

**Family Voices of Minnesota is a network of families whose children, youth and young adults have special health care needs or disabilities.**

Family Voices of Minnesota:

- Assists families in navigating systems of care
- Assures the voices of families are included in program and policy development, implementation and evaluation



# Family Voices MN

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## Notes from the Executive Director

**In 1989** as the parent of a then 4 year old with multiple and complex health care needs I had the opportunity to attend the Association for the Care of Children's Health National Conference. I have never looked at health care in the same way.

At that conference I heard a presentation by Dr. Bill Schwab titled, "Family-Centered Care 101", at which he posed the question, "Is patient and family-centered care (PFCC) an evolution or revolution?" Is it a revolution indicating that health care before patient and family-centered care was all wrong and required a complete overhaul or is PFCC the natural and logical next step in health care? Perhaps it is a little of both.

There were a number of dedicated families and health providers along with a few organizations and agencies that were instrumental in bringing patient and family-centered care to healthcare in Minnesota.

In 1989 staff from Children's Hospitals and Clinics of Minnesota gathered a few families together to form the first hospital Parent Advisory Committee in Minnesota. This committee was one of a handful across the country at that time serving as advisors to the

administration of the hospital.

In the early 1990s Family Voices of Minnesota was established as part of the national Family Voices network and began to work on promoting the concepts of PFCC, especially in the area of parent involvement. This included working with staff from the department of Pediatrics at the University of Minnesota to begin the Parents as Teachers program. This was the first program in the country that provided the opportunity for pediatric residents to visit and learn from families of children with special health care needs and disabilities in their homes.

Family Voices of Minnesota representatives also worked with Children's of MN medical education staff to begin the Parents as Educators program at Children's, which was an opportunity for families to talk with medical students and residents once a month about their experiences caring for their children with special health care needs.

During this same period of time the Minnesota Chapter of the American Academy of Pediatrics (AAP) invited parents from Family Voices of MN and a parent and staff representative

from the Minnesota Children with Special Health Needs (MCSHN) program at the Minnesota Department of Health to serve as ex-officio members of the children with disabilities sub-committee. This model partnership was one of the first of its kind in the country. In addition MCSHN sponsored a quarterly newsletter for pediatricians that included articles written by families side-by-side with articles written by pediatricians.

These are a few examples of how PFCC began in Minnesota. This Family Voices of Minnesota newsletter includes a number of short articles about the history of PFCC and a more detailed look at what it means.

Whether it is a revolution or an evolution - improvements and reform in the health care system will ultimately come from patients, families and health providers working together as colleagues, which is the foundation of patient and family-centered care. Family Voices of Minnesota will continue to be a leader in this revolution.

Carolyn Allshouse  
Executive Director

FAMILY VOICES<sup>®</sup>  
of Minnesota

# What is Patient and Family-Centered Care?

Patient-and-Family-Centered Care is the standard of practice which results in high quality services.

*Institute for Patient and Family-Centered Care*

Over the past 30 years significant work has been done to develop and research the core concepts and principles of patient-and-family-centered care.

Much of that work has been conducted by the Maternal Child Health Bureau, The Institute for Patient and Family-Centered Care and National Family Voices.

The different methods of explaining the concepts of patient-and-family-centered care complement each other, and have equal value.

Patient-and-Family-Centered Care assures the health and well-being of patients and their families through a respectful patient/family-professional partnership.

It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship.

Patient and family-centered care practices include **how** the patient and family are involved in individual care, but also **how** patients and families are involved in program and policy development, implementation and evaluation.

## Principles of Patient and Family-Centered Care

An approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.

*Institute for Patient and Family-Centered Care*

The foundation of patient and family-centered care is the partnership between patients, including children and their families, and professionals. This partnership is based on the following principles:

- Patients, families and professionals work together in the best interest of the patient and the family. As a child grows, s/he assumes a partnership role.
- There is respect for the skills and expertise everyone brings to the relationship.
- Trust is acknowledged as fundamental.

- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is willingness to negotiate.

Based on this partnership, patient and family-centered care:

1. Acknowledges the family as the constant in a child's life.
2. Builds on family strengths.
3. Supports the child in learning about and participating in his/her care and decision-making.
4. Honors cultural diversity and family traditions.

