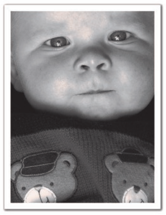


ISSUE 28 VOLUME 4 YEAR 2011

FAMILY VOICES OF NORTH DAKOTA®

Navigating Crossroads to Hope

The Navigator

FAMILY VOICES OF NORTH DAKOTA-A HEALTH INFORMATION AND EDUCATION CENTER ***"SUPPORTING FAMILIES HAVING CHILDREN WITH SPECIAL HEALTH CARE NEEDS AND DISABILITIES AND THE PROVIDERS WHO PROVIDE CARE FOR THEM"***

Navigating Crossroads to Hope

From the Director-
Welcome Back to School! Here is hoping for great success for teachers, students and families!

What a year this has been! Weather has been a huge issue for North Dakotans! One great outcome that I have witnessed is the resilience of our people. It is humbling to say the very least!

People helping people...that is what it is all about. I feel North Dakota takes great pride in our investment in Human Capital. From adversity and strife we continue together to protect what is important to us.

Vaclav Havel said "Hope is a state of mind, not of the world. Hope, in this deep and powerful sense, is not the same as joy that things are going well, or willingness to invest in enterprises that are obviously heading for success, but rather an ability to work for something because it is good."

Our hope is that we will all continue to work together for something good.

We look forward to the year with much hope! The FVND Board has completed a strategic plan, and the staff has been extremely busy over the summer months. In June we held our Parent Leadership Institute. Staff participated in conferences, 1:1 assistance, emotional and informational support, provided trainings and hosted support groups.

For the upcoming fall and winter we have many scheduled topical calls, Parent to Parent trainings, workshops in the days ahead. FVND will showcase their new video soon. We are beginning to plan for the 2012 Leadership Institute and an Family Leaders Retreat. Watch for updates in the days ahead.

Hope….is what FVND is all about. Here is to great successes and the celebration of YOU! Please take note of the letter from our Board President on Page 4. We need your help!

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, Williston, Minot, 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 888-522-9654**

Life is not measured by the breaths we take, but by the moments that take our breath.

I was at the corner grocery store buying some early potatoes. I noticed a small boy, delicate of bone and feature, ragged but clean, hungrily apprising a basket of freshly picked green peas. I paid for my potatoes but was also drawn to the display of fresh green peas. I am a pushover for creamed peas and new potatoes. Pondering the peas, I couldn't help overhearing the conversation between Mr. Miller (the store owner) and the ragged boy next to me.

'Hello Barry, how are you today?' 'H'lo, Mr. Miller. Fine, thank ya. Jus' admirin' them peas. They sure look good.' 'They are good, Barry. How's your Ma?' 'Fine. Gittin' stronger alla' time.' 'Good. Anything I can help you with?' 'No, Sir. Jus' admirin' them peas.' 'Would you like to take some home?' Asked Mr. Miller. 'No, Sir. Got nuthin' to pay for 'em with.' 'Well, what have you to trade me for some of those peas?' 'All I got's my prize marble here.' Is that right? Let me see it,' said Miller. 'Here 'tis. She's a dandy.' 'I can see that. Hmm...only thing is this one is blue and I sort of go for red. Do you have a red one like this at home?' the store owner asked. 'Not zackley but almost.' 'Tell you what, take this sack of peas home with you and next trip this way let me look at that red marble,' Mr. Miller told the boy. 'Sure will. Thanks Mr. Miller.' Mrs. Miller, who had been standing nearby, came over to help me.

With a smile she said, 'There are two other boys like him in our community, all three are in very poor circumstances. Jim just loves to bargain with them for peas, apples, tomatoes, or whatever. When they come back with their red marbles, and they always do, he decides he doesn't like red after all and he sends them home with a bag of produce for a green marble or an orange one, when they come on their next trip to the store.'

I left the store smiling to myself, impressed with this man. A short time later I moved to Colorado, but I never forgot the story of this man, the boys, and their bartering for marbles.

