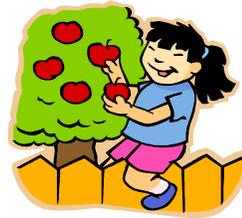


Health Information and Education Center *Creating Partnerships for North Dakota Families*

A newsletter for families and professionals raising children with special health needs



Welcome Fall



Volume 3, Issue 14

Summer/Fall 2005

In the aftermath of Hurricane Katrina, children and youth with special health needs and their families face unique and difficult challenges. The Centers for Disease Control has estimated that there are at least 99,000 children with special health care needs in Mississippi, 193,000 in Louisiana, 488,000 in Florida, and 152,000 in Alabama. Family Voices, a tax-exempt corporation, is taking monetary donations to help these vulnerable victims.

For this reason Family Voices National has launched the Families Helping Families Hurricane Relief Fund.
www.familyvoices.org/

Donate through PayPal or send your donation through the mail to Family Voices, 2340 Alamo SE, Suite 102, Albuquerque, NM. Family

Voices will funnel your dollars to our volunteer family leaders "on the ground" in the affected states. We promise that 100% of your donations will go to help families and their children and youth. Your donations will pay for items and services our leaders have learned are needed - things such as anti-bacterial wipes, diapers, phone cards, medical care, cash for medications, gas and food, rent, toys, and clothing.

Our family leaders will also help families negotiate the confusion of finding temporary shelter, working with insurance companies, filling out forms, and signing up for new schools. We will update our donors on our progress through this website.

Family Voices has compiled a list of resources to assist in efforts to help families

of children and youth with special health care needs affected by Hurricane Katrina. If you would like a copy of this document please contact Family Voices of North Dakota at 888-522-9654

FVND has received some calls from several families who have relocated to ND.

Our hearts go out to our families and friends affected by Hurricane Katrina. Family Voices is committed to helping in any way we can. Thanks from our heart to yours.

Additionally, Family Voices National has initiated a Legislative Alert Center. Please see: <http://capwiz.com/familyvoices/home/>

Please take this opportunity to tell your story and let those who make decisions about our children learn from your experiences.

Together we are
wiser than any one
of us alone.

Author Unknown



Inside this issue:

Hurricane Katrina	1
Resources	2
Individual Health Plan	3
Sherida's Story	4-5
Family Centered Care	6
Farmers Advice	7
Zero to Three	8

Resources For You to Use

The STARBRIGHT Foundation is dedicated to the development of projects that empower seriously ill children to combat the medical and emotional challenges they face on a daily basis. STARBRIGHT projects do more than educate or entertain: they address the core issues that accompany illness - the pain, fear, loneliness, and depression that can be as damaging as the sickness itself. They also have free videos and publications for your child <http://www.starbright.org/about/index.html>

If you do not have access to the internet, please let FVND know.

Bullying- A lot of young people have a good idea of what bullying is because they see it every day! Bullying happens when someone hurts or scares another person on purpose and the person being bullied has a hard time defending himself or herself. Usually, bullying happens over and over. 1) Punching, shoving and other acts that hurt people physically; 2) Spreading bad rumors about people; 3) Keeping certain people out of a "group"; 4) Teasing people in a mean way; and 5) Getting certain people to "gang up" on others.

Check out this website on bullying for more information <http://stopbullyingnow.hrsa.gov/index.asp?area=whatbullyingis>

Pete and Pam Wright/
Wrightslaw & The Special Ed Advocate
<http://www.wrightslaw.com> is a great place to locate a lot of information regarding IEP's. They also have a state resource page and much, much more.

Resources cont.

Why Folic Acid is So Important
Folic acid is a B vitamin. It is used in our bodies to make new cells. If a woman has enough folic acid in her body before she is pregnant, it can help prevent major birth defects of her baby's brain and spine. These birth defects are called neural tube defects or NTDs. Women need to take folic acid every day starting before they are pregnant to help prevent NTDs. To learn more, visit: <http://www.cdc.gov/ncbddd/folicacid/index.htm>

The FVND Care Notebook and New Beginnings Resource Guide is now available online at www.geocities.com/ndfv/ or you may call the FVND office at 888-522-9654 for a CD.

FVND now has a weekly e-newsletter available that has State and Federal Resources as well as other information that may help you. You can be placed on the e-list by e-mailing us at our new e-mail address fvnd@drtel.net or calling the FVND office.

FVND has many new publications which will be ready for use soon. Please check the website frequently for new publications as they become available. Also workshop listings will be included in the e-newsletter.



