

Early Childhood Connection

A Newsletter for Minnesota Families of Young Children with Disabilities

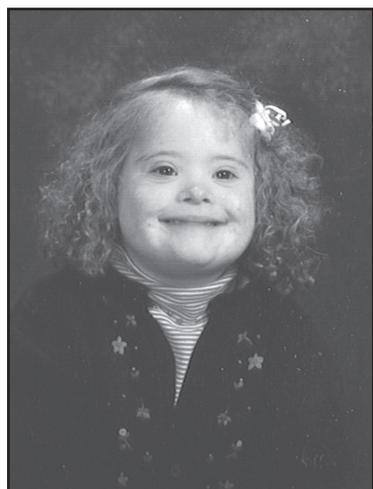
Winter 2005



Rooting for the (Medical) Home Team

The “medical home” team is a new approach that provides high-quality, family-centered health care services to children with chronic health needs.

When Alaina Butcher, now 4 years old, was born prematurely and with complex health needs, her parents faced challenges from the health care system they thought would help them. As Jenny and Kevin Butcher of Watertown, Minn., learned how to provide complicated care for their new baby, they



Hope Salonek is all smiles. She and her family benefit from receiving family-centered health care services.

found they also needed to understand medical jargon, juggle appointments with specialists, and navigate roadblocks to Alaina’s care. Chief among those roadblocks were a lack of coordination among the baby’s physicians and the failure of some in the medical community to recognize the family as partners in their daughter’s care.

Therese and Ted Salonek of Montrose, Minn., had similar difficulties when their daughter, Hope, now 8, was born with Down syndrome and medical needs. Though many of Hope’s health care issues are now resolved, Therese remembers how difficult their experiences were. Serving children with chronic health needs in traditional clinic settings is like “fitting square pegs in round holes,” she said.



Things are looking up for Alaina Butcher, thanks in part to the Minnesota Medical Home Project.

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What Is Family-centered Care?

Family-centered care refers to services that are delivered in a way that respects the central role of the family as caregiver, advocate, and decision maker for the child. It represents a change from the traditional approach of providing services and is built on a foundation of collaborative relationships between families and professionals.

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Rooting for the (Medical) Home Team

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The Butchers and the Saloneks both wished they could do something to help improve the system and make life easier for other families who have children with chronic health needs. Then, their pediatrician asked them to participate in something called the Minnesota Medical Home Project. The year-old effort is part of a medical home grant through the Minnesota Children with Special Health Needs program at the Minnesota Department of Health.

The grant, provided by the federal Maternal and Child Health Bureau, helps 11 medical-home teams based in clinics across the state. Its purpose is two-fold: 1) to improve the quality of care provided to children with special health care needs and disabilities at local clinics; and 2) to discover how the medical home concept can bring comprehensive and competent care to all children.

The two families began to learn more about the project. A “medical home,” they discovered, is a way to provide high-quality, family-centered health care services. It is an approach where the primary care doctor, a clinic care coordinator, and the family have a trusting relationship. They work together to coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child and family.

The project was just the kind of opportunity the two families sought. Their pediatrician, Dr. Kathy Sweetman at Lakeview Clinic in Watertown, leads one of the 11 medical home teams. Jenny Butcher and Therese Salonek were happy to join.

Sweetman’s team began with three goals:

- 1) To help families feel supported in the medical arena, especially families that need to see their doctor often because of their child’s chronic illness;
- 2) To improve collaboration among the child’s medical professionals, school, and community; and



Dr. Kathy Sweetman leads one of the 11 medical home teams in Minnesota. One of its goals is to improve the quality of care for children with special health care needs and disabilities.

- 3) To connect families to resources within their communities.

Soon, the team invited Kate Fasching, an early childhood special education teacher in the Waconia school district, to join them. Fasching had just finished a paper on medical home and family-centered care issues for her master’s degree. Team members liked the idea of connecting the medical team and the school. It provides better care and services to the child, Fasching explained.

“I feel that often we are not catching developmental delays in children early enough,” she added. “Sometimes, their delays are not discovered until their preschool or kindergarten screening. The medical home is not about saying that someone isn’t doing their job, it’s about what is best for the child and the child’s family, and how we can diagnose disabilities at an earlier age.”

