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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-
Ringing in 2012! Hoping you all had a joyous Holiday Season and are ready for the year to come.

I for one am welcoming the mild winter we have had thus far. My apologies in advance to those who enjoy snowmobiling.

What does the New Year mean to you? For some, the approaching New Year may prompt some of you to take stock of all you have accomplished (or not accomplished) during the previous year. For others of you, the New Year may be a time to think about all the things you *hope* to accomplish in the months ahead. New Year's symbolizes rebirth and renewal for some - an aspiration to be a better person. For us at FVND...the New Year means all of the above.

For us as an organization FVND can be proud of the many accomplishments of 2011. The FVND Team has worked very hard in assisting families, providing information, completing workshops, and partnering with others. We look forward to the year ahead in continuing our strong mission and providing assistance to others. The needs are many and we are up to the challenge. The staff have identified many areas of need in each of the regions.

Much of this could not happen without many volunteers, our board, partners, staff and financial assistance from our funders and those who make contributions to FVND.

Families, providers, policymakers and funders….THANK YOU! Our work is reliant on each of you.

"Among the things you can give and still keep are your word, a smile and a grateful heart' Zig Ziglar.

Our thank you to you is with a grateful heart. Here is to each of you in 2012!

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**

A Request From Our FVND President

Pres. Tammy DeSautel and her family

Greetings to all of you!

You may be surprised to know— I know I was….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 $10, $20, $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

DMF
DAKOTA MEDICAL FOUNDATION
presents

Giving Hearts Day

Hosted By: www.impactgiveback.org
24 Hour Online Fundraising Event
2.14.12

Dear Families and Providers,

Double your gift by supporting Family Voices of North Dakota on Giving Hearts Day—**Tuesday, February 14, 2012.**

We are delighted that the Dakota Medical Foundation (DMF) and Impact Foundation have selected Family Voices of North Dakota to participate in the **2012 Giving Hearts Day**, a 24 hour online fundraising event.

Contributions of $10 or more will be matched up to $4000.

With your help Family Voices of North Dakota can raise a tremendous amount of funding to support our mission.

This funding will allow us to continue to assist families of children with disabilities and chronic health conditions across North Dakota. This will support our publications, workshops and trainings, support groups, 1:1 emotional and informational support and much much more….

If Family Voices of North Dakota is one of the top seven organizations to receive the most in online contributions, we will receive additional funding from Dakota Medical Foundation. What a great opportunity!

OUR FAMILIES NEED YOU! YOU CAN HELP US REACH THIS GOAL!
To make a secure online contribution to support FVND and have your donation matched, simply go to: www.impactgiveback.org
on February 14 and click on the Giving Hearts Day "Learn More" button.
On Giving Hearts Day, **you can double your charitable gift** and Give Back with Impact!!! Thank you from our heart to yours!

Thank you to those who have made donations to make this possible!

News from staff across the state

Moe P2P Coordinator

Happy New Year North Dakota Families!! Wow did 2011 fly by fast! I hope that all of your holidays were as blessed and filled with as much joy as ours at Family Voices! In October Vicki recruited four new parents who went through the Parent to Parent Training. Brenda and myself were part of the Non-Profit Day at West Acres Mall in Fargo. Thanks to Missi Baranko, Family Voices added new on-line training course for the Parent to Parent Program. It can be accessed on the Family Voices website: www.fvnd.org.

November brought statewide meetings, fundraising and preparing for our first Project Carson Training that was held in December. What is Project Carson? Project Carson is a partnership with Family Voices, Designer Genes and Pathfinders that will support families receiving a prenatal diagnosis or an at birth diagnosis. The training that was held brought in over 30 volunteer parents! I would like to thank all of the parent volunteers, staff members, and partners who came together and are ready to provide support to Project Carson families. Also a very special thank you to Cassie and Matt for sharing your story and Carson's life with us, he is forever in our hearts.

From October to December I have been continuing to match parents to other parents whether it has been statewide or nationally. I am always in need of more Support Parents and also Parent Leaders for Parent Navigator Teams. If you are unsure if there is a Parent Navigator team in your area feel free to contact me and I can connect you to a training and the team or provide tools to help start one in your community. In order for our children to flourish, we as parents need to: advocate, educate, and form meaningful partnerships with our community, it's members and those involved in our children's lives.

On a personal note everyone in our house is doing well. Kasey has us running with Volleyball and Basketball. Tyler continues to amaze us with his will to keep up with his peers. Both children are elated to see the snow! Rob and I have our fingers crossed that it only snows once! Take care of yourselves and remember that we are always here for you!

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Joscelyn Lynch-Williston

Here in boom town things are kind of crazy. Traffic is as busy as ever, lines at retail stores are outrageous, and every business is backed up by months.

All of this change can bring negativity to some but for me I am welcoming the change with open arms. There is a lot positive change happening and I am anxious to kick off the New Year with a bang! Great things to come this year in 2012 and don't forget our monthly Parent Navigator meeting Celebrating Life (every 3rd Thursday of the month at 6:00 pm).

I have enjoyed doing outreach, meeting new families and providers and doing what I can to bring awareness and assistance to others. If you are a family or provider in the Williston area, do feel free to contact me. If you would like us to come to speak to you group or organization, I would love to hear from you. Here is to a great 2012...