ACCESSING WEB RESOURCES

More and more we have been including web resources in our newsletter. Please remember if you DO NOT have access to these web based resources and information, Family Voices of ND would be pleased to send you whatever information you would like printed out. 888-522-9654 or (701) 493-2634

Individual Health Plan

Individual Health Plan

Have you ever thought of developing an Individual Health Plan for your child with special health care needs?

More and more children with special health care needs are able to attend school. An Individual Health Care Plan or IHCP, helps ensure your child's medical needs will be met during the school day. Even if a child has an Individual Education Program (IEP) and/or 504 Accommodation Plan, if the child has special health care needs, he or she should also have a IHCP.

The most important part of developing an IHCP is good communication between parents and the school. The school nurse is usually the liaison between the school and the family. Work with the nurse to devise a communication method that best meets both your needs. This may include phone calls, written notes, e-mail or face to face meetings. Be prepared to sign waivers, as the nurse may want to consult your child's physicians to: ask questions, obtain medical orders, and get documentation about your child's health care needs.

The nurse will also meet with the child's teachers. Parents

should participate in these meetings and feel welcomed as part of the team. Depending on the child's age and condition, he or she may also want to attend. It can be reassuring for teachers to meet your child in person instead of just learning about their medical diagnosis. It also encourages your child to learn to self-advocate for his medical needs and learn to work as a team member with school personnel. If your child cannot attend the meeting, bring a photograph or tell a story that illustrates your child's personality and strengths.

The IHCP should include:

- ♥ Information about your child's health, including baseline vitals.

- ♥ Medications,

- ♥ The person who will be responsible for monitoring any issues related to your child's special health care needs during the school day, on field trips, and while being transported to and from school.

- ♥ Regular medical care/monitoring/procedures your child needs during the school day and the person who will deliver this care.

- ♥ Interventions and procedures to follow in the event of an emergency

- ♥ Special procedures or accommodations to follow in the event of fire drills, fires or other building emergencies.

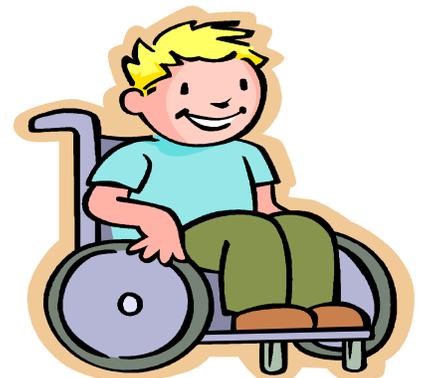
- ♥ Contact information for your child's physicians.

- ♥ Consents for treatment including forms for field trips.

- ♥ Any special transportation needs.

Adapted from Newline, the Federation for Children with Special Needs, Vol. 24, Number 4, Winter/Spring 2004

"To the world you might be one person, but to one person you just might be the world"



Sherida's Story Excerpted & Reprinted with permission from A Work By Edna Uecker

FVND wants to thank Edna for sharing the life with her daughter Sherida! Edna, you are truly a pioneer for children with special health care needs.

The decision we made 40 years ago to keep Sherida at home may not be acceptable for all families with a disabled child. But I believe we would make the same decision today.

As a young couple, on the way to church with our two little daughters, five year old Sherida and two year old Korliss, we felt like a typical American family, but also blessed beyond measure. It was June, 1958.

The drunk driver crashed into the side of the car where Sherida was sitting. The rest of us were bruised and scratched, but the doctor who assisted Sherida at the scene said she had a severe head injury. He drove us to the nearest town and Sherida was air-lifted to Fargo, North Dakota. Serious brain damage was confirmed, and her body temperature of 107.2 was making it worse. She was in a coma.

For three weeks, my husband Charles and I waited anxiously at her bedside then we agreed that Charles had to return to his new veterinary practice back home. Little Korliss, who had stayed with relatives since the wreck, continued to be passed back and forth between caregivers. I moved into an efficiency apartment near the hospital. As time passed, it was evident that Korliss was having a difficult time without her family so we made the decision to move Sherida to a place where I could be nearer the baby and still able to keep watch over Sherida.

The more time passed, the more it seemed to slow down. Sherida's vital signs leveled off, but she didn't wake up. Anxiety, depression and the continued separation of our family seemed unbearable. Finally, just before Thanksgiving, we moved Sherida home.

Back then, there were no programs to assist the family of a disabled child. Even getting domestic help in a small town was impossible. Finally, Sherida came out of her coma and we were thrilled,, but it also required a new totally absorbing schedule. She could not move. She could not speak. We knew she could hear, but because her eyes were permanently dilated and somewhat fixed, we didn't think she could see. The left side of her face and body were paralyzed. This newly-awakened child looked nothing like our little girl of the past, and we weren't even certain she knew who we were. We spoon-fed her a soft diet, got six to eight glasses of liquid a day down her and turned her every two hours to prevent bedsores and pneumonia. We put her through passive exercises twice a day. In not time I was exhausted and irritable. So were Charles and Korliss.