Through the broad expertise of its members, Sweetman’s team is achieving impressive results. They have created everything from comprehensive

records, to conferences, to support groups. Among their achievements:

- **Shared records.** The team developed a system to include all of the child's records—from the doctor's office to the school and beyond. The combined record can be copied for all the child's service and medical providers. It includes information on specialists, their phone numbers, and diagnoses made. This information is especially important when a child's medication changes frequently, said Sweetman. Eventually, the paper record will be transferred to a computer system, so it can be easily updated and sent electronically to all service providers upon the parent's request.
- **User-friendly clinics.** The team worked to make the Lakeview Clinic more user-friendly. Parents of children with chronic needs used to call the clinic, then wait for staff to pull the child's record before they received a response from the doctor. Now, clinic staff immediately transfers them to their child's doctor or nurse to see if the concern can be addressed over the telephone. "This was suggested by the parents on the team and has proved to be a very patient-friendly move," Sweetman said.
- **Family-centered care approach.** The team also worked to improve the family-centered care approach of clinic staff on the telephones. Training included teaching them what kinds of questions to ask the parents when they call.
- **Conference for physicians and the community.** To help physicians better identify developmental delays in some children, the team will conduct a conference for physicians and the community this spring. It will include speakers on early intervention, screening tools, problem-solving techniques, and discussion about compensation—who is going to pay for the medical home and services.



Kate Fasching is an early childhood special education teacher and member of Sweetman's medical home team. Linking the medical team and the school provides better care and services to the child, she says.

In the months ahead, the team also plans to reach out in other ways. They expect to develop printed handouts and brochures on the medical home approach, what it means to the community, and how physicians can practice it. They also want to find ways to connect children with special health needs to community resources, including county and other professionals who can provide needed services to families and children. Other plans include creating support groups for families of children with disabilities and developing better collaboration between the doctor's office and the school.

Team members are pleased with their efforts. Jenny Butcher sees having a computerized care plan for Alaina as a major benefit. Having her daughter's comprehensive records—from information about the family's insurance, to Alaina's allergies, to procedures to avoid—will take much anxiety out of emergency trips to the clinic or hospital, she said. Both mothers said direct access to the physician or nurse will improve care to children.

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“We do not have our care plans working perfectly,” Sweetman noted. “They require many hours and continuous correction, but we have made significant progress.

“I so appreciate the parents’ perspective,” Sweetman added. “It has not been an easy thing to

do. Change never is, but it has been a very rewarding experience and one that will greatly improve the quality and continuum of care that a child receives in the future.”

Did You Know...

The American Academy of Pediatrics (AAP) promotes the medical home approach. It encourages the idea of care that is accessible, family centered, continuous, comprehensive, coordinated, compassionate, and culturally effective. Lack of communication and coordination led the AAP to develop medical home initiatives and *Standards of Child Health Care*, a resource that is still used today.

What Is Family-centered Care?

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Positive collaborative relationships develop as parents and professionals demonstrate their mutual trust and respect, and clarify what they can expect from each other.

Family-centered care:

- promotes a relationship in which family members and professionals work together to ensure the best services for the child and family;
- recognizes and respects the knowledge, skills, and experiences that families and professionals bring to the relationship;
- acknowledges that the development of trust is an integral part of a collaborative relationship;
- facilitates open communication so that families and professionals feel free to express themselves;
- creates an atmosphere in which cultural traditions, values, and diversity of families are acknowledged and honored;
- recognizes that negotiation is essential in a collaborative relationship; and
- brings the mutual commitment of families, professionals, and communities to the relationship, to help children with special needs and their families.

(PACER Center suggests checking with your insurance provider to see if these services are covered benefits for you.)

Adapted from Family Professional Collaboration for Children with Special Health Needs and Their Families, 1993, by the Family/Professional Collaboration Project, Department of Social Work, University of Vermont.

A Family-centered Approach to Care Coordination

Barb Peterson is an expert on children with special health needs. She is a pediatric nurse practitioner, a care coordinator, and the parent of a young adult with a disability. In her job with U Special Kids, a University of Minnesota program that provides family-centered care coordination for medically fragile children, she uses knowledge from all three roles.