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

Vicki in Bismarck-Happy New Year to everyone from Vicki to all the wonderful families. It's hard to believe another year has passed. I have been very busy this year and have met many new families. I feel so blessed to have been in your lives. I am continuing to help families "navigate" the systems, creating parent matches and hopefully having some say in policy making.

This year Family Voices with the assistance of KAT Communications created two videos including one for Good Health TV, which is viewed in our Native American Nations as well. This was a great opportunity to hear the stories and to really put a "picture" to Family Voices of ND. I continue to serve on the Pathfinder Board and enjoy the opportunity to be involved in the education of our children. I am also on the Region VII RICC, attend SHIW (School Health Integrated Work Committee), Restraint and Seclusion Task Force, and attend public Task Force meetings such as the ND Autism Task Force.

I attend several support groups in the Bismarck area and facilitate a SEPTA support group. I am excited that Family Voices of ND will be a partner in the ND SAND Grant (Supporting Autism in ND). I see a definite increase of families moving into this region as well and I hope to keep connecting and forming new relationships. On a personal side, Erik, my oldest, is attending Jamestown College (2nd yr) doing very well and doing what he loves the most, playing baseball.

Aaron, whom will soon be 10, is still continuing to learn to read and enjoying a new part time aide at school and still loving Amy who is just wonderful. He is attending the NDAC (North Dakota Autism Connection) social hrs at the YMCA, going to the library and really starting to love community activities. I am wishing all of you a Joyous, Healthy 2012.

Joan in Grand Forks-Greetings from Grand Forks! The Holidays came and went as fast as 2011 did. It seems like this has been the fastest year ever. And of course December's weather was amazing. I'm not sure if I had mentioned in previous articles that I have the pleasure of not only working for Family Voices but also for Pathfinder Parent Center. The wonderful part of working for both agencies is that they work so well together to help families who have children with Special Healthcare Needs.

I recently attended the Project Carson training. This is a wonderful and much needed program for parents who receive a prenatal or postnatal diagnosis. I have had the opportunity to be a member of the Arc, Upper Valley's board of directors for the past 4 years and thoroughly enjoyed it but my term has come to an end. I hope to be able serve on the board again in the future.

We will be offering an upcoming Topical Call on Spina Bifida. I enjoy these very informational calls which can be done from the comfort of your home with no cost to you. Lisa, from the Spina Bifida Association will be joining us on this call. I am so excited that we are going to be able to offer this call. Watch for the email notification.

I continue to attend the ACT Team meetings at Northeast Human Service Center and also to work with the Family Readiness Center at the Grand Forks Air Force Base.

If you or a friend are in need of assistance with information or resources in Grand Forks or the surrounding areas please contact me at: 701 330-8641 or joankarpenko@hotmail.com

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

HI all...I am Heather Wittliff and I am the new Family Consultant for the Minot Region. I am so excited to be part of the Family Voices Team. A little about me ..I am married to Eric, we have been married for almost ten years and have two children.

When we started talking about what I wanted to do for a living, or what do I want to be when I "grow up"... all I could talk about was supporting families who are newly starting or continuing their journey in the disability community. Much of what has compelled me to want to take this leap, is being a parent of a child who is amazingly funny, a bit sarcastic (that may come from me) and very loving. Our oldest child Michael who is ten and has an Autism Spectrum Disorder. Like many others, it took us three plus years to get a diagnosis. Many times, I wouldn't have been able to figure out the next step, where to search for resources, and connect with others if it hadn't been for the staff at Family Voices who helped my husband and I get to where we are.

Michael is a busy ten year old who for the moment thinks the world should revolve around his electronics. He loves US History and science. School isn't his favorite place but if it is a subject that holds his interest he is so much fun. It is fun to watch him grow. I am delighted to say we also have a princess of a little girl named Ella. She is 6 and loves to play dress up, be a little care giver and read. Ella is a care giver and wants to take care of everyone and everything. Michael is our thinker he is always trying to figure out things. He likes to focus on the parts and not completely on the whole picture. If someone would have told me how different two children could be I am not sure I would have believed them. They are like night and day.

In addition to my family and Family Voices, I am a licensed childcare provider, and teach CPR and First Aid for the American Red Cross. I am on the board of directors for the independent living center, Independence Inc. and I am currently the president of MAPS-4-ASDs the autism support group in the Minot region. When I have the opportunity I love to read, scrapbook, and occasionally sew. I look so forward to the days ahead and getting to know many of you.

Brenda Schmid-Fargo Each quarter Donene asks us, the staff of FVND to write about what is happening in our region. And each quarter we write about the events, meetings, committees we serve on, progress and opportunities to advocate and be the voice for our children, etc. But this quarter, I want to write about something different. I want to talk about my journey with FVND over the past 3 years.

I want to start by saying that the greatest thing that has happened in our region is the growing support for one another. I have met the most amazing parents on this journey. They inspire me; amaze me with their strength and perseverance. They touch my heart with their raw emotion and love for their children. They validate the importance of the work that we do at FVND. Every day I learn something new. Sometimes I learn something new about myself or I learn something new about providers and systems. Families have shown me to look at things from a different perspective. In the world of Special Health Care Needs we all walk a similar walk. However, some may strut, some may walk lightly, some may walk slowly, and some may walk fast…regardless of how we walk we are all on the same path, the path to the "Crossroads to Hope" (yep that is FVND tagline).