During the first year, Sherida passed from crisis to crisis, and time after time we were advised by doctors, friends and family to institutionalize her. I couldn't bear the thought. Without realizing it, I became overly protective of her. I was tired and anxious, yet I couldn't trust anyone else to properly care for her. Even when Charles and I tried to go out for an evening, all I could do was worry about Sherida. Charles got more depressed and withdrew from me and the girls, especially his disabled daughter. In time, he, too thought institutionalization was the only solution.

A year after the crash, we capitulated and sent Sherida to the Sister Kenny Institute in Minneapolis. Able only to visit on weekends, we realized that once again Korliss was spending weekends with relatives and Sherida wasn't getting any better. After three months, we brought her back home. Later, we tried other placements but nothing seemed to help.

Continued Page 5

Cont. Sherida's Story

Two years after the crash, just when we had become fairly resolved to a routine for Sherida. I discovered I was pregnant. I became worried and anxious again, fearing that all the lifting would harm the baby. Beyond that, I couldn't imagine how I could add the care of an infant to my schedule.

Baby Jonathan was born perfect, and he was a happy content baby. However, just as I feared, caring for both of them was grueling. I was so tired and Charles seemed to grow further and further apart. When Jonathan was two and Sherida ten, we considered institutionalization again. But after making several visits, we made the decision the last time—we would care for Sherida at home.

Looking back over 40 years, we have no doubt that the decision we made affected our children. Korliss had to make the greatest adjustment because she went from little sister to big sister after the crash—then again when Jonathan was born. All the moves when she was two and three must have left her lonely and feeling abandoned. Many times I was just too tired to see my children's needs. I didn't always listen to them with my heart. I think Korliss and Jonathan tended to shield their father and me from the bad parts of their lives, sensing that we were too stressed to handle any more. They had to explain Sherida to their friends, but for the most part, their friends were very loving and accepting. Some even got to know her and learned to care for her.

In spite of it all—or perhaps because of it all, Korliss and Jon became compassionate adults with a great deal of perseverance. Korliss received a BA in music from UND. She then earned a masters in opera from Julliard School of Music and is now singing professionally in New York City.

Jonathan graduated from UND with a degree in Archaeology and went on to earn his Doctorate of Medicine. He specialized in psychiatry and currently practices at the State Hospital in Anoka, Minnesota. He, too, has survived many traumatic experiences but has become a compassionate man and a good doctor.

On March 6, 1993, after a five-day hospitalization, our Sherida died as a result of aspiration pneumonia and heart failure. With the help of God, I got through this greatest of losses. We are grateful for having shared her life of 39 years. The purpose of life, after all, is not to be happy all the time but to live so that our presence makes a difference. Sherida could not be productive in a physical sense, but her life made a big difference to all those who loved her.

Charles had a heart attack the year before Sherida died and retired from his practice several months later. He worked tow more years as acting veterinarian at the State Capitol. Now he is content to work on his model railroad and to keep our yard in shape. We can travel together too.

Five years after Sherida died, I finally cleaned out her room, giving her clothing and medical equipment to those who could use them. I have turned her room into a studio where I enjoy art and freelance writing. I hope to publish a book about her life.

It is most difficult to summarize almost 35 years of living, but the bottom line is that our family grew and learned so much about love, compassion, and perseverance from Sherida. We think about what might have been, but mostly we are grateful to have shared in her life. I doubt that at the end of our lives God will be looking for medals. I am more inclined to think God will be looking for scars....Edna

Uecker



Definitions of Family Centered Care/What's All the Fuss!

DEFINITION OF FAMILY-CENTERED CARE

Family-Centered Care assures the health and well-being of children and their families through a respectful family-professional partnership. It honors the strengths, cultures, traditions and expertise that everyone brings to this relationship. Family-Centered Care is the standard of practice which results in high quality services.

PRINCIPLES OF FAMILY-CENTERED CARE FOR CHILDREN

The foundation of family-centered care is the partnership between families and professionals. Key to this partnership are the following principles:

Families and professionals work together in the best interest of the child and the family. As the child grows, s/he assumes a partnership role

Everyone respects the skills and expertise brought to the relationship.

Trust is acknowledged as fundamental.

Communication and information sharing are open and objective.

Participants make decisions together. There is a willingness to negotiate.

Based on this partnership, 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 family-friendly and family-centered in all settings.

