with special needs.

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 _____

- Add my name to the mailing list I wish to talk to another grandparent
- I wish to attend a support group I wish to attend a workshop
- I wish to start a support group in Greater Minnesota or another state



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8161 Normandale Blvd.
Minneapolis, MN 55437

(952) 838-9000 (Voice)

(952) 838-0190 (TTY)

(800) 53-PACER (Greater Minnesota)

(952) 838-0199 (Fax)

pacer@pacer.org (E-mail)

www.pacer.org (Internet)

PACER Executive Director:

Paula F. Goldberg

Early Childhood Coordinator:

John Hoffman

Editor:

Patricia Bill

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.

PACER plans IIP workshops

Minnesota has a new state law that requires, with parent permission, an Individual Interagency Intervention Plan (IIP) for children with disabilities receiving special education services from more than one public agency.

In the past, if a child received services from more than one public agency, each of those agencies met with the family to develop its own written service plan.

With the IIP, special education staff, county social workers, public health nurses, and/or other service providers now coordinate to meet with parents at one time to develop one written plan for the child and family. The plan includes both school district and county services.

PACER Center plans workshops to help parents understand the IIP concept. A workshop is scheduled for early February at PACER Center. Parents can call PACER for information.

To request a workshop in other Minnesota areas, call PACER.

Is your child growing up?

If your child is older than 5 years, *Early Childhood Connection* may no longer be of interest to your family. Please call PACER if you wish to be taken off the mailing list.

If you know a family who would like to receive the newsletter, please call PACER with the name and address.