This fall I attended the Dakota Medical Foundation "Lend a Hand" volunteer appreciation event. During the event they showed a video of the families/individuals that received a "Lend a Hand" match for their benefits. As I watched the video and listened to the heartfelt music accompanying it the tears began to flow. The tears first came from the realization of all those affected by medical crisis. Then more tears followed as I watched and heard about the power of the human spirit and community. When folks pull together great things can happen. I was humbled by the people that surrounded me at this event. Either they were recipients of a "Lend a Hand" match or they were volunteers who held a benefit. If only I could have bottled that energy and goodness in that room that night….it could change the world.

I traveled to Bismarck in November to discuss "Life after High School" (sponsored by Pathfinders and the Anne Carlson Center) for those who require greater supports. This subject in near and dear to my heart as our Hannah falls into this category. At some point all parents dream of what their children will grow up to be or what their life will look like.

Those of us who have children with special needs had dreams for our children prior to them coming into this world.

News from Staff

Brenda (cont from pg 6) Once they arrived we needed to make new dreams…regardless they are dreams and are meant to be kept alive. Like Marin Luther King, Jr. “I have a dream” (please know I am not comparing myself to Martin Luther King, Jr.) my dream for Hannah is to live a happy, healthy, fulfilling and meaningful life without barriers. Similar to the dream I had for her before she came into this world. Difference is this dream is now more real than ever and more difficult than I ever imagined. To ensure her happiness we need to teach her confidence, self pride and acceptance of this world and those in it. We need to provide her with a solid home life, active social life and life filled with opportunity. To keep her healthy we need to provide her with an amazing medical team of doctors, specialist and therapist. To give her a fulfilling and meaningful life without barriers we need to work with the community and the providers to identify how Hannah can give back to her community and work/volunteer doing something she can take pride in and be passionate about. This dream is not one I can do lying on my back. Much like King’s dream it will take a lot of time and energy to make it happen. The dream will be challenged and deflated at times, but like with everything in her life will regain momentum and will someday come into fruition.

Also, in November (Moe Schroeder and myself) held our quarterly ECIC (Early Childhood Information Committee) meeting. This committee is made up of providers of early childhood services in the FM area. It is an excellent time to share what is going on with providers and what services are available for children in our area. It is also a wonderful networking opportunity.

I attended the FEET (Family Education Enhancement Team) meeting for Fargo Public Schools. Once again we discussed transition and what that looks like for children with special needs who require greater supports. We also discussed the upcoming “Parent Involvement Conference” which will be held here in Fargo, April 26-28, 2012.

And last, but certainly not least Family Voices of ND along with Beyond Boundaries Therapy Services held a “Meet Santa” event for children with special health care needs. About 40 children and their families had the opportunity to meet Santa in a safe and stress free environment. In addition to meeting Santa, the Beyond Boundaries staff helped the children make crafts. Jess (Music Therapist for the House of Everyday Learning) sang Christmas Carols and invited the children to play instruments and sing along. Cookies and hot cider fueled the children’s energy (sugar is an amazing thing) and added to the festive feel of the evening. I would like to thank Tammy Desautel, Family Voices President for dreaming up this event. Thank you to Santa for stopping by and spending time with the kiddos. And a huge thank you to Beyond Boundaries and the House of Everyday Learning staff for opening up their facility for this event and for giving of themselves, their time and talents. What a great partnership. On that holiday note I will close. I hope and pray that you all had a happy, healthy, blessed Holiday Season. Brenda

Deb Unruh-Dickinson

My name is Deb Unruh, and I am the new Family Consultant in Dickinson. I am fortunate to have Missi Baranko helping me “learn the ropes” of this new position. Even before starting my job with Family Voices, I was well acquainted with their work, since Missi and Donene Feist have been instrumental in helping my family weather some difficult times. About five years ago, within a short period of time, three members of my immediate family were diagnosed with three different disabilities. These events led me to my role as advocate for my family’s needs. I am excited to be available to help other families, as well!

There have been some exciting things going on in Dickinson. The Dynamic Western Edge PNT (our region’s Parent Navigator Team) has begun to meet again after a summer break. This year the team has decided to alternate between an educational event and a family event for our monthly meetings. In December, a number of families got together and had fun decorating sugar cookies. In January, the team has invited Mark Coppin from the Anne Carlsen Center to come and speak about iPads and Apps, an area of growing interest for families. The Dynamic Western Edge PNT typically meets on the second Thursday of each month at the Early Childhood Center Building in Dickinson. If you would like more information, please contact me at dunruhfvnd@gmail.com, or call 701-260-5371.

In October I participated in an event to assist families of children transitioning out of Early Intervention services. Missi Baranko put together a wonderful set of resources for families, and the event was a great opportunity for families to gain information and ask questions about this transition. (Cont. Pg. 8)

News from staff cont.

