

The Navigator

FVND Back to School 2021

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Meals at school and child care centers at no charge for all students continue!

The U.S. Department of Agriculture will continue reimbursing schools and childcare centers for free meals to all students regardless of their income through the 2021-22 school year. The president's administration extended waivers to allow the meals to continue. Some school districts will ask you to complete the application for free or reduced-price meals in order to help determine eligibility for certain programs or grants. If it is not burdensome for you to complete the application, please do so.

WIC families can purchase more fruits and vegetables! As part of the WIC food package, participants will receive a cash-value voucher for the months of June-September, 2021 to purchase more fruits and vegetables.

Thirty-five dollars (\$35.00) per child and adult, per month, will be made available. (The usual monthly cash-value voucher is \$9 per child and \$11 for pregnant, postpartum, and breastfeeding women.) WIC benefits are now all provided through an electronic benefits transfer (EBT) card, similar to a debit card.

The increase was part of the American Rescue Plan Act. The North Dakota Department of Health, Standing Rock, and Three Affiliated Tribes WIC Programs are all taking part.

WIC welcomes all parents and caregivers. If you are a dad, grandparent, foster parent or any caregiver of a child under 5 years of age, you may get WIC for your child. Changes in income limits that determine if families qualify for WIC benefits was recently changed. To find out if your family might be eligible for WIC, and for more information, please see:

<https://www.health.nd.gov/prevention/wic/WIC-Eligibility>

The Heart of a Special Needs Dad



In my eyes, special needs dads take that definition to whole new level. My husband, more than just a “father”, is a wonderfully loving dad. There are things I see him do every day that clearly display how his heart is worn on the outside of his body. Although I may not tell him often enough, I see all of the little things he does that make him amazing in his parental role.

I see the heart of a special needs dad.

I’ve watched him stay strong and calm while our daughter endured debilitating seizures.

I’ve watched him cuddle and comfort her after they’ve ended, while I’ve all but fallen apart.

I’ve seen him heavy hearted when our daughter was hooked to IVs in the hospital, yet still managing to keep a bright smile on his face for her.

I’ve seen him hug our son tight after a meltdown, speaking peacefully, turning chaos into tranquility.

I’ve seen him read endless articles on Autism, soaking up knowledge to be the dad that our son needs.

I’ve watched him immerse himself into each new interest that our son has become engrossed in.

He’s competently mastered the subjects of reptiles, Minecraft and science fiction podcasts.

I see how his heart swells with pride when our daughter takes an independent step in her gait trainer, turns a page in a book, or brings her spoon to mouth, all by herself.

I watch his heart melt when at six years old, she will crawl over to him and stretch her arms out for him to pick her up.

I see him beaming with delight when our son spends time in a noisy place unscathed, or when he tries a new food.

Even though he’s not in the stands at baseball games or in the front row of dance recitals, he’s there cheering on physical therapy sessions and therapeutic horse riding demonstrations.

I watch him cheer them both on in life, from the front row, and the love for his children is quite visible.

For all the special needs dads out there, I see you.

Your life is filled with moments that others could truly never understand or fully appreciate. Not only do you protect and provide, you do so much more.

You give complete and unconditional love and unending support.

You keep a brave face when the going gets tough and you’re doing a fantastic job.

Posted by Jodi Shenal; Special Needs, Advice & Support—Firefly Blog



Even though Father’s Day has come and gone, we are wishing all the dads out there a very Happy Father’s Day yesterday, today and everyday! We see you and we appreciate you!

ND Power Up Conference; A Virtual Event!

HEALTHY

JOIN US

for a day of healthy tips, healthy eating, healthy exercises and healthy well being – all for a healthier you! Our speakers this year cover a range of topics from healthy sleeping to positive attitudes to dance exercising! It will be time well spent with lots of valuable information, healthy tips and fun!



LIVING

FEATURED SPEAKERS



Matthew Shapiro
6 Wheels Consulting
Presentation:
DisABILITY! Resiliently Thriving in a Covid World!



Emily Wangen
Music Therapy In Motion
Presentation:
Music is Everywhere!

MEET OUR KEYNOTE SPEAKER,

MR. ZACH ANNER

If at Birth You Don't Succeed!