5. Recognizes the importance of community-based services.
6. Promotes an individual and developmental approach.
7. Encourages family-to-family and peer support.
8. Supports youth as they transition to adulthood.
9. Develops policies, practices, and systems that are patient and family-friendly and patient-and family-centered in all settings.
10. Celebrates successes.

Maternal and Child Health Bureau,  
Division of Services for Children with Special Health Care Needs

# History of Patient and Family-Centered Care

In 1984 a report on a conference sponsored by the Association for the Care of Children's Health and the Division of Maternal and Child Health about home care for children with serious health conditions included the concepts of family-centered care.

This occurred during a time when many children with significant health care needs were living in hospitals because home care was either not available or not covered by insurance.

In 1987 Former Surgeon General Dr. C. Everett Koop's report, "Children with Special Health Care Needs, A commitment to Family-Centered, Coordinated Care for

Children with Special Health Care Needs" was released.

Also in 1987 the Association for the Care of Children's Health, (ACCH) released the ground breaking publication, "Family-Centered Care for Children with Special Health Care Needs", which was a guide for professionals and families about what this concept meant and how to implement it. One of the wonderful things about this publication is that families and health professionals partnered in writing it.

ACCH held an annual conference that in addition to professionals included and encouraged the

participation of parents of children with special health care needs and disabilities. It was through these conferences that families started a family network.

In the early 1990s during the President Clinton administration when health care reform was being discussed some members of this growing ACCH family network met and started Family Voices.

Family Voices of Minnesota staff Ceci Shapland and Carolyn Allshouse were among the families that were part of these early and ground breaking events.

## Family-Centered Care led to Medical Home

The foundational work around patient and family-centered care led the American Academy of Pediatrics (AAP) to discuss the important role of quality primary care for children with special health care needs and disabilities. This led the AAP to develop the core concepts of Medical Home.

The AAP along with family leaders began work on a curriculum for primary pediatricians to learn how to implement Medical Home in their practices. In 2000 the AAP with funding from Shriners conducted Medical Home trainings around the country. One of the core elements of these training was to include families of children with special health care needs and disabilities in the training.

Several families were involved in the first Minnesota AAP Medical Home training in June 2000 funded by the Minnesota Children with Special Health Needs (MCSHN) Section at the Department of Health. These parent leaders included Sarah Thorson, who is now the Title V Children and Youth with Special Health Needs Director at the Minnesota Department of Health and Carolyn Allshouse, who is now the Executive Director of Family Voices of Minnesota.

In 2003 the MCSHN Program received federal funding to implement the Minnesota Medical Home Quality Improvement Learning Collaborative. This Learning Collaborative brought together pediatricians from around the

state of Minnesota along with parents from their practice and other clinic staff who worked together to implement the concept of Medical Home in their clinics. This innovative project led to meaningful clinic improvements such as implementation of health care plans, longer appointment times, room right away programs, care registries, pre-visit planning and care coordination for children with special health care needs and their families.

The success of this project that continued until 2009 led to the 2008 Health Care Home Legislation implemented by the Minnesota Departments of Health and Human Services.



**“Raising a child with special health care needs requires patience, caring and lots of detective work. I have learned so much from other parents who have shared their tips for navigating all the systems, and who really understand what I’m going through.”**

**Patricia,  
parent of child with  
special health care  
needs**



## Family Voices of Minnesota’s Parent to Parent Program

Caring for a child who has special health care needs or a disability is an experience that few parents anticipate or plan for and comes with many strong emotional responses and day-to-day challenges.

Parent to Parent can be a valuable source of assistance and information for parents of children with special health care needs and disabilities that is not met by the formal service system.

Family Voices of Minnesota has launched Parent to Parent of Minnesota and is a member of the Parent to Parent USA Alliance. As a member of the Parent to Parent USA Alliance Family Voices of Minnesota’s Parent to Parent program follows best practice guidelines based on over 30 years of research about the effectiveness of Parent to Parent support and information for families of children with special health care needs and disabilities.

Family Voices of MN conducted a very successful Support Parent training in June with support from the Minnesota Department of Health and Gillette Children’s Specialty Healthcare.