10. Celebrates successes.

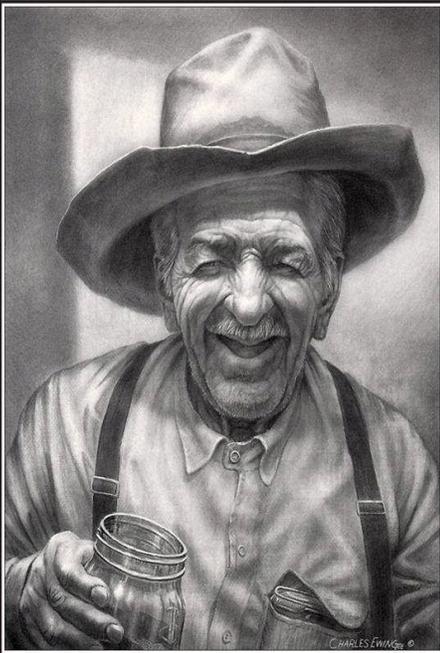
THE ROLE OF CULTURAL COMPETENCE IN FAMILY-CENTERED CARE

Cultural Competence is intricately linked to the concept and practice of **"family-centered care"**. Family-Centered Care honors the strengths, cultures, traditions and expertise that everyone brings to a respectful family/professional partnership, where families feel they can be decision makers with providers at different levels - in the care of their own children and as advocates for systems and policies supportive of children and youth with special health care needs.

It requires culturally competent attitudes and practices in order to develop and nurture those partnerships and to have the knowledge and skills **that will enable you to be "family-centered" with the many diverse families** that exist. It also often requires building relationships with community cultural brokers, who can assist you in understanding community norms and link you with other families and organizations, such as churches, beauty shops, social clubs, etc. that can help promote your message or conduct outreach for services.



An Old Farmers Advice



- ♥Your fences need to be horse-high, pig-tight and bull-strong
- ♥Keep skunks and bankers and lawyers at a distance.
- ♥Life is simpler when you plow around the stump.
- ♥A bumble bee is considerably faster than a John Deere tractor
- ♥Words that soak into your ears are whispered...not yelled.
- ♥**Meanness doesn't jes' happen overnight**
- ♥Forgive your enemies. It messes with their heads.

- ♥Do not corner something that you know is meaner than you.
- ♥**It don't take a very big person to carry a grudge.**
- ♥ You cannot unsay a cruel word.
- ♥ Every path has a few puddles.
- ♥When you wallow with the pigs, expect to get dirty.
- ♥ The best sermons are lived, not preached.
- ♥ Most of the stuff people **worry about ain't never gonna** happen anyway.
- ♥**Don't judge folks by their** relatives.
- ♥Remember that silence is sometimes the best answer.
- ♥ Live a good and honorable life. Then when you get older **and think back, you'll enjoy it** a second time.
- ♥**Don't interfere with something' that ain't botherin' you** none.
- ♥Timing has a lot to do with the outcome of a rain dance.

- ♥If you find yourself in a hole, the first thing to do is stop digging.
- ♥Sometimes you get, and sometimes you get got.
- ♥Always drink upstream from the herd.
- ♥The biggest troublemaker you'll probably ever have to do deal with, watches you **from the mirror every mornin'**
- ♥Good judgement comes from experience, and a lotta that comes from bad judgement.
- ♥**Lettin' the cat outta the bag is a whole lot easier than puttin' it back in.**
- ♥**If you get to thinkin' your're a person of some influence, try orderin' somebody else's dog around.**
- ♥Live simply.
- ♥Love generously.
- ♥Care deeply
- ♥Speak kindly.
- ♥Leave the rest to God.

Donene Feist, Director

Join us today!
PO BOX 163
EDGELEY, ND 58433

Phone: 701-493-2634
toll-free 1-888-522-9654
fax: 701-493-2635
E-mail- feist@daktel.com

PRST
NON-PROFIT
PAID PERMIT
#27
EDGELEY, ND
58433

This newsletter is funded in part by the ND Department of Human Services, Medical **Services Division, Children's** Special Health Services and Centers for Medicare and Medicaid Services 11-P-92506/8-01



Zero to Three: National Center for Infants, Toddlers and Families

ZERO TO THREE'S mission is to promote the healthy development of our nation's infants and toddlers by supporting strengthening families, communities, and those who work on their behalf. They are dedicated to advancing current knowledge; promoting beneficial polices and practices; communicating research and best practices to a wide variety of audiences; and provide

training, technical assistance and leadership development. The ZERO TO THREE webiste has great resources and articles for both parents and professionals alike.
www.zerotothree.org



The important thing is that when you come to understand something you act on it, no matter how small that act is. Eventually it will take you where you need to go.
--Helen Prejean