Several years went by, each more rapid than the previous one. Just recently, I had occasion to visit some old friends in that Idaho community and while I was there learned that Mr. Miller had died. They were having his visitation that evening and knowing my friends wanted to go, I agreed to accompany them. Upon arrival at the mortuary we fell into line to meet the relatives of the deceased and to offer whatever words of comfort we could. Ahead of us in line were three young men. One was in an army uniform and the other two wore nice haircuts, dark suits and white shirts...all very professional looking. They approached Mrs. Miller, standing composed and smiling by her husband's casket.

Each of the young men hugged her, kissed her on the cheek, spoke briefly with her and moved on to the casket. Her misty light blue eyes followed them as, one by one; each young man stopped briefly and placed his own warm hand over the cold pale hand in the casket. Each left the mortuary awkwardly, wiping his eyes.

Our turn came to meet Mrs. Miller. I told her who I was and reminded her of the story from those many years ago and what she had told me about her husband's bartering for marbles. With her eyes glistening, she took my hand and led me to the casket.

'Those three young men who just left were the boys I told you about. They just told me how they appreciated the things Jim 'traded' them. Now, at last, when Jim could not change his mind about color or size...they came to pay their debt.' 'We've never had a great deal of the wealth of this world,' she confided, 'but right now, Jim would consider himself the richest man in Idaho.' With loving gentleness she lifted the lifeless fingers of her deceased husband. Resting underneath were three exquisitely shined red marbles. The Moral of the Story: We will not be remembered by our words, but by our kind deeds. Life is not measured by the breaths we take, but by the moments that take our breath.

Today I wish you a day of ordinary miracles ~
- A fresh pot of coffee you didn't make yourself.
- An unexpected phone call from an old friend.
- Green stoplights on your way to work or home.
- The fastest line at the grocery store.
- A good sing-along song on the radio.
- Your keys found right where you left them.

And remember...
IT'S NOT WHAT YOU GATHER, BUT WHAT YOU SCATTER THAT TELLS WHAT KIND OF LIFE YOU HAVE LIVED

My Child Without Limits-MyChildWithoutLimits.org is an early intervention resource for families of young children ages 0-5 with developmental delays or disabilities, and professionals looking for a single, trusted, aggregate source of information that relates to their needs and interests.

MyChildWithoutLimits.org offers information in three basic areas:

- Understand-helps to answer questions such as “What is autism spectrum disorder?” and “What is cerebral palsy”
- Plan-guidance on where to go for early intervention services, treatments and therapies, assistive technologies and working with experts.
- Act-when you’re ready to explore issues surrounding disability awareness, advocacy and lifespan planning.

They also offer a community section where parents can communicate with each other, ask questions of professionals and service providers, and receive support through the critical period of initial diagnosis. The site includes a national Resource locater where visitors can find local service providers, community organizations and government agencies. Check it out: www.MyChildWithoutLimits.org

Healthcare Tip

Keep a copy of your medical records-Empowered patients are those who become active members of their healthcare team. Obtaining and keeping copies of medical records including images (x-rays, scans, CT, MRI) and lab results is good advice for any person receiving medical attention. For those who have chronic and/or rare conditions, it is even more crucial that these medical records are preserved.

By keeping a copy of records, you can reduce unnecessary duplication of tests and can assist new physicians or specialists in seeing the full picture of your health.

One option for storing and transporting your records to and from appointments is to purchase an art portfolio holder. These carrying cases are usually sold in art supply stores and can easily accommodate large images and documents while providing privacy and protecting the items from the elements.

Another idea is to keep electronic copies of this information (password-protected) on a jump drive that you can easily take with you to appointments.

It is easiest if you ask for a copy of documents, images and test results after each visit. It will save you from a headache later if you do not remember where and when a particular test was performed.

Launched in January 2011 and created by Andy Fine, a parent, teacher and self taught web designer, SlimeKids was created to provide students with a playful, easy to use interface through which they could learn about and access valuable online resources.

The website is designed to self motivate students to make their own choices and judgments about what is most useful for them. One important aspect of SlimeKids is that it helps students to explore their own interests in books and reading.