Deb Unruh cont from pg 7. In November I traveled to Washington D.C. for the annual meeting of the Association of University Centers on Disabilities (AUCD). I am the chair of the Consumer Advisory Council for the North Dakota Center for Persons with Disabilities (North Dakota's Center on Disabilities), as well as the Secretary for COCA (AUCD's Council on Community Advocacy). One of AUCD's goals for the upcoming year is to involve persons with the most severe disabilities in AUCD'S activities, and to ensure that their voices are heard, even if these persons are unable to leave their homes due to medical or other issues. I am excited to be a part of this effort, as well as to be participating in several other great upcoming projects.

In December, several other Family Voices staff members and I participated in training for Project Carson. It was an honor to meet Matt and Cassie, the parents of the little boy that the project was named after, and to hear their story. I am very excited about this new project, which will support families who have received a prenatal diagnosis for their child, or who received a diagnosis shortly after the birth of their child. I know that by providing parents with the help and resources that they need, it can help to relieve some of their stress.

In addition to the events I have already mentioned, I have been working on connecting with families and professionals in Dickinson and the surrounding area. I attended the December RICC (Regional Interagency Coordinating Committee) meeting, and gained a lot of information about what is happening within the different agencies in our community. There are some very unique needs in the western part of the state right now due to the influx of people looking for jobs related to the booming oil industry. However, although it can be difficult, agencies are working diligently to ensure that families in need of services are not falling through the gaps. There have been many other things going on, as well, but I would like to close by wishing everyone a happy and healthy 2012. May your joys be enormous, and your burdens tiny!

Parent to Parent Helping One Another… Hear it from families

While I have only been involved in this program for a little over a year, it has been a tremendous source of support and information. I have a 15 month old son who was diagnosed prenatally with a heart defect and Down syndrome. I received virtually no information from my medical provider about Down syndrome (my FISH test results confirming the DS diagnosis were given to me via a phone call from a geneticist in a Sioux Falls lab). It was not until after my son was born and receiving Early Intervention services that I was informed of the Parent to Parent program.

I am so fortunate to have been paired with my parent to parent mentor.. She also has a child with Down syndrome. She has shared and continues to share her experiences about Down syndrome. Through her I've gain resource information and connected with other families with "extra" special kids. She is a tremendous advocate for our children within the community. She is well-informed and provides myself and other families' new information on a regular basis.

The Parent to Parent program is a great idea. When I first learned of my son's diagnosis I spent hours on the computer trying to educate and prepare myself for what lie ahead. I learned a lot about the medical side of Down syndrome-which was overwhelmingly all the things that could be "wrong" with my child. I wish I could have been connected or provided support information from the point of the initial diagnosis. I have shared this frustration with her and hope that we can somehow get this program and others support group information to medical providers within our region. After my son was born, my doctor's nurse actually called me to see where I got my information about Down syndrome. They recently had another pre-natal diagnosis and were looking for information to pass on to the mother.

You can read all the literature available and hear the medical "facts" about a condition, but in my opinion there is no better resource than a parent who has or is experiencing a similar situation. I very much support Family Voices of North Dakota and the Parent to Parent program. I hope to become involved as a Parent to Parent mentor in the near future.
Best Regards, Nikki German-Mom to Max 15 months (DS and CHD)

What a cutie Max is!

FVND Families Helping Families

Over 16,541 or about 12.2% of North Dakota's children have disabilities or special health conditions. Many of these children have a significant developmental disability that requires long-term care throughout their life span.

Imagine the mix of emotions that parents experience when learning that their child has been diagnosed with a serious health condition, developmental delay, or cognitive disability. Everything that they previously imagined for their child and their family's future comes into question. Depending on the severity of the condition, a life-time of doctor visits, therapy, hospitalizations, and in-home care await. Family Voices of North Dakota provides families with the support they need to navigate this new world of uncertainty. We provide mentoring and individual assistance, training and education, to help parents understand the child's disability and how to effectively advocate for their children – and ultimately achieve the highest quality of life and the best possible outcomes for their future.

Families Helping Families

Family Voices of North Dakota began 11 years ago as a grass-roots effort of families, professionals, and community leaders determined to provide support and information for parents of children with disabilities and special health care needs. The phrase "***families helping families,"*** also reflects our commitment to support families in all forms – grandparents raising grandchildren, single parents, non-custodial parents, adoptive or foster families, and families who speak other languages and represent many cultures. Today, Family Voices of North Dakota serves as North Dakota's Family-to-Family Health Information Center, and as the Parent to Parent Program for North Dakota. Helping parents to access information about health care, community resources, and support services so they can make informed decisions regarding their children's care has been our mission since 1996 when we began through volunteer efforts. We support thousands of North Dakota families each year through our programs and services.

Family Support

At the heart of our services is an experienced parent staff whose role is to provide caring and knowledgeable assistance to families from that very first contact, often at the time of diagnosis. Parents are supported to identify and locate appropriate resources required for the care of their child, for their own education, and the needs of their family. In connecting parents with resources and services, children with special needs are more likely to receive the vital medical care, therapy, school programs, and personal assistance they need to grow and to become successful in leading happy and meaningful lives.

The role of Family Voices of North Dakota is to improve the lives of children with disabilities by providing families with parent-to-parent support, training, information, and individual assistance.

