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FAMILY VOICES OF NORTH DAKOTA®

The Navigator

FAMILY VOICES OF NORTH DAKOTA-A HEALTH INFORMATION AND EDUCATION CENTER ADDRESSING THE NEEDS OF FAMILIES OF CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND DISABILITIES AND THE PROVIDERS WHO ASSIST THEM.

Creating Partnerships for ND families

Achieving and Measuring Success: A National Agenda for Children with Special Health Care Needs– The National Agenda for Children with Special Health Care Needs builds on past experiences and success to assure that policies and programs are in place to guarantee that: a) children have access to quality health care services which are coordinated; b) providers are adequately trained; c) financing issues are equitably addressed; d) families play a pivotal role in how services are provided to their children and e) children grow up healthy and ready to work.

These changes must occur in ways that will provide optimal outcomes for children with special heath care need and their families.

FVND works on the six national outcomes that have been selected as critical to guide efforts within the Division of Services for Children with Special Health Care Needs. The Health Information and Education Centers like FVND are designed to assist in addressing these outcomes.

Core Outcomes to be Achieved

1. All children with special health care needs will receive co-ordinated ongoing comprehensive care within a medical home.
2. All families of children with special health care needs will have adequate private and/or public insurance to pay for the services they need.
3. All children will be screened early and continuously for special health care needs.
4. Services for children with special health care needs and their families will be organized in ways that families can use them easily.
5. Families of children with special health care needs will partner in decision making at all levels, and will be satisfied with the services they receive.
6. All youth with special health care needs will receive the services necessary to make appropriate transitions to adult health care, work, and independence.

Bloom Where You're Planted

Family Voices of North Dakota provides many opportunities for families and providers alike! Staff is located across the state in Dickinson, Fargo, Grand Forks, Bismarck and Edgeley to assist families and providers with their needs. Whether it is a workshop, assistance in navigating this complex system, 1:1 emotional support from another family or just to talk. It is our mission to assist you in whatever your needs may be. Raising a child with special health care needs is life changing and a challenge. You don't have to go it alone. It may change the path you were on, but it does not need to change who you are! We are here to help! **"Bloom Where You're Planted" Call us today 888-522-9654**

Cannon's Story *by Jodi Hebl*

Identifying and providing families emotional and informational support early is essential.

I am Jodi Hebl and the mother of almost 5 children and married to an amazing guy named Kelly. My 12 year old son is Rally, Shanel just turned 9, Autumn is 3, Cannon Bear would be almost 2, and we are about ready to have a little girl in December. Rally is a football playin' young man; he is very mature and helpful. Shanel is my drama queen!! Just combing her hair is more dramatic than the norm. Autumn is my passionate one, I say passionate and mean opinionated and cranky. Cannon is my lovable, cuddly, beautiful boy. And I am scared to find out what this new little lady will be like.

All my pregnancies have been straight out of What To Expect When Your Expecting, nothing major happening. Rally was a c-section, Shanel and Autumn were both VBAC'S, we just assumed Cannon would be a VBAC also, but after an hour of pushing things went wrong. . I was turned to my side to get him to straighten out in the birth canal and that's when the pain started. I had a great epidural, but my chest started to hurt, I thought I was actually having a heart attack. Then the nausea hit and I started to go in and out of consciousness. The nurse called the OB in, that's when Bear's heart rate started to drop, we were rushed into surgery, and 10 minutes later he was born.

The doctor told me that my uterus had ruptured and my placenta had fully detached. Both Cannon and the placenta were out of the uterus and in my upper abdominal cavity. The pain was from me bleeding into my abdomen and it putting pressure on my diaphragm and organs. When Cannon was removed he was not breathing or responding to stimulation. I got to see him for a few seconds and he was taken to the NICU.

I am unsure what happened in the next hour and a half since I was in recovery, I don't even remember if Kelly was allowed to go into the NICU and stay with Bear. What I do remember is finally getting to see my baby boy. He was laying there with monitors and cords everywhere, with his little chin quivering. I didn't get to hold him, but I did get to hold his little foot. I thought he is crying and he has good color he will be fine.

I was then wheeled to my room where all my family was and that is when it hit me that something was wrong with my son.

Why didn't the nursed tell me they would bring him into my room or had they said something and I didn't even hear it? A friend of mine took Rally and Shanel in to see their new brother, I have pictures of them standing next to Cannon holding his foot and they look so scared for him, it breaks my heart every time I look at them. When we went back to the NICU the doctor was there and told us that Cannon had been without oxygen for at least 10 minutes when my uterus ruptured, he had to be intubated because he was not breathing on his own anymore and she thought he was having seizures.

They let me hold him and all he could do was cry, a cry that was different from any other cry I had felt, that was the beginning of a life stay and a crazy roller coaster ride.

Over the next few weeks Cannon had EEG's that came back abnormal, our neurologist told us that "his outlook was not good" and that he would be behind his entire life. Maybe not walk, talk, smile and other things, I was to mad at him to even hear anymore.