SlimeKids is an interactive website through which students can read, search, watch videos and play language arts-related games. SlimeKids is an acronym for school library media kids because it combines all of those elements. Check it out at www.slimekids.com

Reaching Out to Children and Youth Following Disasters

The impact on children and families of disasters, terrorism, trauma or violence presents many challenges to families and health professionals.

“Reaching out to Children and Youth Following Disasters Resource Brief”, available online through the Maternal and Child Health (MCH) Library at Georgetown University provides resources for helping children and adolescents cope with injury; loss of loved ones, destruction of homes and schools and other trauma.

Check it out at:
www.mchlibrary.info/guides/reachingout.html

“Too often we under estimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around.”

Leo Buscaglia

Pres. Tammy DeSautel and her family

A Request From Our FVND President

Greetings to all of you!

You May be surprised to know….One in Five Households across North Dakota has a child with a chronic health condition or disability! We are one of those very households. Hi, my name is Tammy DeSautel and I am the Board President for Family Voices of North Dakota (ND). I have been involved with Family Voices of ND since its inception in 1997 and I have seen repeatedly the positive impact it has had on ND families who have children with special healthcare needs.

Our daughter, Macy, is my heart and soul. Because of a traumatic delivery Macy has a severe brain injury and is diagnosed with Cerebral Palsy. Family Voices of ND did not exist when Macy was born. Macy's first years were very challenging, not only were we new parents but now we were new parent's of a beautiful baby girl who needed a great deal of special care. We had nowhere to turn. Any resources we found were on our own. Thankfully Family Voices of ND has changed that and when a family finds themselves at a crossroad they now have Family Voices of ND as a place to navigate through those crossroads.

North Dakota has seen its share of natural disasters this past year; everything from debilitating snow storms to horrific flooding. Alone, these disasters are difficult to endure without having to consider providing best of life circumstances for those families who have a child or children with special needs.

Initially, when a child is diagnosed with a chronic health condition or disability it is a shock to the family. It can be a crisis of immeasurable magnitude, but like all crisis there is help and there is hope. Family Voices of ND provides that hope.

Through its services, Family Voices of ND offers many vital linkages to families who have special healthcare needs. Some of these services include:
1) ND Parent to Parent Program which offers 1:1 emotional and informational support;
2) Family Leadership Institute to assist families in reaching their own personal goals and become stronger advocates;
3) Regional Parent Navigator Teams identifying needs and gaps in particular areas of the state both rural and urban and together finding solutions;
4) Assistance navigating and understanding systems, often connecting families with the resources they will need to raise their son or daughter with special needs.
5) Training and education to families and providers regarding systems, diagnosis, best practices and much much more!

With One if Five Households in the state, having a child with special health care needs, I ask you…"How are the children?"

"How are the children" is a common greeting among the Masai Tribe of Africa. The Masai Tribe is among the most accomplished and fabled tribes of Africa, no tribe was considered to have warriors more fearsome or more intelligent than the mighty Masai. It is perhaps surprising, then, to learn the traditional greeting that passed between Masai warriors:"Kasserian Ingera," one would always say to another. It means, "And how are the children?"

It's nice to know that Family Voices of ND is always there when a family is in need. Providing these valuable services is not always easy. The staff at Family Voices understands the challenges and crossroads that are faced by the families they serve because they have been there; they are parents of children with special needs. We need your help!

With your help of $1, $5, $50, together, we will be able to say, "The Children Are Well!"

Just remember **One in Five Households**…it could be your neighbor, someone from your church, a family member. Won't you help us today? Let us all do our part to say "the Children are Well". For your convenience we have enclosed a self addressed envelope.

Sincerely,

Tammy G DeSautel

News from staff across the state

As I write this, the kids have now been back to school for a few days and we are trying to get back into checking backpacks nightly and doing homework. This is a hard thing to do when the evenings still feel like summer and all you really want to do is sit on the deck eating ice cream! I keep hearing, "Where did the summer go, I can't believe school has started!" I greatly agree, but I know exactly where summer went this year.

