FAMILY VOICES® of Minnesota

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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:

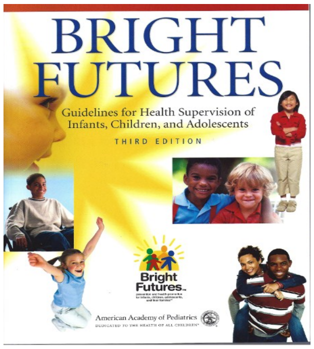
- *Assists families in navigating systems of care*
- *Connects families with one another*
- *Assures the voices of families are included in program and policy development, implementation and evaluation*

Notes from the Executive Director

Family Voices of Minnesota has been awarded a Federal Maternal Child Health Bureau Grant to expand the work we are doing in our parent to parent peer support program. This three year grant is an important opportunity to build parent to parent support as a best practice with primary care providers across the state of Minnesota with a focus on underserved and underrepresented families.

The third edition of Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents by the American Academy of Pediatrics provides guidance to health care providers about well child care, including care for children and youth with special health care needs and disabilities. One section of this guide discusses promoting support for families of CYSHCN and states that, “health professionals should identify ways to link families with community resources. Organizations in which parents help other parents (e.g. Family Voices) and other consumer directed organizations can provide remarkable support to families. For many families, informal support is as important as receiving specific services.”

These recommendations came from 30 years of research about the outcomes related to parent to parent support and information for families whose children have special health care needs and disabilities (see page 2 of this newsletter).



If you are a health provider working with families — you now have a parent to parent program to refer families: Family Voices of Minnesota’s Parent to Parent Program.

If you are a parent wishing to talk with another parent, or would like to become a Volunteer Support Parent — call or e-mail Family Voice’s of MN Parent to Parent Program: 1-866-334-8444 or P2P@familyvoicesofminnesota.org.

We would like to hear from you.

What information should we include in future newsletters?

Would you like to contribute information to be include in future newsletters?

What topics are you most interested in?

Please call or write us with your ideas.

Many thanks for all your support,

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What Does the Research Say About Parent to Parent?

Research has shown that parent to parent peer support is an evidence based, essential component of health care. Several research studies attest to the efficacy of parent to parent peer support as part of a program of comprehensive care for children and youth with special health care needs or disabilities (CYSHCN).

Peer support is so effective in part because of the equal and mutually beneficial relationship created through the sharing of experiences and knowledge with others who have faced or are facing similar challenges. (CA Health Report, 2008). After receiving emotional support and information, parents have shown increased confidence in parenting their children with special needs (Singer et al). Increases in self-efficacy, in turn, are associated with a variety of improvements in health care utilization and participation at all levels of planning from individual medical planning for a child to organizational planning for a clinic (Wagner, Austin, & Von Korff, 1996).

In another study of parent to parent peer support, the focus was on parents of young children with disabilities. It found that mothers who participated in parent to parent programs in five different states had increases in their sense of being effective parents, had increases in their positive attitudes about their children and family, and they made more progress on meeting specific needs than parents in a comparison group.

Peer support benefits the giver as well as receiver of support. The California Health Report speaks to "the growing evidence that providing social support to others may result in health benefits comparable or even greater than receiving support." Individuals, who provide social support through volunteering experience less depression, heightened self-esteem and self-efficacy as well as improved health behaviors and health outcomes (Walker, 2006).

The support both given and received by another parent has been termed "the cradle of leadership" because it is often through this relationship that parents discover within themselves their voice for advocacy.

Confident, knowledgeable parents are better able to partner with providers and increase their skills to become involved in program planning and policy.

Family Voices of Minnesota will add to the body of knowledge about the outcomes of parent to parent support and information through the research that will be conducted as part of our new Maternal Child Health Bureau Grant. The outcomes of this project expect to show significant increases in parent's confidence in partnering with providers in decision making about their child's care and accessing needed care for their children.

The Family Voices Parent to Parent Grant Program will provide opportunities for parents from underserved and underrepresented communities to build on their strengths by offering training for emerging leaders in policy, health care financing, advocacy and other areas of leadership development.

Family Voices of Minnesota Parent to Parent (P2P) program uses the best practice guidelines established by Parent to Parent USA. These guidelines are based on the body of research that also show the importance of providing structured training for parents providing support and information, along with systematic follow-up with both the referred parent and the parent providing support. (Singer et al, 1999).

To learn more or get involved in the Family Voices Parent to Parent Program contact: Family Voices of MN: 612-210-5547, toll free 1-866-334-8444 or by e-mail: P2P@familyvoicesofminnesota.org.

