



Family Voices of
North Dakota
Health Information
and
Education Center

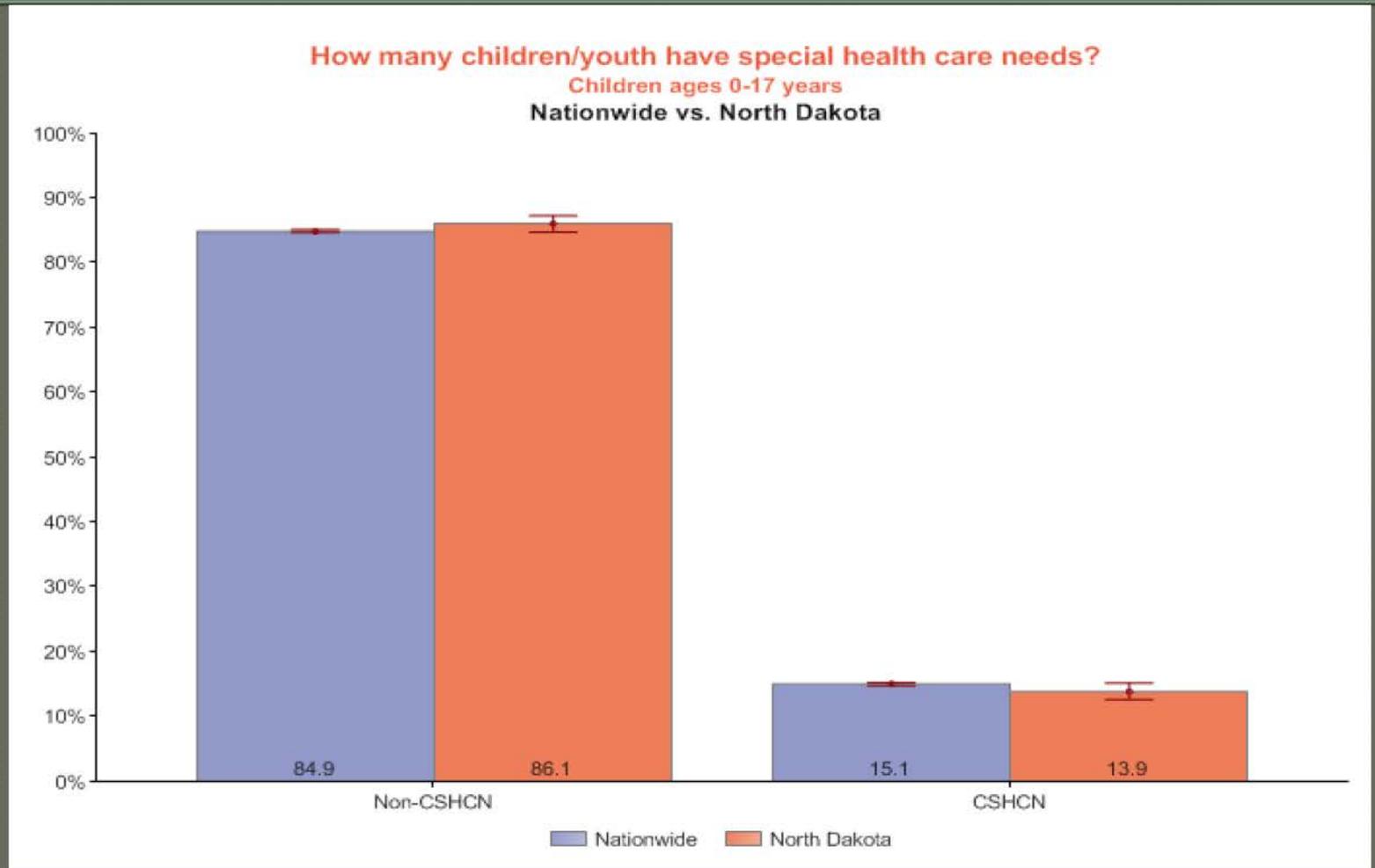
About Children and Youth with Special Health Care Needs

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

Definition developed by Maternal and Child Health Bureau July 1998

By this definition ND has nearly 20,000 Children with Special Health Care Needs. Enough to fill the Fargo Dome.