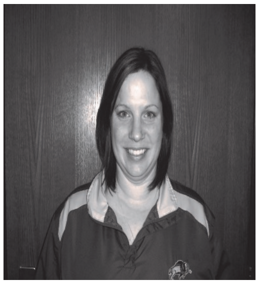
It was spent running the kids all over with fun activities like Ukrainian Camp and 4-H as well as running to many doctor appoints for both myself and two of my children. The days were spent in the backyard jumping on the trampoline or mowing the lawn and the evenings were spent thinking about what the future will look like. As we all know, none of us has control of our future. Sure we can try to do things to get it to go the way we hope, but essentially some things just happen.

For many of us with children with special health care needs and for those of us with our own medical issues, we especially know this is true. This summer I had the opportunity to experience health concerns that were significant enough for my doctor to tell me I must slow down.

It was not easy to hear and at first I didn't want to listen. But the doctor (and my family) were right. In July, I made the very difficult decision to resign from my position with Family Voices of North Dakota. I will greatly miss everyone as well as the work I did, but I continue to reassure everyone, that just because I am not officially employed with FVND doesn't mean you won't be seeing me around. I will continue to serve on some of the state committees as well as continue to work part time in Early Intervention. I am so thankful for all the support I have received and know that my journey ahead is much better because of my experiences and the support I have been given. FVND recently hired a new coordinator, Moe Schroeder, who will be great in this position. Moe and I have worked together in the past and I look forward to hearing about all the great things she is doing with FVND! Again, thanks to everyone for all the wonderful memories. Don't be a stranger, email me anytime to let me know how you are doing. (missi.baranko@gmail.com)

And with that, I will leave you with my new favorite saying, "Very little is needed to make a happy life."

Thank You Missi for your dedication, compassion and hard work



Welcome Melissa (Moe) I began supporting parents long before I found myself needing to be supported. I connected with parents by providing In-Home Supports while caring for their children. Since beginning my journey with all of them, my husband Rob and I have had two beautiful children, Kasey and Tyler.

Kasey is a bubbly, shoe shopping, book loving, sports playing girl. Her kind heart is always worn on her sleeve.

We envy her unselfish willingness to put others first.

Tyler is our little fireball who has had us on our tiptoes since utero. He was prenatally diagnosed with a complex form of congenital heart disease at 22 weeks. Since birth he has had three open-heart surgeries. The possibility of needing a heart transplant at some point in his life is highly likely, but for now medication is enough for him to carry on and be himself. Tyler loves music, swimming, and reading books. We have learned to enjoy today and worry about tomorrow when tomorrow comes.

Since Tyler's birth I have found myself wanting to reach out to other parents by providing support and helping them steer through the resources that our state has to offer. I am currently working as an Experienced Parent in the Fargo Region. I also joined the Family Advisory Board for Children Special Health Services and also provide information from a parent's perspective for the Sanford Fargo Medical Home Team.

Words cannot express how excited I am to be part of the Family Voices Team!! I am anxiously waiting to meet all of you!

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

Vicki in Bismarck-Hello everyone, Vicki Peterson from the Bismarck-Mandan region. This summer has been a very unusual summer. I want to extend my thoughts and prayers for all those affected by the Floods of 2011. My own family has been affected as well as many families I work with and know. I feel very proud to live in communities where we know we can count on volunteerism and come together to help others in need. The loss is enormous but I know we all will rebuild our communities.

I spent the early summer weeks sandbagging, as did so many North Dakotans and people from around us as well. I learned a lot and hope that we can create some good emergency management plans from what we learned. I also participated in a wonderful Make A Wish walk where we all had the privilege of celebrating a special birthday for Allison Restemayer and to walk and raise hope and money for many children. I have met many new families in the region and continuing to support them. Finished another legislative year in ND and followed the bills that affect the children with special healthcare needs. Participated in the Legislative Working Committee here in Bismarck which is always a wealth of knowledge? Preparing materials for my Special Education Support Group which will start up again in September. . Have had a great opportunity to match many more parents in our Parent to Parent program and would like to extend a huge thanks for all those parents supporting other parents. I continue to be on Region VII RICC and a board member on Pathfinder. Pathfinder lost their building in the flood in Minot but continue to help the community.