Cannon was put on CPAP after 4 hours and the nasal cannula after about a week. That is when a doctor finally asked us "has anyone talked to you about your son".

NO, no one has told us anything.

She informed us that Cannon has Hypoxic Ischemia Encephalopathy, and that translates to lack of oxygen to the brain, it took her a half hour to tell it to us in normal terms.

In other words Cannon had suffered severe injury to his brain during and after delivery and that it cannot be repaired.

(Continued Next Page)

Cannon’s story

Cannon had lost his suck/swallow reflex and had a g-tube placed at 19 days old and we were allowed to take our Bear home at 22 days old. On our discharge date we were enrolled into Infant Development and DDCM, which was the start of a great support team.

Over the next few months Cannon started to smile, giggle and do the things a 1 month old does, but he was 3 months old. We also started to see a PT, OT, and Speech Therapist, to the cities for eye appointments, shiners, neurologist and the bi weekly pediatric appointment. We had weekly visits with Michelle our Infant Development therapist, which made me feel normal for at least an hour. Knowing that she saw families going through the same things we were made me feel not so alone, even if had not met another one of these families. We had great support from family and friends but their children where “normal” and I didn’t think anyone felt the loneliness and isolation that I felt. Everyone drove to work like normal, fed their babies with bottles and went out to eat with friends, just moved on with their lives.

What I didn’t realize is that Cannon was showing me this amazing “other” world, a world filled with these strong and courageous children. A world that almost no one knows exists. In this place milestones are not “baby sat” at this age and “said mama” at this age, but “baby tolerated feeding”, “baby is weaned off seizure meds”.

On November 13th I went to get Cannon up from his nap and found him not breathing and without a heartbeat. We called 911 and they took him to the emergency room where they did get a heartbeat back, he was then air lifted to the PICU at Merit Care. After 3 days and repeated EEG’S we were told that Cannon would not wake up and the only thing keeping him alive was machines and medications, we were left with the choice of removing his ventilator or letting him pass over time. Kelly and I told the kids together and let them know that we would not let Bear go until they were ready. We spent an amazing day with Cannon. Now I Lay Me Down To Sleep came and took pictures, the nurses did footprints and hand casts with the kids. The nursing staff took something so tragic and turned it into a beautiful and amazing milestone in our lives. We laid in bed with our kids and read books, tickled Cannon and played with him before Rally and Shanel look at Kelly and me and said we are ready to let him go.

The nurse called the doctor in and pulled the tube from Cannon’s mouth, all the while we held him and told him we loved him. They called his time of death on November 16th at 12:59 in the morning. We held him in our arms for hours after just cuddling and remembering everything we could of our Cannon Bear.

In the nine and a half months of Bear’s life we assembled the most amazing support team.

I had never heard of Early Intervention or Family Voices and all that these programs can offer families. I wish now that I would have used them more and not felt like I was being a burden.

I am happy to say that all that Cannon taught me is going to good use, I work for Infant Development now as an Experienced Parent and cherish every moment I get to spend with our families, it makes me feel closer to our son.

If I could say one thing to every family it would be to use these program to your full advantage and don’t feel like you are putting people out, this is what they are here for and are passionate about. These teams are specially formed and built for you and your family. Accept all the help that is offered to you. And love every moment of your of your new world.

Thank you Jodi for sharing your story!

Ali's Boundless Playground is coming very close to being completed. It was opened in August. The finishing concrete and sign work are currently being done. We do have a few more pieces of equipment that will be put up in the spring.

How it happened...It was my dream to have a community playground that was accessible to children with disabilities. I entered the "Win A Boundless Playground Essay Contest" sponsored by Hasbro, Playskool, and GameTime in November of 2006. I was one of 20 finalists out of 930 entries nationwide. Although I did not win, we were offered the equipment at a huge discount. The Park District donated the land and helped us tremendously. We formed a committee of about 15 people. With the support of friends, family and various community organizations, we worked to raise $200,000 for the new Boundless Playground in Grand Forks.

I was born with Spina Bifida. I am very blessed, as I have a very mild case of it. Many of the problems I face are hidden to most, as I am very physically able. I did not begin the playground project for myself. I did it for the kids like me who have a disability, but aren’t as lucky as I am.

Boundless Playgrounds are tailor-made for the way children are naturally drawn to play. They are universally accessible so everyone can play side by side at his or her own highest level of ability.

I think every kid should be able to have fun and feel like they belong. It's nice to have a place where kids with disabilities and their siblings can have fun together!

Ali Karpenko, 15, Grand Forks, North Dakota


05/27/2009

Financial Assistance for Health Care

Many programs have changed. You may not have previously qualified for Medicaid programs prior but we strongly encourage you to reapply!

Children with Disabilities Program families encouraged to apply!!!!!!!!
The Children with Disabilities Coverage is a unique coverage in that it has elements of both the Children & Family and the Aged & Disabled Coverage's.