Children with SHN in ND



Keyword Search

Browse the Data

- [Browse by Survey & Topic](#)
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- [Browse Data Trends](#)
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- [Browse Healthy People 2020 Topics](#)
- [Medical Home Data Portal](#)
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Home > Browse the Data > Browse by Survey > Survey Results

Current Search Criteria

Survey: Compare all years - National Survey of Children with Special Health Care Needs
Starting Point: CSHCN Prevalence and Demographics
State/Region: Nationwide vs. North Dakota
Topic: Demographics and CSHCN prevalence for all children ages 0-17 (n=371,617)
Question: How many children have special health care needs? (details)

Edit Search Criteria

Compare States:

Compare Subgroups:

[Return to single year data results](#)
[Change question, topic or survey](#)

How many children have special health care needs? (details)

Select a Response Category:

		2001	2005/06	2009/10
Nationwide	%	12.8	13.9	15.1
	C.I.	(12.6 - 13.0)	(13.7 - 14.1)	(14.8 - 15.3)
North Dakota	%	12.4	12.2	13.9
	C.I.	(11.5 - 13.3)	(11.3 - 13.1)	(12.7 - 15.2)

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics.

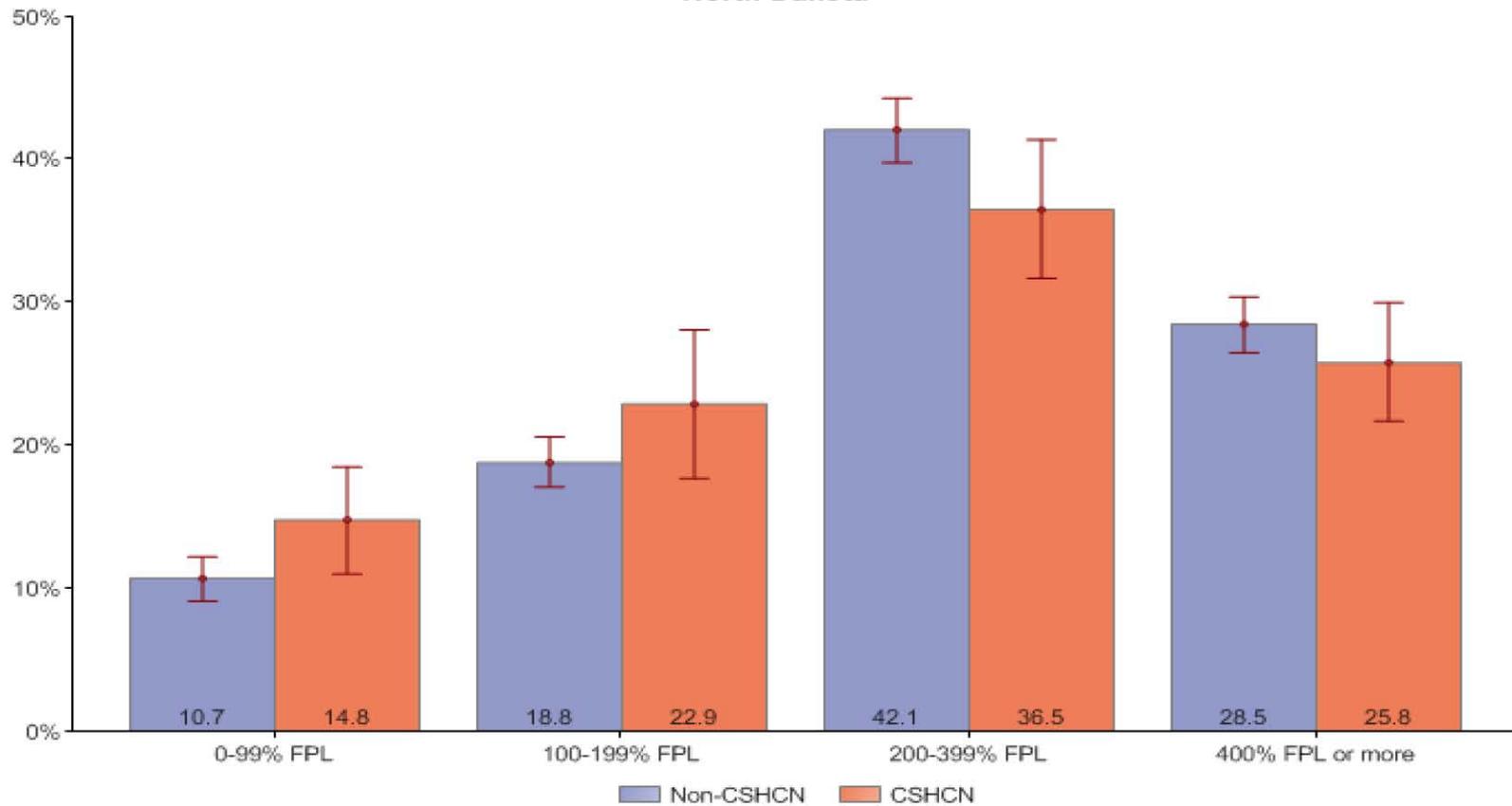
DATA ALERT: Changes in survey methodology from 2001, 2005/06 and 2009/10 may have an impact on the observed differences between survey years. Formal statistical analyses to test those differences require special consideration due to the inclusion of a cell phone sample in 2009/10. Additional information is available in the 2009 NS-CSHCN Codebook.