The NDAC Annual Autism Walk was August 13th . Changes are happening, and the change at Family Voices of ND will be the resignation of Missi Baranko. I will miss you Missi but know you will do well in your new endeavors.

On a personal note, my son Aaron whom has autism learned to read from adaptive library that was created and it was just the BEST present, to know he has gone from non verbal to verbal to reading, I want to thank his great team of teachers. Erik, the baseball guy, finished his last season of Legion Baseball and had a great year…highlight hitting two homeruns in one game to win the game!! Summer is winding down and we're getting geared up for another school year.

Joan in Grand Forks-
Greetings from Grand Forks! Summer has gone so fast, I hope everyone was able to enjoy it! It is hard to believe another school year is just beginning. It will be a milestone, as my daughter is a senior and is beginning the transition process not only from high school to college but also to adult medical care. I don't know where all of those years have gone!

My daughter and I attended the Spina Bifida Association of America National Conference in June. We attended many interesting sessions. I'm thankful to have been able to attend and return with lots of information to share with our families. We really enjoyed meeting other kids and adults with Spina Bifida and hearing their amazing stories.

We attended the ND Transition Youth Leadership Conference in Bismarck, in July. Teenagers and young adults were able to listen to several great presenters on how to advocate for themselves. We enjoyed it very much and look forward to attending again next year.

National Night Out was just held in Grand Forks. It is a huge block party presented by the police department to fight crime and drugs. I enjoyed meeting new families and their children!

I have been attending the ACT Team meetings at Northeast Human Service Center. I thank them for inviting me to be a part of the team. I look forward to participating in the "Family Resource Fair" at the Grand Forks Air Force Base in September and being able to assist military families in the area.

I have enjoyed meeting new families and being able to assist them with information and resources they are in need of. I really enjoy connecting them with support parents as that was such a positive in my life when I learned of my daughter's diagnosis. We are still in contact and great friends after 17 years! If you are in need of any help in this area of the state please contact me at: 701 330-8641.

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.

News from Staff

Joscelyn in Williston-
Things are going great in Williston!
This town is as busy as ever and I am eager to meet new people!

We have a parent navigator meeting every 3rd Thursday of the month at 6:30, Our Redeemers Lutheran Church. Everyone is welcome!!!

I have been connecting with new families and with school starting I hope to connect with more! I have been reaching out and be coming involved with professionals in the community.

I also attend college, and back to school is already here which is so hard to believe.

Looking forward to new opportunities for parents, assisting in any way that I can!!!

Thanks to all of the FVND Board and staff for their dedication!

Brenda in Fargo

Greetings from Fargo and the surrounding area. I continue to work on partnerships with providers. We at Family Voices want providers to understand that we are partners in supporting families of children with special health care needs. At the end of the day we all want the same thing for the families we serve. We want families to have the guidance, support, resources and tools to help them take care of their child with special health care needs. We want families to thrive in their environment and situation or as better stated on the cover of the newsletter "Bloom Where You're Planted".

The message of "Collaboration" is loud and clear in the work that we do through Family Voices of ND. As described in the Wikipedia, the free encyclopedia - Collaboration is working together to achieve a goal.

Sanford Health in Fargo has a strong focus on "Family Support". They consistently refer families to Family Voices of ND. In addition to the referrals Sanford graciously collaborated with Moe Schroeder, Experienced Parent – Region V and myself and formed a NICU support group.

In April I attended and facilitated a session on "Recreation for Children with Special Needs" at the Annual AT Expo in Fargo. The event was well attended and offered many learning opportunities for everyone. The Exhibitor Hall was filled with vendors and service providers. We are so thankful to have an AT EXPO of this caliber held in our state. In late April I traveled to Mandan, ND to attend the Parent Involvement Conference (Brought to us by: PTI, PIRC, Pathfinder Parent Center). The 2012 Parent Involvement Conference will be held in Fargo. We are very excited to have this event in our Region.

In May Acumen (Fiscal Agent for ASD, MFW, and Traditional SDS) held a training/ information polycom for consumers and providers. It was a great opportunity to ask questions and learn about some new online features.