The Deficit Reduction Act of 2005 authorized states to allow families with disabled children the option of 'buying in' to Medicaid to receive the state coverage. In 2007, the ND state legislature authorized the
ND Department of Human Services to implement this program.
*A child must be under age 19, and may be covered through the month in which he/she turns age 19;
*A child must have an approved disability as determined by the Social Security Administration;
The child must 'choose' to be treated as a disabled individual for Medicaid purposes;
*The **net** countable family income must not exceed 200% of the Federal Poverty Level;
If the employer of the child's parents offers health insurance (major medical, doctor, hospital) that will cover the child for which the employer pays at least 50% of the premium, the child must be enrolled in that health insurance; This would not apply if the coverage is only for Dental or Vision coverage.

How To Checklist
How to apply!
Contact Your County Social Service Office and ask to speak to an Eligibility Worker regarding the "Children with Disabilities Coverage" (Medicaid Buy-In)

You may have to fill out the following forms with the County Eligibility Worker.
Eligibility Report on Disability/Incapacity (SFN 451)
http://www.nd.gov/eforms/Doc/sfn00451.pdf
Application for Assistance (SFN 405)
http://www.nd.gov/dhs/info/pubs/docs/sfn-405-application-for-assistance.pdf

YOU DO NOT HAVE TO APPLY FOR Social Security first! But... If you have not applied for Social Security for your child, you may consider contacting the Social Security Administration (SSA) Office (701-250-4200) or visit the SSA website to fill out the starter kit.
http://www.ssa.gov/disability/disability_starter_kits_child_eng.htm

Other Info: The child's premium is 5% of the family's **gross** countable income

Any health insurance premiums paid by the family that cover the child may be deducted from the Children with Disability premium to arrive at a net Children with Disability premium for that child.

Frequently Asked Questions

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Q. Three of my children are disabled. Is there one premium for all? Does each child pay a premium? If not, is the premium prorated?

A. Each child has a separate premium. The premiums are not prorated between them.

Q. I have 2 disabled children. One's needs are covered very well under the Healthy Steps program. The other has psychiatric needs that Healthy Steps will not cover. Can I keep the one child covered under Healthy Steps and have Children with Disabilities coverage for the other?

A. Yes, eligibility for the Children with Disabilities program is determined on a child by child basis.

Q. The Social Security Administration (SSA) has not made a disability determination for my child because our income and/or assets are too high. What can we do to see if our child has an approved has an 'approved' disability?

A. When SSA cannot make a disability determination, they will send you a letter. That letter, along with a Medical Social review (which you get from your eligibility worker) is then submitted to the ND Medicaid State Review Team; who can then make that determination

However….a determination can be made within the state through the review team above.

We encourage all families to apply, even if you have previously applied for other Medicaid programs, as some things have changed!

Questions??? Call 1-877-KIDSNOW Call your County Eligibility Worker/ Social Services Office Call 1-800-755-2604 and ask for the Eligibility Unit

Vivian Modin Helping Hand's Fund

Vivian Modin, is the grandmother of Vicki L Peterson, a ND Family Voices Consultant. Vivian was born in 1912 and recently passed away.

One of the memorial funds set up in her memory will be to Family Voices of North Dakota. These memorial Funds will be used to help families in the state of ND.

Vivian served on the Kenmare Hospital Board for many, many years, she was also elected on the National Medical Association Board as well.

Vivian had been very involved in politics and policy making during her years of service. She was also an educator and taught in rural ND schools for over 35 years. My grandmother spent her whole life in rural ND and was very interested in agriculture, farming, and rural life all together. She was also concerned and helping out families where she could. Vivian also served on the American League of Women.

Vivian's great-grandson, has autism. She had spent her latter years concerned and interested in children with special needs, including children with autism.

I think and remember fondly all my conversations with her about my son Aaron, and also about how Family Voices has changed my life and perspective of what I want to do and accomplish. I will miss her deeply and think of her everyday of my life. She had no regrets and that is what inspires me the most.

We are very grateful for this fund and hope it will continue to grow and flourish to assist families. Thanks to the Modin family for such a wonderful tribute!!

News from staff across the state

FVND staff are in Bismarck, Dickinson, Fargo, Grand Forks and Edgeley
Call us at 888-522-9654

Missi in Dickinson-
It has been a busy few months. It is hard to believe that the cold weather is back along with the flu! It has been one year now that I have been coordinating the Parent to Parent program and what a year it has been!

We are now starting another program to go with the Parent to Parent Program, called the Parent Navigator Teams. This year (and next) I will be traveling to each region to host a Parent to Parent workshop and a Parent Navigator Workshop! So watch for info on me coming to your area soon.

I spent much of my summer on the go and attended the National Parent to Parent conference in Texas in June where I was able to learn a lot about new technology that can be used to connect parents to each other.