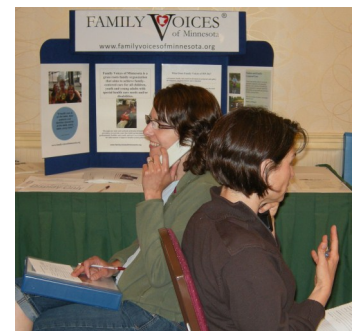
Through this training a group of volunteer Support Parents who are all parents of children with special health care needs and disabilities learned about using good communication skills, how to share their own story in ways that are supportive and the importance of confidentiality in parent to parent matches. The training also included information about state and community resources available to support families.

When the parent of a child, youth or young adult wishes to talk with another parent they can call or e-mail Family Voices of Minnesota Parent to Parent program and will be asked a few questions to help find the right match. For example sometimes a parent would like to talk with

another parent whose child has the same diagnosis as their child, or maybe they would like to talk with another parent who has gone through a similar experience such as having a child in an intensive care unit.

Parent to Parent staff will connect the parent seeking the connection with the trained Support Parent who is the best match. Parent to Parent staff will follow up with both parents to assure the match is working and meeting the need. Many parents say the most helpful information they received was from another parent.

To learn more about Parent to Parent of Minnesota call Family Voices of MN: 1-866-334-8444 or e-mail: . P2P@familyvoicesofminnesota.org





## Local Pediatrician Recognized Nationally

Marilyn Peitso, MD, a board-certified pediatrician with CentraCare Clinic –Women & Children, was named the national winner of the 2011 Spirit of Women Healthcare Hero award.

The Spirit of Women award celebrates women who take action to make their communities healthier, safer and more inspirational places to live.

Peitso says health care has changed a lot since those days when she, her parents and her seven siblings got their medical

care from a local doctor in a little town in northeastern Minnesota.

She is a champion of a concept known as health care home, which is a partnership between primary care providers, families and patients to improve health outcomes and quality of life for individuals with chronic health conditions and disabilities.

She worked closely with the Minnesota Legislature, the Minnesota Department of Health, Family Voices of Minnesota and

the Minnesota Chapter of the American Academy of Pediatrics to develop health care homes in pediatric practices across the state. This work culminated in 2008 with health care home legislation being passed in Minnesota.

Dr. Peitso is the current president of the Minnesota Chapter of the American Academy of Pediatrics.

Congratulations Dr. Peitso!



## Volunteers Needed for Ronald McDonald Room

Ronald McDonald has opened a wonderful Family Room at Gillette Children's Specialty Health Care. There are individual and group opportunities to volunteer at the Family Room such as being a house warmer, cooking meals for families, collecting pop tops, and video game recycling. Volunteer shift hours are Monday—Sunday, 9am-1pm, 1pm-5pm, and 5pm-9pm. Please contact Carynn Roehrick, Director of Volunteers, for more information: [carynn@rmhc-um.org](mailto:carynn@rmhc-um.org), 612-767-2788

## Are You Interested in Being a Support Parent?

Family Voices of Minnesota has two upcoming Parent to Parent trainings for parents interested in becoming a Support Parents: October 10, 2011 in St. Paul and November 10, 2011 in Willmar, MN. If you are interested in participating in either of these trainings please contact Carolyn Allshouse: [Carolyn@familyvoicesofminnesota.org](mailto:Carolyn@familyvoicesofminnesota.org) or 612-210-5547 or 866-334-8444.



**Keeping families at the center of health care**

**E-mail: [network@familyvoicesofminnesota.org](mailto:network@familyvoicesofminnesota.org)**

**Phone: 1-866-334-8444**

**Web-site: [www.familyvoicesofminnesota.org](http://www.familyvoicesofminnesota.org)**

For up-to-date information follow  
Family Voices of Minnesota on



**Family Voices is the Minnesota resource for the latest information on what is happening in health care and how it affects you and your family.**

- **Family Voices of Minnesota provides information and support to families of children, youth and young adults with special health care needs and disabilities so they are able to navigate the health care system.**
- **Family Voices of Minnesota facilitates family and youth involvement in the development, implementation and evaluation of health system programs and policies.**

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