In June I had the opportunity to travel Bismarck to meet with stakeholders regarding Life After High School for Students with Significant Support Needs. The meeting was hosted by the Pathfinder Parent Center of ND and the Anne Carlson Center for children. As a parent and employee of FVND I am very excited to be part of this exciting work.

In July a group of very special mom's and myself organized a benefit for a little girl and held the event on July 21st at the El Zagel Shrine. It was a beautiful day filled with love and support. We called the event "Zoe Zelebration" in honor of Zoe and her incredible Grandmother, Deb. The tag line for the event was "Always Together, Never Alone, United We Roll". This clearly describes the unity of the special needs community. We couldn't have done it without all the support of our donors, volunteers and the El Zagel Shrine. Most recently, Hannah and I strolled with friends at the 2011 Stroll for Epilepsy here in Fargo at the Fargo Dome. The Stroll is a fundraising, however, you cannot put a price on the support and awareness the Stroll generates for those affected by seizures.

In September I will Co-Chair the local ECIC (Early Childhood Information Committee) with Moe. I want to encourage all providers of Early Childhood services in the Fargo area to participate. It is an excellent networking and learning opportunity. Please contact me if you are interested in receiving future meeting notices.

And last but not least I continue to hold a monthly support group meeting in Fargo for parents/guardians of children with special health care needs. I serve on the Sanford Family Advisory Council, Metro Area Mayors Committee, NDSCDD and Riding on Angels Wings Board of Directors. Needless to say I stay very busy, but love being involved in all the aspects of the special needs community. ..as this is the community I too live in. Again, if interested or have any questions about the information in this article, please do not hesitate to contact me. Brenda Schmid – 701-235-1781 – schmid@cableone.net.

Parent to Parent Helping One Another

Having a son with cerebral palsy, it is reassuring to be connected to other families with similar situations, or that may have had similar needs for their sons or daughters. There are many challenges that can be faced when you have a child with special needs, whether they are equipment needs, school situations, or just finding ways to be assertive for services that you need for your son or daughter. It is also very helpful when trying to find resources that are available in the community, or events geared toward children with special needs. It is invaluable to talk with someone who truly understands and can offer advice and support. I think this program is very important and beneficial to families in ND, and I hope it can continue to serve the area.
Sincerely, Jennifer Hansen

Brian and Amanda Lausch family

Family Voices of ND has been a valuable resource for me and my family. They have provided me with valuable training and knowledge about resources networking in my community and areas around me. My husband and I now have a better understanding of how “the system” that our child, with special health care needs, is in. Everything can be so confusing, but this knowledge has better equipped us. There have been topical calls to further enhance our learning. This is extremely beneficial to us and other families, so we can understand what everything is all about in this world that we must now live in, that we were so totally unprepared for. Also, a big thing I am so thankful for, about FVND is that their line is always open. Sometimes, I just don’t know where to begin. I know I need something for my child, I know something just isn’t right, but where do I start, where do I go from here? One call is all it takes. This is immensely valuable. FVND usually doesn’t just give me the number and say, “try this.” Often, the call is made for me, and things get going. Then, I get a call from someone if I needed a referral to another place. I don’t end up spending an hour or more on the phone trying to get to where/who I need to. What a relief.

The Parent to Parent program has been an excellent resource as well. I was matched with another parent when I wanted to talk to another parent close in my area who had a child similar in diagnosis to mine. It was very nice not to be paired with someone in another state away. We could discuss what works, what doesn’t, and things like local providers and state resources. I felt reassuring to have someone near by to talk with. Then, I was paired with a parent to who wanted to talk to me about their child and I was going to support them. Interestingly, it worked both ways. We enjoyed talking with each other and were able to learn from each other. What kind of things had worked and providers we had found. We actually both benefited and were able to improve the care for both our children!

The Parent Navigator Team has been fun. This has been an empowering team. A few of us attended a training about how to start a team. Since then, we have been working on starting a support group for our town for other parents with children who have special heath care needs. As parents, we felt really quite disconnected from each other, not knowing who each other were in the community. It has been nice to be able to get together and get to know each other. It can be difficult sometimes to go to gatherings when you have a child that is no always up to par. It is nice to have a group to get together with, where it is all accepted and everyone understands. We are also planning events to support each other in the future in the events that children go in the hospital, support the siblings of the child with special health care needs, and other fun events to get together. We are looking forward to our group growing.