In July we started a BigTent group (**www.bigtent.com/groups/ndp2p**). It has been fun to watch this group grow! So if you haven't joined yet, go check it out, **it is FREE!**

I also participated in both Parent Leadership Institutes in Edgeley (in May and August). It is such an amazing experience spending the weekend with wonderful parents in North Dakota! Other than that it has been meetings and paperwork as usual I look forward to seeing all of you when I come to your region!! **Parents in ND Rock!!!**

Congrats Vicki Peterson FVND staff! The Arc of Bismarck's Professional of The Year. As a parent and a professional she works tirelessly to address the concerns of families. She serves on the Bismarck Public Schools Autism Task Force and the Region VII ICC. She is very knowledgeable in the areas of autism and systems; additionally, she has been very active with Bismarck's Legislative Working Committee and advocated on behalf of several disability-related issues during the past legislative session. Vicki was nominated by Roxane Romanick of Designer Genes.

Vicki in Bismarck-How quickly time goes by. On a personal note for our family, my oldest son will be graduating from Century High School spring of 2010, and has already made his plans to attend college in Jamestown to play baseball. My youngest, Aaron whom has autism, is in first grade this year and doing very well. We are so fortunate for his team at school is top notch! As for me busy with Family Voices and meeting new families. Many new referrals come in and I enjoy talking and helping families find the resources they need. Last May, I attended the Family Voices Leadership Weekend in Edgeley ND. This was a great experience and so much fun. In late summer, Missi Baranko held Parent 2 Parent training in Bismarck, great turnout and lots of great information. I am so happy to be a part of and announce the Parent Navigator Program. This project is a team of volunteer parents who help and strengthen their community for families whom have children with disabilities and special healthcare needs. I have traveled with Missi, the director, to Dickinson and Devils Lake to help with this very exciting project. Upcoming dates in other cities across ND, in Bismarck February 20th, 2010 and In Minot May 8th, 2010. Keep these dates! Just recently here in October I had the opportunity to attend the largest Assistive Technology Conference in the US, Closing the Gap. This 3 day event gives the opportunity to explore new assistive technology, try it out, and watch and hear demonstrations. I also attended the first Great Plains Interdisciplinary Autism Diagnostic Clinic in Minot. Had an opportunity to observe and participate for family support. I have visited the autism support group in Minot/MAPS to talk about Family Voices and also at the CSHS diabetes clinic in Devils Lake.

North Dakota Parent To Parent

What ND Parent to Parent Offers:

☑ One-to-one matches of families who have similar needs and experiences.

☑ Emotional support for parents when they learn their child has a developmental delay, disability, or other special health needs.

☑ Current information on a variety of disabilities and health issues.

☑ Training for parents who would like to become a *supporting parent.*

☑ Information on local, state and national resources for the child and family.

☑ List of informative books on issues related to children with special needs.

For more information regarding Parent to Parent, if you would like to be matched with another parent or become a supporting parent contact fvnd@drtel.net or call our toll free number at **888-522-9654**

News from staff across the state

FVND staff are in Bismarck, Dickinson, Fargo, Grand Forks and Edgeley
Call us at 888-522-9654

I have attended quite a few IEP meetings early this fall, making sure health care plans are being updated and reviewed or implemented with the child's IEP. Most of all I enjoy working and meeting the families and working with the Experienced Parent in our local region and across the state. Wishing everyone health and happy holidays to come.

Brenda in Fargo-
Greetings from Fargo. It has been a busy fall. Donene and I attended the High Impact Fund Raising Training through the Impact Institute in September. The training was excellent and we hope to devise a productive fundraising strategy soon. The need for more training, support and advocacy for families of children with special health care needs is growing in our state and the difficult economy dictates the need to actively fundraise in order to continue to meet the needs of the families we serve. If you as a parent, guardian or provider have any suggestions for our fundraising efforts or know of any individuals who share our passion in supporting families of children with special health care needs that may be interested in becoming a donor please contact Donene or myself.

Last month one of my dreams for the Fargo area came true. We started our first support group for parents/guardians of children with special health care needs ages 3-21. We had 8 parents attend our first meeting and I am confident this number will grow very quickly. The support group will meet every month.

I have mailed an announcement to all of the families in the FM area that are in the FVND database. If you would like to receive an announcement by email, please email me at schmid@cableone.net.
I helped plan and coordinate the "Old Navy Special Day" for 2 local groups. 10 kids from "Riding on Angels Wings" (therapeutic horseback riding) and 10 kids from Hope Inc.
Hope Inc. (recreational activities for children with mobility challenges) won a drawing to take part in a very special day provided by Old Navy (Fargo, ND) and a handful of other local businesses.
One of my biggest jobs this fall has been trying to keep Hannah (our 12 year old with special needs) healthy.
There has been a great deal of "stuff" on the internet about the H1N1 vaccine. If you have any questions or concerns about the vaccine contact your child's primary physician. To learn about distribution of the H1N1 vaccines in the Fargo area go to www.meritcare.com and look under "Featured Articles" and/or http://innovis-health.wordpress.com/h1n1/ .