At U Special Kids, Peterson provides care coordination and comprehensive medical summaries for families of children experiencing complex health issues and special health needs. Her focus is on guiding clear and frequent communication among the family, medical specialists, community health care providers, educators, and others. She shares these thoughts on care coordination.

“Care coordination involves a broad array of activities that support children and their parents and caregivers, so that the physical, emotional, and psychosocial needs of the child are met,” Peterson said. She assists families with day-to-day problems and illness management to help avoid hospital admissions and prolonged stays. In addition, Peterson and her colleagues are alert to mental health issues, and they connect families to appropriate resources, as needed.

Care coordination is different from case management, Peterson noted. Case management is traditionally more limited than care coordination, she explained. Often a child may have a case manager in each of the systems providing care—education, social service, and insurance, for example—but the systems may be fragmented if the child does not have a care coordinator.

At its best, care coordination frees the child and family to participate in their home, community, and family activities to the greatest extent possible, Peterson said. In family-centered care, which



Pediatric nurse practitioner Barb Peterson

respects the central role of family as parents, caregiver, advocate, and decision maker for the child, care coordination is vital.

A goal is to have parents become confident in making decisions about their child’s care. “Family members are assisted in developing advocacy skills so they can be active participants in advocating for the care of their child across settings and among service providers,” said Peterson.

“Parents, caregivers, and family members know their child best, and they are the key members on the care coordination team,” she continued. “A family-centered focus is imperative so that the needs of all the family members are considered. This way, the highest level of health can be promoted.”

In addition, a care coordinator can:

- Assist parents and professionals in negotiating who will coordinate specific tasks in the child’s care as needs and resources change.
- Anticipate needs so that mothers and fathers have time to “parent,” as well as provide care.
- Understand each family’s history, culture, and individual needs, so that the family receives sensitive, culturally competent care.
- Incorporate care appropriate to the developmental stage of the child and family.
- Help family members understand the systems involved in their child’s care and find ways to communicate their preferences to professionals.

“There is no one method that works for all families or for any one family all the time,” noted Peterson. “Coordinated care needs to be individualized for each child and family situation.”

See page 8 for information on the IIP and coordination of services among schools and public agencies.

Meet the Staff: Carolyn Allshouse

Through PACER's Health Information and Advocacy Center, she helps parents find a voice in the health care system.

When families talk with Carolyn Allshouse, the first thing they may notice is her voice. It is warm, calm, strong, clear. When she speaks about children with disabilities and the challenges they can face in the health care system, it grows rich with a passion born of both professional training and personal experience. When she talks about the role families can play in their child's health care, it is clear that she wants parents to have a strong voice, too. In fact, it is her mission.

As the coordinator of PACER's Health Information and Advocacy Center, Carolyn helps families and health care providers understand how collaboration can create effective, family-centered care for children with disabilities or special health needs. "Families should have a voice in how programs for their child are designed, implemented, and evaluated," Carolyn said. "I assist families in how to use their insurance effectively, file appeals, and understand their coverage. I also help physicians understand the benefits of family involvement and partnership. I really support the goal of families being educated health consumers.

"Every family has strengths," she added. "Even when it's not necessarily obvious, they do. What they may lack is the tools to navigate the system. I help families find useful tools and support so they can advocate for their child."

Carolyn has spent more than 15 years as an advocate for family-centered care—starting with her own family. Her son, Jack, now 19, was born with multiple complex health conditions and is medically dependent on technology. "When Jack was around 10 years old, he developed an acute medical condition," she recalled. "The problem grew worse because the pediatrician didn't take our concerns seriously, and Jack ended up in the hospital. That was when we knew we needed to find a new doctor.

"We started asking parents and hospital staff for recommendations. We asked *why* they were recommending that particular person. Then we



Carolyn Allshouse has been involved in health care information and advocacy for several organizations.

interviewed five pediatricians. We told them we were looking for someone who would work in partnership with us and share decision-making about Jack's care. Through that process, we found our current pediatrician. He works with us as a colleague. I've been able to see the value and benefit of this collegueship for my child. It has made all the difference."