Zach Anner is an award-winning comedian, show host, TV writer, viral sensation, disability advocate, and public speaker. In 2011, he won his own travel show on the Oprah Winfrey Network, *Rollin' With Zach*. He tried his hand at sports and fitness on his YouTube series, *Workout Wednesdays*, and he's an Ambassador for the Cerebral Palsy Foundation and has worked with UCPLA Wheels for Humanity which supplies wheelchairs to people in developing countries. His videos have over 100 million views over social media platforms.

Virtual

FRIDAY,

SEPTEMBER 10, 2021

9:00 AM – 12:00 NOON CST

Registration Costs:

\$5/individual
\$75/professional - 7 contact hours

Contact Hours:

Up to 7 contact hours available for social work, nursing and SLPs

How to register:

- Register on Eventbrite (www.Eventbrite.com) and search for **PowerUp Health Conference**
- Or call 1-800-233-1737 and ask for Korie.

Financial Assistance:

Contact the ND State Council on Developmental Disabilities, www.nd.gov/scdd



Contact Susie Mack
for more information!

Email:
susie.mack@minotstateu.edu

Phone (800-233-1737)

PRE-RECORDED BREAKOUT SESSIONS

- **Sleep Well, Be Well** - Annie Schlecht, Zen Sleeping Consultant
- **Mindfulness & Meditation** - Kim Zoller, ID360 Inc.
- **Come On! Don't Settle!** - Scott Bernstein, GoUniversal
- **Celebrating Employment** - Michele Burney, Malinda Kragh, and Zoey Winkler, NDCPD
- **ABLE Accounts** - Vicki Peterson, Family Voices
- **Benefits of Adaptive Sports** - Krystal Butgereit, Prairie Grit
- **From Advocate to Game Changer** - Matthew Shapiro, 6 Wheels Consulting
- **Make & Take Music** - Emily Wangen, Music Therapy in Motion

**all breakout sessions will be pre-recorded and available online after the conference.*

HEALTHY EXERCISE

Learn the Signs. Act Early

Learn the Signs. Act Early is a program out of the CDC that helps families, caregivers, and medical providers monitor developmental milestones ages birth to 5. The program aims to improve early identification of children with autism and other developmental disabilities so children and families can get the services and supports they need.



Why Should You Monitor? Monitoring your child's developmental milestones allows you to celebrate their successes as well as recognize when they may have fallen behind. The Learn the signs. Act Early materials follows milestones on how your child learns, speaks, acts, and moves. The materials also teach and empower parents to speak up when there is a concern and help find resources to get your child back on track. As a parent, you know your child best. If your child is not meeting the milestones for his or her age, or if you think there could be a problem with the way your child plays, learns, speaks, acts, and moves talk to your child's doctor and share your concerns. Do not wait. Acting early can make a real difference!

Each state has a dedicated Act Early Ambassador, appointed by the CDC. Your state ambassador can help you connect to the materials and resources in your area. North Dakota's state ambassador, Hilory Liccini, and co-project lead Vanessa Rovig, have been working with Head Start programs across the state to deliver the Learn the Signs. Act Early developmental monitoring materials to families across North Dakota. Some of the materials included:

- ◆ CDC's Learn the Signs. Act Early. App
- ◆ Milestone Checklist
- ◆ Children's Books
- ◆ How to Talk with the Doctor Tip Sheet
- ◆ Milestone Brochure

If you would like more information on these materials, please visit:

<https://www.cdc.gov/ncbddd/actearly/index.html> or contact the North Dakota State Ambassador:

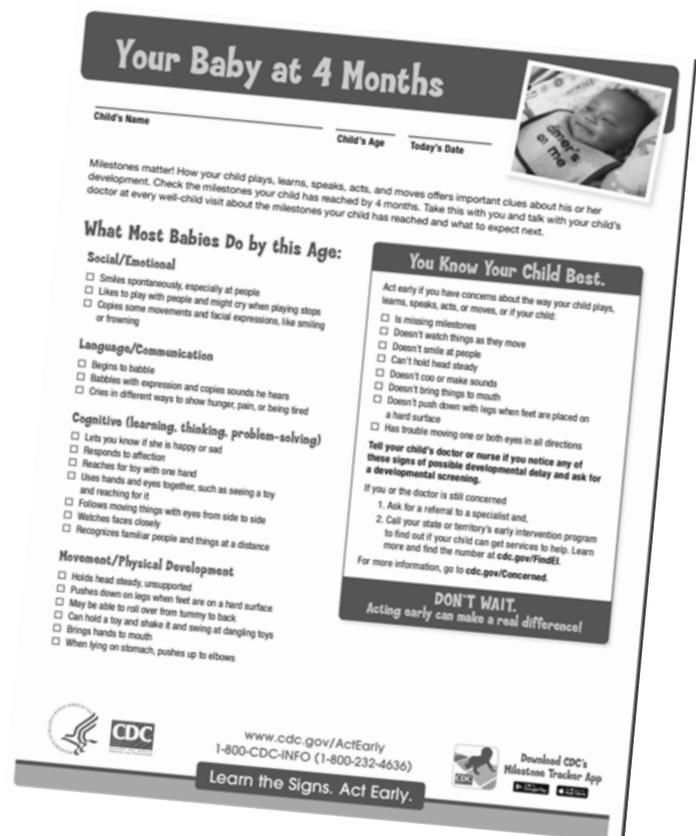
Hilory Liccini

Associate Director, NDCPD

ND Act Early Ambassador

701 858 3008

Hilory.Liccini@MinotStateU.edu



Help your child grow and thrive

Download CDC's free **Milestone Tracker** app

Track & Share Milestones | Get Tips & Activities | Learn When to Act Early

Learn more at [cdc.gov/MilestoneTracker](https://www.cdc.gov/MilestoneTracker)

There's an APP for THAT!

Does your older child need help improving their community and social skills? There are many apps available now that can give you the tools you may need to help your child learn how to navigate better in the community.

1. Community Success (Attainment Company)

This app includes many different categories including Getting Around, At Home, With People, Out Shopping and Around Town. Within each category, includes subcategories with steps (for sequencing), a story and a video.

2. Social Success (Attainment Company)

Social Success is similar to Community Success in that the format is similar but it focuses more on the social interaction within the community, school and vocational program. It even has a topic named "Using Technology" which discusses cell phone and texting etiquette with videos and questions included.

3. Read to Learn (Attainment Company)

Read to Learn helps emphasize literacy within the community. If you have a child that struggles with reading, getting around the community can be difficult. With this app, keywords are emphasized and functional words are reviewed. The app is sectioned into three categories. Life Skills Readers, Focus on Feelings and Safety Skill Reader. Each category includes several stories that give you the option of reading to yourself or having the book read to you. These apps include a Free trial that allows you to test the app before purchasing it. *Recommendation by Becca Eisenberg, MS, CCC-SLP, a speech-language pathologist, author, instructor, and parent.*



Our Mission:

Family Voices of North Dakota (FVND) aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through our national network, Family Voices provides families tools to make informed decisions, advocates for improved public and private policies, builds partnerships among professionals and families and serves as a trusted resource on health care.

Our Vision:

Every child and youth with special needs receives family-centered care.

"WITH THE NEW DAY COME NEW STRENGTH AND THOUGHTS"

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THANK YOU!!

To our Board Members

Understanding How Trauma Affects Health and Health Care

What is Trauma?

Individuals and families living in poverty, such as those served by the clinic described above, are more likely to experience multiple forms of trauma. Traumatic events can include, but are not limited to:

- Experiencing or observing physical, sexual, and emotional abuse;
- Childhood neglect;
- Having a family member with a mental health or substance use disorder;
- Experiencing or witnessing violence; or
- Sudden, unexplained separation from a loved one.

While trauma can affect anyone regardless of their socioeconomic status, many people living in poverty routinely witness violence in their community, have relatives who have been incarcerated, and experience ongoing institutional discrimination — all of which exert a toll on their health.

Trauma's Impact on Health

Experiencing trauma causes the body to produce adrenaline and cortisol, activating normal protective processes of fight, flight, or freeze. Unresolved traumatic experiences can stimulate these responses even in non-threatening situations. Experiencing trauma, especially in childhood, can actually change a person's brain structure, contributing to long-term physical and behavioral health problems. Children and adults often develop coping mechanisms to alleviate the pain of trauma, some of which are classified as "health risk behaviors." These can include eating unhealthy food or overeating, using tobacco, abusing substances, or engaging in risky sexual activities. When childhood traumatic stress goes untreated, these coping mechanisms can contribute to anxiety, social isolation, and chronic diseases like hypertension, diabetes, cancer, or substance use disorders. Often, "non-compliant" behaviors, such as taking medication consistently or not attending appointments, can also be linked back to patients' history of trauma.

What Can Health Care Organizations Do?