In closing I would like to share a personal note. Thanksgiving is one of my favorite holidays. Thanksgiving is a time to be thankful for all of the blessings in our lives. Hannah has taught us how to be thankful for everyday, for every little accomplishment, to be thankful for each other, family, friends, doctors; providers…take nothing for granted. Wow she is one amazing little girl…I bet some of you reading this have a pretty amazing kid too.

Joan in Grand Forks-
We are so excited to have partnered with Infant Development in Grand Forks and started a Family and Friends support group for families in the Grand Forks and surrounding area.

We held our first meeting on October 8th and had a great turnout. It was a "Meet and Greet" pizza party and really rewarding to see families bond with each other. We look forward to upcoming meetings, and play groups! All meetings are held at The First Seasons Community Center in Purpur Arena.

We are looking forward to the Parent Navigator and Parent to Parent workshops at Northeast Regional KIDS Infant Development, 1826 South Washington, Suite 33B.

Our all accessible playground is nearing completion. Ali's Boundless Playground opened the end of August. There are still a few pieces of equipment to be installed. It is so much fun to see kids of all abilities enjoying it. **(See Ali's story on Page 3, Congrats to Ali and all involved in the playground)**

Family Voices Of ND

One in every 5 households in North Dakota has a child with special health care needs.

Who are these children we speak so fondly about?

They are your next door neighbor, they are the girl in the choir, the boy in Scouts, they are the child under your own roof, they are the alter server, one of the kids who helped sandbag, the football player, the dancer, the piano star, they are a part of each and every one of us.

Our role at FVND is to be a network of families, friends and providers whom advocate for health care services that are family friendly, community based, comprehensive, coordinated and culturally competent for all children and youth with special health care needs
Promoting the inclusion of all families as decision makers at all levels of health care and policy.
Assuring services are understood.
FVND encourages, supports and works diligently to assure essential partnerships between families and professionals occur.

New Parent Navigator Teams!
Coming to an area near you soon!

I am excited to announce that we have formed two Parent Navigator Teams in North Dakota. The first Parent Navigator Team Workshop was in Region 8 (Dickinson) and the second one was in Region 3 (Devils Lake). Between now and May 2010, I will be traveling to each region in North Dakota to help parents create their regional teams.

Parent Navigator Teams are teams that work to strengthen families, especially those with disabilities and special health care needs, through a region wide parent-led volunteer network. Navigator Teams help to find or develop resources to meet the unique needs of their region. They serve as a point of contact in the community, work in partnership with local leaders, share their knowledge of local resources and provide guidance to other families. Navigator Teams are a project of the ND Parent to Parent Program under the supervision of Family Voices of ND.

The Navigator Team is a diverse blend of parents, professionals and community leaders. Each team has:

A Leader who oversees the activities of the local team. This person serves as a main point of contact for each Navigator Team.

Members who attend meetings, help plan events, receive information and help to do the work that needs to get done.

A Resource Network composed of agencies or other interested parties that collaborate with the Navigator Teams on activities and events.

Here are some of the comments from parents about the most valuable thing they learned at the first Parent Navigator meeting in their region:

- "Just being able to get together with other parents and discuss issues we want people to be more aware about."
- "It just felt empowering."
- "Being given the opportunity to make positive changes in the community."
- "That we can accomplish a lot of we work together."

Join us at the next Parent Navigator Workshop in your region:

- **Williston, Sat., January 9th**
- **Bismarck, Sat., February 20th**
- **Fargo, Sat., March 20th**
- **Jamestown, Sat., April 17th**
- **Minot, Sat., May 8th**

Contact Missi Baranko (701-290-8711 or 888-522-9654 or missi.baranko@gmail.com) if you are interested in attending one of the above Parent Navigator workshops or if you want to part of the Parent Navigator Teams in Region 8, Dickinson (The Dynamic Western Edge Parent Navigator Team) or Region 3, Devils Lake (The North Central Crew).

What's Happening

Parent Navigator Team in Devils Lake

The North Central Crew Parent Navigator Team has recently formed. We are currently looking to increase our membership.

We have determined some of the goals our group would like to address. As one of our highest priorities is expanding on the social opportunities of our kids, we have planned a bowling and potluck get together for Veteran's Day at the bowling alley in Devils Lake. Be looking for more details on BigTent.com or in the Family Voices e-newsletter if you are in our area and would like to attend!
Marcia Schneider Team Leader

Parent Navigator Team in Dickinson

The Region #8 Dynamic Western Edge Parent Navigator Team is formed and already coming up with great ways to assist families within our Region.

We have had one official meeting, picked a team leader, had a start up donation provided, and have discussed fundraising ideas and events that we want to have.

Also discussed were what approach our group is going to take in getting our mission and purpose out to the communities that we serve. We are all very excited to be part of such a worthwhile organization and can't wait to start making a difference on the Western Edge of North Dakota in Region #8.
Thank you! Melissa Pavlicek

Congratulations Family Leaders

Family Voices of North Dakota hosted two Family Leadership Institutes in May and August 2009. Both have been a great success, thanks not only to the families who have attended but also because of our partners on the planning committee. They are: Carlotta McCleary and Deb Jendro, Federation of Families for Children's Mental Health, Holly Major and Cathy Haarstad, Pathfinder Family Center, Vicki Peterson, Missi Baranko, and Linda Schatz, Family Voices of ND Jen Restemeyer and Roxane Romanick, Experienced Parent, Deb Unruh, and Sue Burns, Children's Special Health Services. Each has played a tremendous part in making this weekend a success.