Overall, there have been fabulous things going on in the state of North Dakota to support families with children with special health care needs. At the beginning of our diagnosis of our daughter, I felt disconnected, afraid, and outnumbered by children who seemed to live lives as “usual.” I have felt quite thankful for the groups that I have been a part of and believe they are a vital part of our system. Amanda Lausch Jamestown North Dakota

Acts of Kindness and Hope

Do you need a fall project??? Please encourage your schools to participate as a class project!

We all know that our children are affected in different ways when a disaster happens. We also know that art is a way for children to express feelings that they may have.

For this reason, Family Voices of North Dakota and VSA North Dakota The State Organization on Arts and Disability are partnering together on a project to let our children who have been affected by this disaster know that others in many communities are thinking of them.

We are asking families and providers to send one of the following options: A note of kindness, a note of hope

A picture drawing/coloring from your child about the flooding and their thoughts about how this will affect children who lost their home etc.

Families who have been affected by this disaster can write a note as well or have their children draw a picture with their thoughts.

The purpose is to collect the notes, pictures….and we will put together a collage. One for Minot and surrounding area and one for Bismarck and surrounding area. Collage and pictures will be utilized for an exhibit in the months ahead as recovery is in full swing for display in each of the areas. We are hoping to get enough from around the state and country to utilize in the recovery effort as a fundraiser for these communities.

Notes and pictures, drawings and colorings and monetary donations to complete the collage can be sent to:

Family Voices of North Dakota PO Box 163, Edgeley ND 58433 If you have questions please call: 888-522-9654

For those families who have a child that may need additional assistance, we encourage you to have someone transcribe or assist….We want to collect as many as we possibly can…....

If you will be sending in a picture or drawing, please send in a larger envelope as not to fold it…so that it won't be ruined through having creases.

NDCPD at Minot State will be assisting with efforts when collages and artwork are made for exhibiting in the Minot area. We are working with others in the Bismarck surrounding area for exhibits in Bismarck. Watch for updates!

"ICE" Your Phone.

We all carry our mobile phones with names and numbers stored in it's memory but nobody other than ourselves, knows which of these numbers belong to our closest family or friends.

If we were involved in an accident or were taken ill, the people attending to us would have our mobile phone but wouldn't know who to call. Yes, there are hundreds of numbers stored but which one is the contact person in case of an emergency? Hence the "ICE" (In Case of Emergency) Campaign.

The concept of "ICE" is catching on quickly. It is a method of contact during emergency situations. As cell (mobile) phones are carried by the majority of the population, all you need to do is store the number of a contact person who should be contacted during emergency under the ICE (In Case of Emergency) name.

The idea was thought up by a paramedic who found that when he went to the scenes of an accident, there were always mobile phones with the patients but they didn't know which number to call. He therefore thought that it would be a good idea if there was a nationally recognized name for this purpose. In an emergency situation, Emergency Service personnel and hospital staff would b e able to quickly contact the right person by simply dialing the number you have stored as "ICE". For more than one contact name, simply enter ICE1, ICE2, ICE3 etc. A great idea that will make a difference!

Let's spread the concept of ICE by storing an ICE number in our mobile phones today!

Please pass it on. It won't take too long before everybody will know about this. It really could save your life, or put a loved one's mind at rest.

ICE will speak for you when you are not able to!

Other Trainings and Opportunities

Parent Support is growing across the state! Support groups are being held. Community projects are being tackled. Families are feeling supported! North Dakota has amazing parents leading the way to providing support to families across the state! If you are interested in starting a Parent Navigator Team in your community, contact Donene or Moe at 1-888-522-9654 or email us at fvnd@drtel.net. Parent Navigator Teams are groups of individuals (both parents and professionals) that work together through a parent led volunteer network. Teams help to find or develop support and resources to meet the needs in the community.