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The Importance of Parent to Parent

Member of the Parent to Parent USA Alliance,
Committed to Parent to Parent USA-Endorsed Practices

Parent to Parent support offers families the opportunity to not be alone.

To find answers and support from others who have been

My name is Jennifer and my husband and I are the proud parents of three wonderful little boys, ages 5, 4 and 2. Our oldest son, Reier, has the diagnosis of spastic quadriplegic cerebral palsy and epilepsy.

Reier was born 6 1/2 weeks early, but after a three- week hospital stay in the special care nursery we went home with what we thought was a healthy little boy. When Reier was 5 months old we took him to the pediatrician due to continued issues with constipation. It was at that point this journey really began for us.

From the age of 5 months to 10 months, we were told there wasn't a diagnosis they could give us. His eyes were still crossing and his MRI revealed a somewhat abnormal picture. It was something we would need to wait and see what happened with his development. The local school district's birth-to-three program began coming to our home weekly and a private physical therapist came to our home every other week to assist Reier in developing his skills.

Each time a therapist came to our home, we tried to prod them for answers. Initially, it was more concern about what to call this thing, but after several months of seeing our baby not develop as other typical children, we wanted to know more specifics. Will he walk? Will he talk? How will this impact his life? There were no concrete answers.

We were finally given the label of cerebral palsy at 10 months of age. With the diagnosis in hand, we began searching the internet for answers. Unfortunately, there were none. The degrees and areas of impact can vary dramatically for cerebral palsy and there was no known "cure".

The first couple of years were the most difficult. There were the feelings of guilt, (could we have done something differently), the feelings of fear, (I don't know what this means. How will it impact Reier and our family?), and the feelings of loneliness (No one understands this. We don't know anyone in this situation.)

We had never dealt with disabilities in our families. Friends & family would tell us, "It will be okay", "God only gives you what you can handle", "Don't worry", "Special babies are given to special people", but they had no idea what this really meant. It was just something to say that made them feel better. Some were fearful, some were concerned, and some just stopped coming around. A few jumped in to help.

Having a child with special needs, there are many situations that happen I don't think parents of typical kids understand. From the simple things, such as increased appointments, paperwork, and the need to always plan and prepare for any adventures outside of the home. To more complex issues, such as the increased physical demands to care for your child, the emotional toll of ongoing surgeries, missed milestones, and dealing with the stares in the community.

The first time I felt less scared in this new world of special needs was when our son's physical therapist connected us with another family who had a child with a similar diagnosis and demographics. When I first spoke with her, it was so reassuring to hear her story and to share similar experiences. I finally felt like someone understood me.

Parent to parent support offers families the opportunity to not be alone. To find answers and support from others who have been there ahead of them.

There is empathy but not sympathy.

There is understanding but not pity.

Parental support offers less judgment, less fear, and more comprehension. It offers parents a place to belong in an unusual circumstance.

Consumers As Colleagues Conference

This past June, Family Voices of Minnesota brought together over 50 adult health care consumers and families of children and youth with special health care needs to learn about what patient and family-centered care **really** is and how to be an effective advisor on a health system committee.

Dr. Bill Schwab, a family physician, family member of a person with disabilities and long time trainer with the Institute for Patient and Family-Centered Care talked about the important role of consumers and families in improving the health care system.

Nancy DiVenere, President of Parent to Parent USA spoke about confidentiality and telling your story. All of the conference participants who completed an evaluation gave the highest rating for the overall conference.

To learn more about patient and family-centered care and tips for being an effective advisor in the health care system go to: www.familyvoicesofminnesota.org, and the Institute for Patient and Family-Centered Care: www. Ipfcc.org

Tips for being an Effective Advisor on a Healthcare Committee

Based on their experiences of being service consumers patients and families bring a perspective to health care systems that providers and policy-makers do not have - the perspective of someone very close to the system but not constrained by the traditions of the system.

Patients and families are important resources to improve the health care system because they are able to:

- Explain how services really work
- Shed light on the unique experiences of patients/ families.
- Suggest creative ideas for improvement
- Inform clinics if improvements are working before they are fully implemented.
- Help professionals understand other systems and resources

1. Begin with your own experience. Share your thoughts and information about your experiences in ways that others can learn from it. Strive to be positive. Your story is very powerful. Be brief and make sure that the story you are telling has to do with the topic/ conversation at hand.

2. Learn about the committee: Learn who the people and programs are and what they do. Don't be afraid to say, "I don't understand", and ask for clarification.