In May 2009, our guest speakers were Joyce Smith who presented the group with information on identifying personality types through Colors workshop, Patti Hackett, Healthy and Ready to Work project and Bruce Murry Protection and Advocacy.

In August 2009, our guest speakers were Dave Pearce, Julie and Katie Beckett and Teresa Larson from Protection and Advocacy.

The Family Leadership Institute was developed to provide families the information and tools necessary as they advocate for their child with special health care needs. Learning the various systems of services and tools to help each of them grow as a leader.

This year's Family Leadership Institutes were made possible in part by: ND State Council on Developmental Disabilities, Robert Wood Johnson Foundation, Children's Special Health Services, and the Maternal and Child Health Bureau.

Watch for announcements for the 2010 Leadership Institutes!

Family Leadership Institute May 09

Family Leadership Institute Aug 09

Vivian Modin Recipient

Jonah Pavlicek wants to author a book one day. Jonah is the first recipient of the Vivian Modin Helping Hands Fund. A Dragon Naturally Speaking software was purchased to help him achieve his dream.

Pictured with Jonah is his mom Melissa and Vicki Peterson who presented to him the software.

Positive Parenting

*Compliment and encourage your child every day...
Smile a lot in your home.
*Always have a listening ear and feeling heart with your child.
*Tell them you love them as a person. Although there may be a behavior you dislike.
*Understand and try to meet your child's need for attention in a positive way to reduce the need for negative attentions
*Each child is an individual. Treat each child as being special and unique.
* If your child fails at something, remind him of all his successes and that he will succeed again.

We Are In This Together

A mouse looked through the crack in the wall to see the farmer and his wife open a package. "What food might this contain?" The mouse wondered –he was devastated to discover it was a mousetrap.

Retreating to the farmyard, the mouse proclaimed the warning. "There is a mousetrap in the house! There is a mousetrap in the house!

The chicken clucked and scratched, raised her head and said, "Mr. Mouse, I can tell this is a grave concern to you, but it is of no consequence to me. I cannot be bothered by it."

The mouse turned to the pig and told him, "There is a mousetrap in the house, There is a mousetrap in the house!

The pig sympathized but said, "I am so very sorry, Mr. Mouse, but there is nothing I can do about it but think of you. Be assured, you are in my thoughts.

The mouse turned to the cow and said "There is a mousetrap in the house! There is a mousetrap in the house!

The cow said, "Wow, Mr. Mouse. I'm sorry for you, but it is no skin off my nose."

So the mouse returned to the house, head down and dejected, to face the farmer's mousetrap alone.

That very night a sound was heard throughout the house—like the sound of a mousetrap catching its prey.

The farmer's wife rushed to see what was caught. In the darkness she did not see the venomous snake whose tail the trap had caught.

The snake had bit the farmer's wife. The farmer rushed her to the hospital, and she returned home with a fever. Everyone knows you treat a fever with fresh chicken soup, so the farmer took his hatchet to the farmyard for the soup's main ingredient.

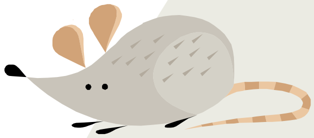
But his wife's sickness continued, so friends and neighbors came to sit with the farmer around the clock. To feed them, the farmer butchered the pig.

The farmer's wife did not get well; she died. So many people came for the funeral, the farmer had the cow slaughtered to provide enough meat for all of them.

The mouse looked upon it all from his crack in the wall with great sadness.

So, the next time you hear someone is facing a problem and think it doesn't concern you, remember —-when one of us is threatened, we all are at risk.

We are all involved in this journey called life. We must keep an eye out for one another and make an extra effort to encourage one another.



Fruits and Vegetables Recipe Database

Getting tired of coming up with ideas for meals? The Center of Disease Control (CDC) has a neat web feature that allows you to select the fruit(s) or vegetable(s) then it brings up recipes containing fruits and vegetables selected. You can also find recipes by meal type i.e. breakfast, dessert, entrée, soups, etc.
Visit them on the web at http://apps.nccd.cdc.gov/dnparecipe/recipesearch.aspx

Homemade Baby Wipes

In these tough economic times it sometimes is helpful to find other resources...Here is one

Take a roll of quilted Bounty and cut it in half (an electric knife works great).
Put in a container that has a tight seal.
Mix 2 cups of boiling water with 2 Tablespoons of baby oil.
Pour over paper towels and seal.
Let set for 30 minutes and then turn the paper towels.
Let it set for another 30 min.
And then pull out the cardboard insert. Pull the first one from the center and you are ready to go.