Programs and services are offered free of charge, without regard to the child's disability, family income, qualifying conditions or other eligibility factors.

Parent-to-Parent Program

Through our network of trained Parent-to-Parent mentors, our staff connects new families to a supportive cadre of experienced parents of children with special needs. With one-on-one mentoring and support, our parent volunteers and staff assist families of children who have had life changes with a child's diagnosis, been newly diagnosed, starting a new treatment or procedure, or just needing emotional support and provide them with on-going support for meeting difficult challenges. Each year, families discover the benefit of being "matched" with another family for individual Parent-to-Parent support. Family Voices of North Dakota uses an evidence-based practice for parent mentoring endorsed by the national alliance of parent organizations, P2P USA.

Parent Leadership

Family Voices of North Dakota creates vital opportunities for parents to become agents for change, community ambassadors, and state-level advocates for children of special needs. Experienced parents interested in expanding their leadership roles in the community are provided with ongoing training, opportunities, and support to assist with training of professionals, presenting at conferences, providing public input for policy-making bodies, and serving on state advisory and advocacy councils.

FVND Families Helping Families

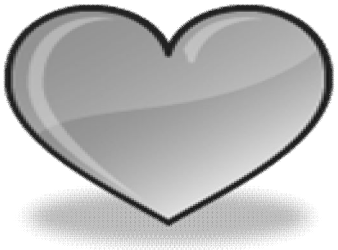
Educating Parents and Professionals
Ongoing education for parents and the professionals who serve them is the key to increasing knowledge and achieving good outcomes for children. Family Voices of North Dakota hosts numerous free workshops for parents, educators, health, and human service professionals.

Families attend classes that cover topics in parenting, behavior management, special education, communication skills, and health care to improve their ability to educate and care for children with disabilities. These training opportunities aid family members as well as professionals in acquiring knowledge and skills in the collaborative partnership needed for appropriate medical decision-making and for educational planning and appropriate services.

Many times we utilize parent panels and parent presenters assist the staff in preparing and presenting workshops for professionals in all systems of care. Workshops for professionals provide background on relaying sensitive information, breaking the diagnosis, the family perspective on disability, and issues relating to Medical Home, care coordination, and family-centered family professional partnerships and culturally appropriate practices.
Family Voices of North Dakota assists with other projects such as NICU *(Neonatal Intensive Care Unit)* outreach to establish a referral network for nurses, social workers, and medical professionals to help parents find community resources once they leave the hospital and begin the journey of caring for an infant with significant health needs. We offer a wide variety of workshops as well as topical calls for providers and families. Professional partnerships are a vital component of the work we do at Family Voices of North Dakota.

One Success Story

This is one of the success stories that makes us proud to assist families!!
"I believe that Family Voices of ND helped me find my voice. They encouraged me to speak out and to fight for our daughters needs. They encouraged me to tell our family's story. I have had many opportunities, big and small, to ask questions and to question answers. I honestly do not know that I would have had the ability or the confidence to question people I considered to be authority figures (Dr's, Social Services, even teachers) without the knowledge that Family Voices helped me gain. As a result of my questions, I know without a doubt that our family is better off. Medical professionals have been asked questions they could not answer and then have been pushed to find an answer. I have been able to raise some awareness of a rare disorder. Family Voices of ND gave me the opportunity to stand before our state legislators and put our family situation out there so they could put a face and a name to the reason ND needs additional services for Children with Special Health Care Needs. I am proud that I have been able to share our family story and I am proud that there are ND legislators that will not forget our daughter's name. Most of all, I am extremely thankful for giving me the access to information, and the encouragement to speak out. Knowledge is power… Family Voices of ND gave me power by being a much needed resource."
Mom of a child with significant health issues



Here’s How Family Voices of North Dakota Helped the Mom in Success Story from Page 10:

First, Family Voices of North Dakota met with mom to identify the needs of the family. Family Voices staff provided assistance in locating and following up with appropriate community resources and a range of other social service programs that could potentially assist. Staff attended meetings with mom and provided ongoing emotional and informational support. Secondly mom was matched with a trained and experienced parent mentor to provide information, encouragement, and support.

Many of the families we assist request to be volunteers for Family Voices of North Dakota, through one of the programs that we offer. They assist Family Voices of North Dakota to help other parents and families of children with disabilities. This is the Family Voices of North Dakota network of caring and family support which for over seventeen years has helped thousands of parents.

Another Success Story

“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.” *Jennifer Hansen*

The Demand for Help is Growing

As a nonprofit organization, Family Voices of North Dakota generates funding through a combination of federal grants and public contracts, as well as charitable contributions from generous foundations, corporations and individuals. These sources combine for total annual revenue of approximately $250,000 dedicated to family-to-family support services and educational programs.

Currently, our services reach about one-fourth of the children diagnosed each year. Moreover, our dedicated team of volunteer parents and staff are able to serve about 3,000 of the families raising children with disabilities in North Dakota. **We seek to do more.**

Creating even greater urgency is the continual and progressive elimination of public funding dedicated to these social services at the state and federal level. Not only is funding shrinking but the increase in population in the state due to the booming oil industry has caused an increase in the demand for services. Families cannot wait! When assistance is needed it is urgent and staff are ready to meet the need. In calendar year 2011, FVND assisted over 3600 individuals across North Dakota, provided 73 workshops, outreach and trainings and attended 417 meetings for children with special health care needs and disabilities. Additionally, reaching out through our publications 190,000 pieces of information have been provided.