Health care organizations, especially those serving people with complex needs, often have trouble engaging their patients and have high no-show rates. Patients may not consistently take their medications or follow through with recommended lifestyle changes. Considering the impact of trauma on physical and emotional health may help providers empathize with their patients and understand their patients' behaviors, enabling more effective communication and relationship-building that may lead to better outcomes. Shifting the question from "What's wrong with you?" to "What happened to you?" allows health care organizations to begin addressing trauma head-on. This helps providers and staff better understand the magnitude of trauma — and its potential effects — patients are experiencing. Likewise, understanding patients' life experiences is an essential part of delivering trauma-informed care. Adopting trauma-informed approaches, like staff training and creating a safe, calm physical environment, is facilitating enable patient engagement and helping patients and staff feel more at ease in the clinic. Health care organizations can take steps toward becoming trauma-informed to help create a safe environment and work toward improving patient engagement.

To learn more about trauma-informed care and emerging best practices for implementation, visit the Center for Health Care Strategies through support from the Robert Wood Johnson Foundation.

Applied Behavior Analysis (ABA) Services and the IEP services

Medicaid Autism Applied Behavior Analysis Service is the assistance provided to a qualifying individual with an autism spectrum disorder (ASD) diagnosis and who are under the age of 21. The service includes program oversight supporting comprehensive assessment, care plan development, referral, monitoring and follow-up, and skills training for qualifying individuals and their caregivers. Services can occur within the home, community, a provider's facility or within a child school day.

If requesting the school to allow ABA services for your child during the school day, the request must be to address behaviors that are occurring during school. Services within the school are the responsibility of the school, under Individuals with Disabilities Education Act (IDEA) – Part B. Therefore, to have ABA services start, a parent must request an Individualized Education Program (IEP) team meeting to discuss independent evaluation and the possible need to update of current IEP. During this meeting, the team will identify needs of the child and then pair the need to specific special education and related services to address the academic, developmental and functional needs determined by the evaluations. ABA services is a related service within the IEP process. The IEP team will also determine the length of service to include amount of service to be provided within the school day. These services are contracted through the local school district. The IDEA's IEP process is designed to ensure that an appropriate program is developed to meet the unique individual needs of a child with a disability, and that services are identified based on the unique needs of the child by a team that includes the child's parents.

If you are requesting ABA service outside of your child's school day the child must be eligible for Medicaid and will need proof of an ASD diagnosis, a current EPSDT screening, and a recommendation from a primary care provider for ABA therapy sent to the department.

Legislative Updates

Legislative Updates on Behalf of Special Health Services, a Division in the North Dakota Department of Health:

House Bill 1288 adds coverage of continuous glucose monitors (CGM's) for individuals with diabetes to the ND Medicaid state plan. Although the bill originally started as only adding coverage for children, it passed as adding coverage for all individuals with diabetes.

Senate Bill 2224 adds coverage of medically necessary metabolic supplements (many OTC) to the ND Medicaid state plan. In the bill it is referenced that continued collaboration with Newborn Screening will continue.

House Concurrent Resolution 3011 is a study of impact of substance abuse and neonatal withdrawal syndrome, including a focus on Fetal Alcohol Spectrum Disorders, including treatment, services available, potential prevention, and whether existing policies for children and adults are appropriate. The North Dakota Department of Health currently funds the Fetal Alcohol Center at UND under Dr. Larry Burd.

House Bill 1247 combines the North Dakota Department of Health and North Dakota Department of Human Services by September 2022. This will create a unified health and human services team will streamline programs and services for the citizens of North Dakota.

Children's Hospice Program

In 2010, North Dakota Medicaid implemented a program to assist families dealing with end of life for their child. The Children's Hospice program is able to assist children between the ages of birth to their 22nd birthday. This program provides multiple services to children and their families who have a life limiting diagnosis.

The unique part of this program is Medicaid Eligibility only looks at child's income not the full family's income, to determine eligibility for the child.

Services included in the program are:

- ◆ Case Management
- ◆ Respite
- ◆ Skilled Nursing
- ◆ Hospice
- ◆ Palliative Cares
- ◆ Grief Counseling
- ◆ Expressive Counseling
- ◆ Equipment/Supplies



These services are designed to assist the family in dealing with their child's diagnosis and the emotions when preparing for the possible death of their child. In addition, the program will make it possible for a family to continue to explore curative measures at the same time they are utilizing hospice services.

Applications can be found at <https://www.nd.gov/eforms/Doc/sfn00743.pdf>.

For further information, contact Katherine Barchenger at 701-328-4630.