KINfolk

Providing Laptop Computers and Internet Access to Stay In Touch- Ask any teen, he will tell you that communication with friends, family and school is about as important as it gets. Now consider the child, of any age, who is hospitalized, sometimes far from home. Communication literally becomes a lifeline.

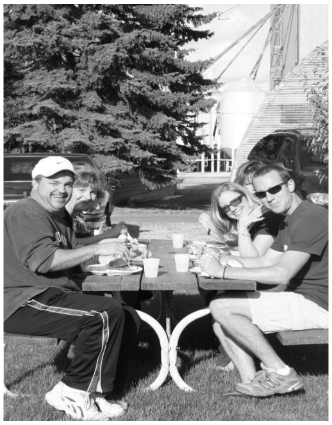
That's where KINfolk can help. Since 1999, KINfolk has been lending laptops and internet access to children whose lives have been disrupted by disease and injury. These laptops provide children nationwide and their families a means of communication—with the very people who love and support them at a time when they need it the most. The laptops are loaded with games and fun sites for kids along with internet filter to prevent access to undesirable sites.

KINfolk Hospital Program– provides laptop computers to pediatric hospitals who request the service. The computers support dial up, wired and wireless Internet connections. We encourage hospitals to assign laptops to children in their rooms so that they have access to the laptop 24 hours a day. Parents and siblings are encouraged to use the laptop as well.

KINfolk Direct Loan Program- with a referral from a health care professional, KINfolk process a loaned laptop to children who are convalescing at home. Because the computer will be used by just one child, each is tailored to the specific needs of that child. The child may use the computer from both home and hospital. After the proper referral, they deal directly with the child's family, although in some cases, the child's social worker or hospital volunteer helps with the arrangements. When the child no longer needs the laptop, it is returned directly to the KINfolk.

For more information contact them at: (302) 765-9550; E-mail: kinfolk1@verizon.net

Finding Peer to Peer Support as a Parent



We all know the saying that it takes a village to raise a child. When the child has special needs, this saying is even truer. We need a village to help us with all aspects of raising our children with complex issues, including physical help, assistance with caregiving, medical assistance, practical guidance from others who have walked in our shoes, or emotional support.

Finding peer support as a parent is probably the most important part of this "village." Not only can peer support provide you with the emotional support you need, but peers have also typically gone through many of the same experiences as you have. They can guide you through the many medical, legal, and educational challenges you may face, as well as providing practical tips on everything from equipment and technology to therapy and services.

How do you find peer support? There are four overlapping types of groups that may be helpful to you.
These are:
-National organizations (mostly disease or condition-oriented)
-Local support groups
-Online support groups
-Peer-matching or parent to parent services

National Organizations-National and international organizations, most of which have a discrete focus on a specific disease or condition, can be wonderful in helping you connect with other families from all over the world who are sharing the same struggles. Many of these organizations are quite large and have both a national and local presence in the community. Some, like Easter Seals or UCP, have a broad focus on helping all children with disabilities, while others are established solely to connect individuals with the exact same disease. The best way to find these sorts of national organizations is to search the internet for your child's condition. If the condition is very common, like cerebral palsy or autism, it may be helpful to search for both the name of the condition and the word "support."

Local Support Groups-Local support groups differ from national organizations in that they attempt to provide support between families in a more direct, face-to-face manner. Many have weekly, monthly, or bi-monthly meetings to socialize, plan events, and provide support. Many allow the entire family to participate, while some are restricted to certain types of individuals, such as dads or siblings.

Local support groups can be invaluable because they are filled with individuals who have not only walked in your shoes, but have done it in your very own community. They tend to know the best doctors, therapists, and services available, and can give very specific advice and support based on availability in the community.

Local support groups can be more difficult to find, especially if your child has a rare condition. Many times, local support groups have a broader focus, such as all children with physical disabilities or all children in special education.

Online Support Groups

Online support groups have grown and flourished over the past decade and have become the backbone of support for many families. Online groups not only allow people from all over the world to connect on a daily basis, but they have also made it possible for families with very unusual or rare conditions to find each other and provide emotional or practical assistance. One fantastic thing about online support groups is that they allow you to both provide and receive support on a day-to-day basis. Many parents feel empowered when they are able to share their knowledge and support others, and many have commented that providing support has ultimately been the key to their own happiness and acceptance.

Finding online support groups is usually easy. Some may be associated with national organizations or on organization resource pages. Others, specifically tightly-focused or disease-specific groups, are typically housed on the sites Yahoo Groups or Google Groups, both of which have their own search engines. Larger and more broader sites, such as parent to parent sites, can be found by searching using terms like "special needs support site." The quality of online support groups varies widely, and one group may or may not be a good fit for you as an individual. If this is the case, look for another group. They are out there.