Families of children with these disabilities face enormous challenges:

One in four children have conditions that cause parents to cut back or stop working

One in three families experience serious financial hardship because of the child’s disability

45% lack adequate public or private health insurance to pay for needed services

Looking to the Future

Family Voices of North Dakota must keep pace with the needs of families of children with disabilities. These families are an “at risk “population in an environment where resources are becoming ever-more scarce. Within the next few years, we envision the expansion of our current programs, the launch of new support services, workshops, trainings and collaborations, and the development of an endowment to enhance the sustainability of our work in the face of continued public funding reductions in critical areas that address the special care needs of children.

To realize this vision, Family Voices of North Dakota will grow support and private funding from individuals, foundations, and corporations. We look forward to forging new partnerships with philanthropic leaders and institutions that care deeply about the well-being and success of North Dakota’s special kids. We appreciate your leadership, opinions, and insights as part of this process.
Although much has been achieved, there are enormous challenges in the future. Together, we can be successful in making a difference for more families and children. We hope you will be with us every step of the way.

Kids As Self Advocates

By Ali Karpenko

A North Dakota KASA (Kids As Self Advocates) chapter is in the works! KASA is a national youth organization through the National Family Voices organization. The National KASA has met with us and approved the beginning work of a North Dakota KASA Chapter.

KASA’s mission is to enable youth, who have a disability, to use their voices to advocate for themselves and others.

KASA provides resources to youth that helps them speak out and create awareness of various issues that impact their daily lives.

We hope to begin the process of the North Dakota KASA Chapter in the next couple of months….look for updates soon.

If you know or are a young person who may be interested in joining KASA, we encourage you to read more about KASA at www.fvkasa.org

If you are interested in the development of the ND KASA Chapter, please contact Family Voices of North Dakota and let us know of your interest. We look forward to hearing from you at 888-522-9654

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

Parent Leadership Institute

The 2012 Parent Leadership Institute will be held June 8, 9, 10
You may register at this link:
http://www.surveymonkey.com/s/656JH5Z
or call FVND and we will assist you.

We hope you will apply to attend. We accept 25 applications per year. Get your application in early!!

Below is an article by Jen Skjod about the Parent Leadership Institute

Top 10 Excuses Not to Attend the Family Voices Leadership Institute

After a couple years of receiving (and saving) email invitations to Family Voices of North Dakota's Leadership Institute, I finally made the leap and attended this year. What took me so long? You could say I have the bad habit of over-analyzing a situation. Here is my refuted list:

10. Edgeley, North Dakota? Do they have a rest area in that neck of the woods? Will we be staying in tents? To my pleasant surprise, Edgeley is a beautiful, clean little town pretty much right smack in the middle of the state. It really isn't much a drive for anyone. They not only have a rest stop, but a tidy hotel right next to the building that the leadership institute is located. They even have a bar –that serves margaritas, but what do I know. I was so ecstatic to have a night without children in my bed that I fell asleep in the bathtub reading a book.

9. **I don't have a masters in social work, or anything for that matter. Who am I kidding –ME a leader? Humpf.** It really doesn't matter. There will always be people more or less educated than yourself. My dad never graduated from high school and he is the smartest man I know. **Attending the institute educated me way more than Macro Economics ever did**.

8. Will I be the oldest, youngest, etc.? Seriously. See item #9. There are older and younger. If not, just lie about your age if it makes you feel better. I'm 24 (going on 40).

7. Is this going to be one of the affairs where everyone speaks political mumbo jumbo and ends up throwing things by the end of the day? Between you and me, I have completely lost faith in the two-party system --and I was okay. You will be too!

6. **My kids are grown. Can I really make an impact?** Most definitely! In fact, I am waiting to make the most impact after they have flown the coop. (Just kidding.)

5. Will I have to commit to chairing a committee or starting a new branch of government? Um… no. Not unless you want to, of course. Many of us find making positive changes for the good of our families motivational enough.

4. **I'm just too busy to attend.** I was employed 35 hours a week when I attended. The institute is geared for the weekends right before the big summer vacation blitz --so it couldn't have worked out better.

3. Won't it be selfish to leave my child when he needs me most? By now you've probably heard the crashing plane analogy. The pilot rushes around slapping air masks on everyone else and then passes out for lack of oxygen… Pick up the mask the save yourself! That small act will make you strong and wise enough to help others.

2. **Do I have to talk?** Not much. It might be rude to not say HELLO. But some people are reserved about being specific about challenges their family faces. No one is going to pressure you. They are there to support, not terrify.

1. Can my husband attend as well? If your significant other would like to apply learned knowledge through the institute, they are welcome to apply as well! But I did learn that it is not okay to allow them to lie on the bed all day just to fan you with feathers and feed you grapes after class session. (That would never happen to me by the way. Not that I'm jealous or anything.)

We hope you will join us for the Parent Leadership Institute! Learn something new, meet others and become a great advocate! Call 888-522-9654 for questions.