Through all the ups and downs, challenges and achievements, Carolyn has developed a warm compassion for families dealing with a child's complex health issues. "Not every family is at a place where they can be a good advocate," she said. "Families have to be supported. They may set different priorities at different times. Maybe they choose to advocate in the education system right now, but not the health care system. We have to be kind to ourselves and do what we can do." When families are ready to advocate in the health care system, Carolyn is ready to help.

For more information, call Carolyn at (952) 838-9000 or (800) 537-2237, or visit www.pacer.org.

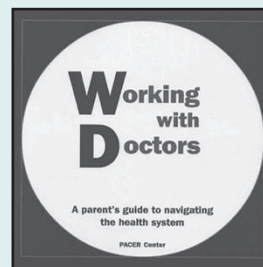
Parents Can Help Expand the Medical Home Concept

Parents who are interested in the idea of a “medical home” for their child can help promote such an environment. That is true even if they are not part of the Minnesota Medical Home Project (see page 1).

Creating a “medical home” for a child with special health care needs takes time and effort. Parents need to find a pediatrician who is willing to partner with them as a colleague. Fortunately, resources and support are available to help parents find such doctors and learn how to develop a cooperative relationship with them and other health care providers.

Working with Doctors: A Parent’s Guide to Navigating the Health System offers specific tools and advice on how to choose and work with a pediatrician to help encourage family-centered care. The booklet, published by PACER Center, includes:

- basic information on finding a health care provider that will work with you and your child;
- practical ideas for interacting with doctors, clinics, and other family members;
- an appendix with valuable forms that can help you organize information. These include an emergency information form and a sample Individual Health Plan form.



The booklet is available in English and Hmong. A Spanish version will be available soon. Minnesota parents of a child with a disability may receive one free copy. For professionals, the cost is \$8.

To order, visit www.pacer.org and select the “publications” link, or call PACER Center at (952) 838-9000 (voice); (800) 537-2237 (toll free); or (952) 838-0190 (TTY).

PACER Resources

PACER Center provides a wide variety of resources for families of children with disabilities. Here are some publications that may be of interest:

Families are Important: An Early Childhood Guidebook for Families of Young Children

This guide helps families of children with disabilities or delayed development understand Minnesota’s early intervention system and how to obtain services for their child.

Choices: Opportunities for Life

This offering suggests how parents can help their young child with disabilities make choices. Illustrated. English.

Family Strengths Series

The five booklets in this series teach and encourage parents of young children (birth to age 5). All are simply worded and beautifully illustrated with photos of children and families of various ethnic and cultural groups. 2000. Also available in audio tape. English, Hmong, Spanish. The five booklets are:

- Lovable Me! A Guide to Your Baby*
- Lovable Me! A Guide to Your Preschooler*
- Lovable Me! A Guide to Your Toddler*
- I Am My Child’s First Teacher*
- My Child Has a Disability*

Visit www.pacer.org for ordering information or to sign up for one of PACER’s newsletters, or call PACER Center at (952) 838-9000.



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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 (Web site)

PACER Executive Director:
Paula F. Goldberg

Early Childhood Coordinator:
John Hoffman

Editor:
Marcia Kelly

Designer:
Elizabeth Timmons

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IIP Coordinates Services Among Schools and Public Agencies

The articles in this issue of *Early Childhood Connection* focus on coordination of health care services. Did you know that the education system also offers a service to coordinate efforts among schools and public agencies?

The service is from a state law and is called the Individual Interagency Intervention Plan (IIP, pronounced “triple-i p”). It is available to children with disabilities and their families who receive special education services (from schools) and services from at least one other public agency.

The IIP is both a process and a document. The *process* is an option. Everyone who provides services and supports can be at the same table with you to solve problems, coordinate services, and share resource information. The *document* is a standardized form that contains all the elements of the Individualized Family Service Plan (IFSP) or the Individualized Education Program (IEP) plus parts of other agencies’ plans. It replaces the other individual plans.

For more information on IIPs, call Barb Ziemke at PACER Center, (952) 838-9000 (metro) or (800) 537-2237 (Greater Minnesota). You can also find information at www.pacer.org.