Peer-Matching Services-Most states have a parent to parent program that will match families on a 1:1 basis for emotional and informational support. **FVND houses the Parent to Parent Program for North Dakota. We are connected to the other parent to parent programs around the country and can assist you in locating what you may need. Join the Family Voices North Dakota Parent to Parent Program at BigTent.com www.bigtent.com/groups/ndp2p**

Reap the benefits-At first, it may be awkward and uncomfortable to reach out to others for emotional or practical support. Take it one day at a time and you will most likely begin to see the benefits, as parents with experience help you through some of the most difficult situations you may encounter. Even if you can't do it for yourself, do it for your child. Every child, and especially a child with special needs, needs a village.

Children with special health care needs are those children who have or are at risk for chronic physical, developmental, behavioral or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.

The above definition was developed by the Maternal and Children Health Bureau, Division of Services for Children with Special Health Care Needs in collaboration with many experts in child health including parents, and has become widely accepted. This definition includes children with a broad range of conditions or chronic illnesses such as cerebral palsy, developmental delay, ADHD, depression, asthma, sickle cell anemia or cystic fibrosis as well as children who develop a significant medical problem that is expected to last at least twelve months.

The Maternal and Child Health Bureau definition helps to identify children based on the impact of their special health need and their need for health and related services, rather than only on their diagnosis. Many children have more than one special health need.
A recent national population based survey estimates that over 9 million (12.8 percent) children in the United States presently have a special health care need. One in five households include children with special health care needs. diagnosis and routine treatment and monitoring.

Who Are Children with Special Health Care Needs?

Some children with special health care needs require only an accurate diagnosis and routine treatment and monitoring. Other children will need life-sustaining technology, treatment, and medicines throughout their lives. Children with special health needs tend to receive their health care from a combination of private and public financing and delivery systems, and many depend on multiple providers. Almost all children with special health care needs, no matter the severity of their condition, live at home with their parents and brothers and sisters.
Children with special needs above all deserve a health, happy childhood and a chance to grow up to be productive adults. Like all children, they live with their families in towns, cities and rural areas of the United States , going to school, attending worship services, enjoying community events. However, unlike most children, they also have challenging health conditions that usually make their lives and their families' lives more complicated. Any child, at any time, could develop a disability or

Integrated Services Grant and Medical Home Update-

Medical Home in North Dakota Can I MapQuest it?
Well the answer is yes, sort of. While we all know that Medical Home is not a building or a clinic but a way of providing family centered care for children and youth with special healthcare needs (CYSHCN), you can now MapQuest it.

There are five primary care provider teams across the state working as a pilot medical home project under the North Dakota Integrated Services (NDIS) at North Dakota Center for Persons with Disabilities. These Medical Home Pilot Site teams have dedicated their time and staff to take a critical look at ways to improve care for the CYSHCN population they serve. They have partnered with families from their practice and made them team members and decision makers on the team. Thank you to those parents on the teams who are giving their time and lending their expertise in order to be a voice for all families in the practice. The following practices are working hard to improve care, document improvement and implement change that will benefit all who are in their practice: Thomas Carver DO- Trinity, Minot; Cynthia Davilla MD-Standing Rock Indian Health Services, Fort Yates; Russ Petty MD- Devils Lake Community Clinic, Devils Lake; Chris Tiongson MD- MeritCare, Fargo; Myra Quanrud MD- Innovis, Jamestown

NDIS is currently working on recruiting three more primary care practices in certain areas of the state. If you think your provider would be interested please use contact information below. For more information go to www.ndcpd.org/ndis or contact Kora Dockter, Project Director at 1-800-233-1737 or kora.dockter@minotstateu.edu

IN OTHER NEWS

National Center for Cultural Competence

The National Center for Cultural Competence (NCCC) has a project dedicated to children and youth with special health needs and their families. The purpose of the Children & Youth with Special Health Care Needs (CYSHCN) Project is to assist state Title V Maternal and Child Health and CSHCN programs to design, implement and evaluate culturally and linguistically competent service delivery and support systems. They have many resources available for you, check them out today: **http://www11.georgetown.edu/research/gucchd/nccc/projects/cyshcn.html**

> "I'm excited to be part of the medical home team because I feel empowered. Being part of a team that is making a real difference in how our medically complex children are cared for is amazing. I'm proud of the hard work that each team member is investing in this effort. Change is not easy, but things like care plans and care coordination make a world of difference. Being a parent on the team allows me to share my experiences to help shape care changes not only for my child, but for all children with special health care needs."
> ***Parent Partner-Meritcare***

Donene Feist, Director

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How Can We Help You and You Help Us? Support FVND by becoming a member or donor today.

You could help us by assisting in workshops, writing articles, being a Support Parent and much more…Or you can provide a Cash Donation by making a contribution to FVND which will assist with workshops, matching a parent 1:1 for emotional assistance, Regional Parent Navigator Teams and much more!

_____To be used where needed ________Endowment _________________
____In honor/memory of ______________ _____Living Tribute for_________________

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Enclosed is my tax deductible to FVND
Donation of _______ $250 _____$100 _____$50 _____$25 _____$10 ______$5

Fill out this form, cut out and mail to Family Voices of North Dakota PO Box 163 Edgeley ND 58433

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