Project Carson

WE ARE PLEASED TO ANNOUNCE: Project Carson is a new collaborative between Designer Genes of North Dakota, Pathfinder's Parent Center and Family Voices of North Dakota. Project Carson provides outreach to new parents with a ***prenatal or at birth diagnosis***.

Project Carson offers support to families through a partnership of professionals, organizations and parents who have personal experience in receiving a prenatal or at birth diagnosis.

The goal of Project Carson is to assure that families receiving a diagnosis, whether it be before or at birth, have access to a support network of parents and organizations that understand the emotions, joys and challenges that come with the word "diagnosis".

As a parent to parent support program, Project Carson provides emotional and informational support to families of children who have unique needs at birth. Our network of experienced parents can help access supports that may available such as: Financial Assistance, Family Support, Early Intervention Services for your child and family.

On December 4 and 5, 2011 many families from each region in North Dakota who have received a prenatal or at birth diagnosis gathered for an in-depth, First Responder training and introduction to Project Carson. Sarah Cullen from the Massachusetts Down Syndrome Congress provided support and information on Understanding Grief and the First Responders Training, Marie Scheutzle, MSCGC provided a genetics overview. We are extremely pleased to have had the opportunity to offer this in-depth training to families. Trained First Responder families are available in each region of the state.

What happens when you connect with Project Carson? Once a referral is made to the Project Carson team, either by faxing Project Carson form (this will be on the FV website) or by making a call to 888-522-9654 you will receive a call from a representative of Project Carson.

The person contacting you can answer questions and provide information to help you better navigate this sometimes confusing time, make sure the family has the support it needs to walk down this unexpected path.

A SPECIAL NOTE TO PARENTS

Dealing with the diagnosis of your child can be stressful and heartbreaking.

In dealing with our own personal experience, we decided to help make a change.

Our goal with Project Carson is to offer families, like yours, the one to one help, resources and support you need during this challenging time in your lives.

We are here to help.
Carson's Mommy and Daddy
Cassie and Matt

Matt and Carson

Other Trainings and Opportunities

Parent Support is growing across the state! Support groups are being held and, community projects are being tackled. Families are feeling supported! North Dakota has amazing seasoned veteran 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.

Additionally….We NEED Support Parents!!! Are you interested in learning more about Parent to Parent (P2P) Support or becoming a Veteran Parent for the Parent to Parent Program?? Give us a call! We have a variety of ways to offer Parent to Parent Training such as, in person, online, and via topical call.

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.

Materials are sent that allow you to follow along during the conference call. 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.)**

We have added a *NEW* ONLINE Parent to Parent Workshop Training. Completing this training will enable you to assist other families and become a Support Parent to another family for our Parent to Parent Program. You can do this in the privacy of your home. If you are interested in the new online training contact us at 888-522-9654; fvnd@drtel.net and we will connect you to this new opportunity!

Topical Calls and Family Nights

This year FVND has broadened the number of topical calls that we have sponsored.

What are topical calls? Topical calls are a series of mini workshops for families and providers to expand their knowledge regarding various systems, learn something new and prepare for the future with your children and youth. This year we have chosen a wide variety of topics based from our strategic plan and input from families through our evaluations process. North Dakota is a geographically vast state with many challenges such as the weather! FVND's goal is to provide as much information to families and providers as we could in a cost efficient manner. All topical calls are recorded and uploaded to our Family Voices of North Dakota website.

Announcements regarding Topical Calls are updated weekly in our e-newsletter and announcements to families and providers are provided via our list serv. If you are not receiving the E-Newsletter, drop us a line at fvnd@drtel.net or give us a call at 888-522-9654 and we will ensure that you are added to this weekly mailing.

Family Nights are new at FVND. We have started to have Family Nights as a means of discussing topics related to a particular diagnosis such as Epilepsy, Spina Bifida, Cardiac Conditions, Down Syndrome, etc. The goal is to meet new families via teleconference, learn and share resources and continue to build a support community across North Dakota. We hope you will join us!

PATHFINDER PARENT CENTER

Don't miss the 2012 Parent Involvement and Technology Conference. This year's conference will be held in Fargo at the Doublewood Inn on **April 26th, 27th and 28th**. Registration is FREE for all parents of children with special needs. Stipends are available for families who live at least an hour away from the Fargo area. Stipends cover the cost of a hotel room at state rates. Featured Keynote speakers include **George Sugai** (Positive Behavior Supports), **Janet DesGeorges and LeeAnn Seaver** from the National Hands and Voices office (Implementing IEPs), **Luis Perez** (Assistive Technology) and **Isaac Baldry** (Youth Leadership). This year we are partnering with the Anne Carlsen Center to offer a separate track on technology. Participants will be able to registered for the TECH – ONLY track OR for the Parent Involvement track which will feature several technology sessions. **Please contact Pathfinder Parent Center for further information.**