Vicki Peterson, Nominated for Family Voices Leadership Award!

Vicki Peterson, Bismarck Family Consultant and parent mentor to many, was nominated, and was selected as an awardee for this year's Family Voices Leadership Award. This award is given in recognition of outstanding family or youth leadership, critical to achieving Family Voices mission and goals in advancing children's health and wellbeing. It is awarded to an established or emerging Family Voices adult or youth leader whose priorities and goals for children and families at the local, state, or national level inspire others' commitment and action.

The Awards Ceremony was on June 15, 2021. All of us at Family Voices and families want to again, Congratulate Vicki on her nomination. We express our gratitude for her exemplary commitment to assisting families and keeping them at the center of children's health care. Congratulation Vicki!



Medicaid Health Tracks/Well-Child Visit for Children with SHCN

Regular checkups are an important way to keep track of your child’s health and physical, emotional, and social development. These visits are important for ALL children, including children and youth with special health care needs who may also be under the care of specialists. Conversations can range from sharing your successes and milestones, to overall concerns about child development, to challenges in daily routines. Think of these visits as an opportunity to learn as much as you can about the best ways to help your child grow.

Your child’s provider will take measurements, conduct a head-to-toe examination, update immunizations, and offer you a chance to talk about any concerns you may have. Your well-child visit includes four specific activities:

1. Determining whether your child has any health concerns;
2. Offering ways to keep your child from developing health concerns;
3. Providing support for your child’s overall health and well-being; and
4. Talking through health information and offering advice.

To get the most out of your well-child visit take a few simple steps to prepare. For example:

1. Make notes about what you have noticed about your child’s health and development. Including any changes in behavior or family routines.
2. Write a list of questions you wish to ask.
3. Gather information that might be helpful for your health care provider. Share information from school (such as your child’s Individualized Education Program) or child care to help them learn more about your child.

Well-child screenings are recommended at these ages:

Newborn	12 Months
2-5 days old	15 Months
1 Month	18 Months
2 Months	24 Months
4 Months	30 Months
6 Months	Every year from age 3 through 20
9 Months	



For more information on Health Tracks/Well-Child Visit:

<https://www.nd.gov/dhs/services/medicalserv/health-tracks/index.html>

ND Assistive Loan Library: More Options Through Collaboration!

Since October of 2020 when we eliminated the Loan Library fees, the number of loans for assistive technology has increased dramatically! In fact, the number of device loans from October 1, 2020, to today, June 24, 2021, is 99% higher than the same time period last year. AND this increase was during COVID! Fantastical!

Due to the high demand, though, a new problem has been created. We now have many loan items on waiting lists, several people deep. We are mitigating this waitlist in two ways: 1) by shortening the loan periods on some of the higher-demand, lower-tech devices and 2) by adding more equipment to our loan libraries.

One of the ways we were able to obtain new equipment for short-term equipment loans was through a collaboration with Family Voices of North Dakota. Family Voices received funding from a COVID grant this past year, earmarked to help the children they serve. They provided some of these dollars to ND Assistive to purchase assistive technology such as tablets and communication apps for our short-term loan library, so more children of North Dakota in need can try before they buy. Amazing! The Kindle Fire with Wireless Charging Station, in the pictures below, is one example of the equipment we were able to purchase! Their donation will allow us to serve more individuals in a timelier manner to help them make informed equipment purchase decisions. A HUGE thank you to Family Voices and their Executive Director, Donene Feist!

If you know a child with a disability who would benefit from a free short-term equipment loan to help determine the appropriate assistive technology for purchase, please contact us at 1-800-895-4728, info@ndassistive.org, or visit our website to look up equipment to borrow.



Witten Jeannie Krull, Program Director for ND Assistive (formerly IPAT). She is an ASHA certified speech/language pathologist and a RESNA certified Assistive Technology Professional, who has worked with people with disabilities of all ages since 1991.

Enjoy and Share the Harvest!

September is the time when gardens finish up, and vegetables like potatoes, squash, carrots and more are harvested and enjoyed! If you grow a garden, and have more than you can eat or put up to store, please consider donating to a local food helper organization. Find a food pantry or soup kitchen eager for your garden vegetable donations at the Hunger Free North Dakota Garden Project site:



<https://www.nd.gov/ndda/produce-donation-sites>

If you are in need of some food for your family, this is a list where you can find where people are donating fresh produce. Find a list of all the food pantries and soup kitchens in the state at:



**GREAT PLAINS
FOOD BANK**

https://www.greatplainsfoodbank.org/get_help/pantries_and_soup_kitchens.html



Grand Forks Happenings

Greetings from Grand Forks! Fun was had by all at the Teen Night Out Car Bingo event in June. We are looking forward to another event before school begins!