Each month Family Voices of North Dakota hosts two conference calls for **Parent Navigator Teams** and those interested in being part of a Parent Navigator Team. During these calls we share ideas, ask questions and brainstorm together. The calls are on the **FIRST WEDNESDAY OF EACH MONTH** FROM 12:00-1:00 (central time) and on **the THIRD TUESDAY OF EACH MONTH** FROM 8:00-9:00 p.m. (central time). Join us to find out more about the Parent Navigator Teams across North Dakota.

Are you interested in learning more about Parent to Parent (P2P) Support or becoming a Veteran Parent??

Watch for future notifications to sign up for the upcoming ND P2P Phone Conference Workshops.
We will also be hosting the Parent to Parent (P2P) workshops regionally. We want to provide as many options to families to continue to grow the Parent to Parent Program
You can do it from within your region or in the comfort of your home and it is FREE!
All you have to do is let us know you want to participate and we will send you a toll free number to use to call in on the date of the workshop.
We will also send out training materials that allow you to follow along during the conference call. Phone Conference Workshops will begin in October. You do not have to complete them in order, so if you miss one, you will be able to catch it again during the next go around. For questions, contact Donene Feist or Moe Schroeder at 1-888-522-9654 or fvnd@drtel.net
Thank you!

(If by chance you are not receiving the weekly Share the Wealth E-News, which lists what is happening across the state each week...let us know and we will be happy to add you to the list.)

Parent Leadership Retreat

In June FVND held its annual Parent Leadership weekend. Twenty families were in attendance at this year's Leadership weekend. Over 30 registered for this year's event but due to the flooding and weather events, not all could attend.

The purpose of the institute is to assist families in developing leadership skills. First and foremost for their own children with special health care needs, but also in assisting others.

The first day, families learn about the systems of which their children receive services. In addition to our panel we were pleased to have with us Julie and Katie Beckett. Julie is a founding mom of Family Voices national.

Leaders not only learn about the various systems, but they also learn about advocacy, what it means, and the many types of advocacy.

Katie shared with the group the importance of teaching your child early on to become their own self advocate.

Jodee Bock spoke with leaders, guiding them in their leadership skills and utilizing those skills to take them to new adventures.

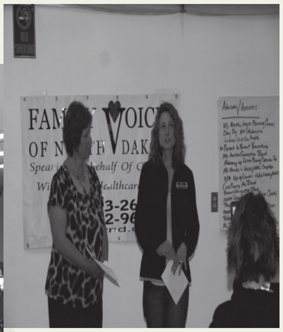
Other topics that are covered: Understanding Family Centered Care and Medical Home, Finding the Right Provider, the importance of record keeping, and why it is important to connect with others.

Families are provided tools and resources to build a personal portfolio, and develop a plan with another leader on what they would like to accomplish in the next year. It is a jam packed weekend with additional events of fun!

The planning has started for the 2012 retreat. Announcements will be coming out soon to register early for the coming year's event.

The natural mentoring that takes place among each group is wonderful to see.

The weekend could not happen if not for a wonderful committee who assist in the weekend event! **Thanks to the Leadership Committee members: Sue Burns-Children's Special Health Services; Roxane Romanick-Designer Genes and Early Intervention; Donene Feist Missi Baranko and Vicki Peterson-FVND; Deb Jendro and Carlotta McCleary-ND Federation of Families for Children's Mental Health; Cathy Haarstad and Teri Wilder-Pathfinder Family Center; Deb Unruh, and Jennifer Restemayer. Thank you all for your hard work and dedication!**



Remember to register for 2012 early! Announcements soon!

In Other News

Supporting Parents

There are many different ways parent support and information opportunities are available to parents. Some are directed by parents; sometimes the support is provided in a group setting and sometimes the support is provided individually.

Sharing the family experience with others in similar circumstances is an important source of support. Family Voices of North Dakota is proud to offer parents an opportunity to support each other.

In the coming months, we will provide family stories. These stories will be a source of hope, help, encouragement and support to another.

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, FVND would be pleased to send you whatever information you would like printed out.

Just call us at:

888-522-9654

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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!

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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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