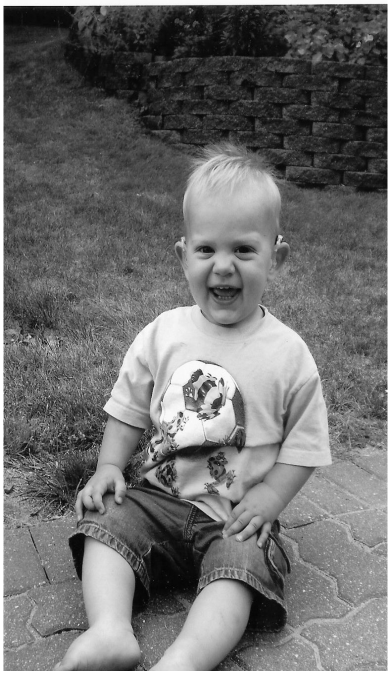
This is a great opportunity for parents, teachers, program managers, early interventionist, social workers and administrators to learn more about technology, early intervention and family support. Concurrent sessions will include information on technology, reading, transition, parent involvement, early intervention and much more. CEUs, Graduate and Social Work credit are pending. The block of rooms at the Doublewood are reserved only through March 27th so we encourage people to register early. Best Western Doublewood Inn & Conference Center – FARGO 3333 13th Avenue South Fargo, ND 58103 (800) 433-3235 Registration will open on February 1st. To learn more about stipends, call toll free at 1.800.245.5840 or locally at 701.837.7500

North Dakota Hands and Voices

HANDS & VOICES™

Hands & Voices is a nationwide non-profit organization dedicated to supporting families and their children who are deaf or hard of hearing, as well as the professionals who serve them.

They are a parent-driven, parent/professional collaborative group that is unbiased towards communication modes and methods. Their diverse membership includes those who are deaf, hard of hearing, and hearing impaired and their families who communicate orally, with signs, cue, and/or combined methods. They exist to help our children reach their highest potential.



The North Dakota Hands and Voices has worked hard to obtain Chapter Status and is ready to meet new families and providers. If you have a child who are deaf or hard of hearing or are a provider…. give them a call and consider becoming a member. Watch the FVND E-News for a future Topical Call from our North Dakota Chapter of Hands and Voices. Family support in North Dakota is growing. Family Voices of North Dakota is pleased that this group will address the needs of deaf and hard of hearing children. Kudos to the efforts of many to make this a reality for North Dakota families. You can contact the President Stephanie Stiel for more information at 701-281-6098 or 701-866-6410;

email: handsandvoicesnd@midco.net or more information is at: http://www.handsandvoices.org/chapters/northdakota.htm

SAND (Support Autism in North Dakota)

North Dakota Center for Persons with Disabilities in partnership with Family Voices of North Dakota, Children's Special Health Services, Department of Public Instruction, and the State Autism Spectrum Disorders task force has been awarded a three year Autism Spectrum Disorder grant. Below are the highlighted activities we will be working on in the upcoming years to help combat Autism Spectrum Disorders in North Dakota:

1) Train individuals, Early Childhood educators, Medical professionals, and school personnel working directly with children to recognize the early warning signs of ASD
2) Present information in ND pediatricians on the importance of ASD screening, methods of incorporating screening into existing practices, and follow up options.
3) Develop a Road Map of "what's next" to guide families and professionals through screening, diagnosis, educational options, and family support.
4) Partner with Children's Special Health Services to revise and disseminate the CSHS Autism Resource Booklet.
5) Provide data, information, and testimony to relevant legislative, policy and regulation discussions.

We look forward to this partnership in the days ahead. If you are a family who needs assistance please let FVND know at 888-522-9654. For more information or questions about the SAND project please contact: Hilory Liccini @ HIlory.Liccini@minotstateu.edu or 701-858-3008 toll free 1-800-233-1737 ext. 3008

ACTIVITIES for our Children

In December FVND was pleased to partner with Beyond Boundaries for a visit with Santa in Fargo. Our children don't always have the opportunity to meet with Santa Claus. This year on one special evening many children and their families gathered to meet Santa at Beyond Boundaries in Fargo.

Plans are in the works for future events such as this to meet the needs of our children. Some of the suggestions from families have been Easter Egg Hunts, Santa Days, Halloween events etc.

If your business or organizations would like to partner on events such as this in the future for children with special health care needs, please give us a call.

888-522-9654

DID YOU KNOW?

Family Voices of North Dakota can also be found on Facebook? Join us for daily updates on resources and information! Go to:

https://www.facebook.com/FVND1

Also…

Do you want to meet other families online to share resources and support??

Family Voices of North Dakota also has a site called Big Tent. This is an additional site that we have for families to meet one another, share resources and learn from tips that families share. Join other families on Big Tent

https://www.bigtent.com/groups/ndp2p

Baby's First Test

The Genetic Alliance recently launched a HRSA, HHS funded newborn screening resource: www.BabysFirstTest.org

The website is an objective resource for expecting and new parents to learn about newborn screening and is a place for families and health professionals to share their questions and experiences. This resource also features condition specific information, state information, family videos, and a Community Corner section, where visitors can learn about reliable sources of information pertaining to maternal and child health.

If you think you are too small to make a difference, try sleeping with a Mosquito~~~African Proverb

FAMILY VOICES
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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 _________________
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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

We Thank Our Professional Partners

This newsletter is funded in part by the ND Department of Health, Children's Special Health Services,
ND Dept. of Public Instruction,
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