Planning for our annual Trunk or Treat event has begun. The Alerus Center has been so kind to collaborate with us this year. Trunk or Treat will take place in the Alerus Center V.I.P. parking lot on Sunday, October 24th, 1:00 – 3:00pm. Children of ALL Abilities are welcome! Businesses, organizations, families, and individuals are also welcome to host a trunk!

If you or someone you know are in need of assistance in Grand Forks or the surrounding area or would like information about Teen Night Out or Trunk or Treat, please contact Joan at 701-330-8641 or joankarpenko@fvnd.org

Bismarck Happenings; a letter from Vicki

Hello to everyone! I want to extend a hope that all of our Family Voices of ND families have been healthy and safe through the Covid-19 pandemic and hopefully we have turned the corner for the good. Many things I have learned through the “social distancing” and helping families include how telehealth has now expanded and I hope this will continue. Lessons I learned was where the needs are for education and training, the need for wider and improved broadband, how children and youth with special health care needs (CYSHCN) have been able to utilize telehealth for specialists, behavioral health, well child visits, access to therapies, Early Intervention visits and more. I continue to see many referrals from Bismarck, Minot and surrounding areas and towns from both providers and families. I want to thank the providers in this region for their continued support and knowing the need and importance for care coordination for families. Currently, I am doing telehealth care coordination for Pediatric Mental Health Care Access Program. This program offers families who have children and youth with behavioral and mental health needs access to resources, emotional support and care coordination through Family Voices of ND. I am working as well on a training for Youth in Transition through a grant received from ND Special Health Services. Summertime is always a time to catch -up with all my families and supporting the new families.



I also would like to mention our roles in ND Legislation for CYSHCN and their families, and with having remote access to the legislative body, gave many more the opportunity to participate and hope this practice continuous. Working together~ Vicki

Bismarck Happenings– We have expanded!

Hello my name is Rita Gieser. I was born and raised in Mandan, ND were I currently reside with my husband and 3 children. Sophia (8), Easton (6), Madalyn (22 months). I have been a stay at home mom for over the past 8 years. I started with Family Voices just as a parent looking for help, guidance, not knowing what direction to turn when my oldest daughter Sophia was diagnosed with Autism at the age of 3. I then felt this passion deep inside me to help give back all that had been given to us. Over the next five years I was a volunteer parent doing event planning for local children in our area. In October 2020 I became a Family Support Consultant with Family Voices of ND. This journey that we are on is what brought me to yet another family. It really does take a village to raise a child. I am so glad I found mine! You can Contact Rita at: rita@fvnd.org



Donene Feist, Director

PO Box 163

Edgeley, ND 58433

Phone: 888-522-9654

Fax: 701-493-2635

Local: 701-493-2634

E:mail: fvnd@drtel.net

Web: www.fvnd.org

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Find us on the Web!
<http://fvnd.org/>

“Supporting Families having children with special health care needs and disabilities and the providers who provide care for them”

Every year WE-Fest does a bucket drive and a different charity is selected per day. FVND has been selected this year as their charity on Friday, August 6th!! For those of you not attending WE-Fest in person, you can still donate to this great cause. Bob 95FM donated T-Shirts for the volunteers and Venmo Technology is assisting us to make the donations. We are welcoming donations through Venmo @FamilyVoicesND! This fundraiser is split between ND and MN area charities around the lakes, so your money stays local. All donations will assist families with special health care needs.

You can donate via snail mail too!

You could help us by assisting in workshops, writing articles, being a support parent and much more! You can provide a donation by making a contribution to FVND which will assist with workshops, matching parents for emotional support, regional parent navigator teams family events and so much more!

To be used where needed Endowment Events
 In honor/memory of _____
 Living Tribute for _____

Name _____

Address _____

City _____ State _____ Zip _____

Phone _____ E-mail _____

Enclosed is my tax deductible to FVND

Donation of: \$250 \$100 \$50 \$25 \$10 \$5

Please fill out this form, cut out and mail to:

Family Voices of North Dakota | PO Box 163 | Edgeley, ND 58433

We Want to 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, North Dakota State Council for Developmental Disabilities, and the Maternal and Child Health Bureau
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