3. Develop the big picture: Educate yourself about the issues. See beyond your own personal experiences and represent the needs of other patients and families who have had different experiences than you.

4. Learn to Collaborate: Praise other team members for their willingness to work together. Stay involved, you can be the energy in the group. Don't 'demand' respect from professionals, 'expect' it by being prepared for meetings, coming on time, and giving input and suggestions that can make a difference.

5. Be patient – sometimes change takes longer than you would like, it is worth the wait.

6. Be prepared: Read information sent for the meeting. Ask questions.

7. Learn to say "no": Don't take on too much. Know when you need a break.

8. Share the spotlight: Suggest other patients or families who can also participate in advisory activities. Provide encouragement and support to them; such as offering to drive if that is an option or meet with them before or after the meeting to discuss the meeting. This extra support is especially helpful for families who may be typically under-represented, such as families for whom English is a second language.

9. Assume the best about people: Build bridges. Respect the perspectives of others. Model partnership.

Look for the complete consumer guide on the Family Voices of MN web-site: www.familyvoicesofminnesota.org/ patient-and-family-centered-care/

P2P Assistant Coordinator Position Available with Family Voices of Minnesota

Family Voices of Minnesota has a part-time position (approximately 12 hours per week) available as the Parent to Parent Assistant Coordinator.

Qualified candidates would have:

- Experience working with families whose children have special health care needs or disabilities,
- Great communication skills
- Good organizational skills

Parents of children, youth and young adults with special health care needs or disabilities encouraged to apply.

For more information contact Family Voices of Minnesota by e-mail: P2P@familyvoicesofminnesota.org,

or phone: 1-866-334-8444.

Opportunity for Youth and Young Adults to Share Their Experiences

The University of Minnesota is conducting a study about healthcare access for youth and young adults with disabilities.

There is not enough known about the barriers youth and young adults with disabilities face when trying to getting appropriate care or what helps them navigate the healthcare systems.

Researchers a the University of Minnesota are looking for 400 youth and young adults to participate in a survey about their experiences with healthcare and how its different between people with and without disabilities.

Adolescents and young adults can participate by completing an online (or telephone or in-person) survey.

All answers and information will be completely confidential.

In return, participants will receive a $25 gift card as a thank you.

Participants will also have the opportunity to invite others to take the survey and get more gift cards.

Eligible youth and young adults are:

- 16 – 24 years old
- Have mobility limitations: Use a wheelchair or some other assistive mobility device OR
- Have any difficulty walking or getting around due to a spinal cord injury, spina bifida, cerebral palsy, muscular dystrophy, etc.
- Have never taken this survey before

Participants will be asked to provide their:

- Name
- Birth Date
- Address
- Phone Number
- Email Address
- This Code: FVM1

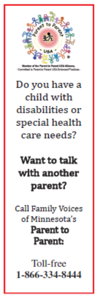
Check out the MyPath Facebook page: http://www.facebook.com/mypath.umn.edu

Please encourage youth or young adults you know to be part of this survey.

Help Get the Word Out About Family Voice of Minnesota

Help us get information out to families about Family Voices of Minnesota and the Parent to Parent Network.

Call or e-mail to request copies of the Family Voices brochure or Parent to Parent bookmark: 1-866-334-8444, network@familyvoicesofminnesota.org



Parent to Parent USA

Do you have a child with disabilities or special health care needs?

Want to talk with another parent?

Call Family Voices of Minnesota's **Parent to Parent:**

Toll-free
1-866-334-8444

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Keeping Families at the Center of Health Care

www.familyvoicesofminnesota.org

Consider Becoming a Volunteer Support Parent

We conducted a very successful Volunteer Support Parent training two weeks ago in St. Paul with an amazing group of parents.

Here is what parents had to say about the October 10 Parent to Parent Support Parent Training when asked what was most helpful:

- "All of it was helpful"
- "Sharing stories"
- "Being able to practice calls with another parent"
- "Having the presenters be parents was so helpful"

The next Support Parent trainings is:

- November 10 at Rice Hospital in Willmar, MN

Parent to Parent USA

Member of the Parent to Parent USA Alliance,
Committed to Parent to Parent USA-Endorsed Practices

Future trainings will be:

- The first week of December in St. Paul and,
- Mid-January in Duluth.

To register for one of these upcoming trainings please e-mail:

P2P@familyvoicesofminnesota.org or call: 1-866-334-8444

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Phone: 866-334-8444

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

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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 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.