How many children/youth have special health care needs?

Children ages 0-17 years
 Nationwide vs. North Dakota
 CSHCN



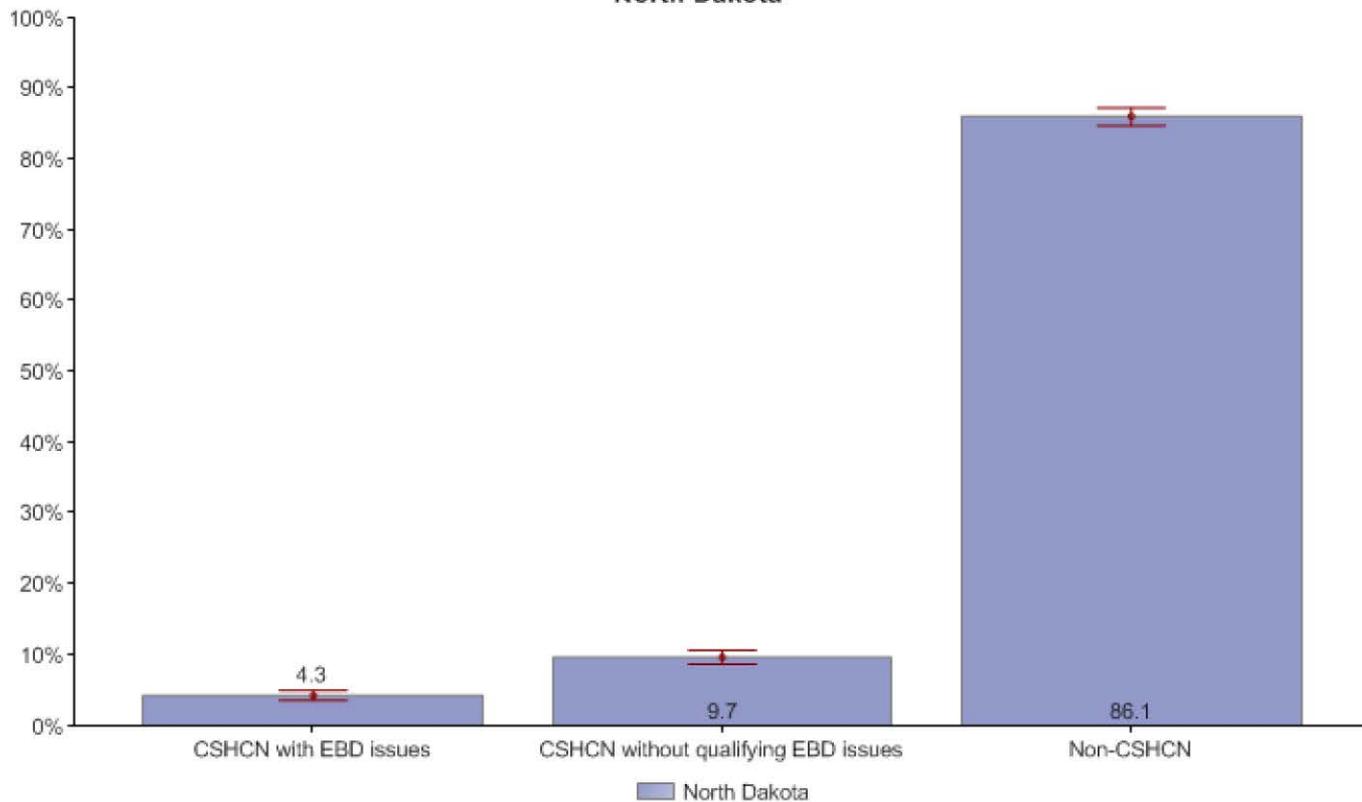
Distribution of household income among all US children 0-17 years
Children 0-17 years
North Dakota



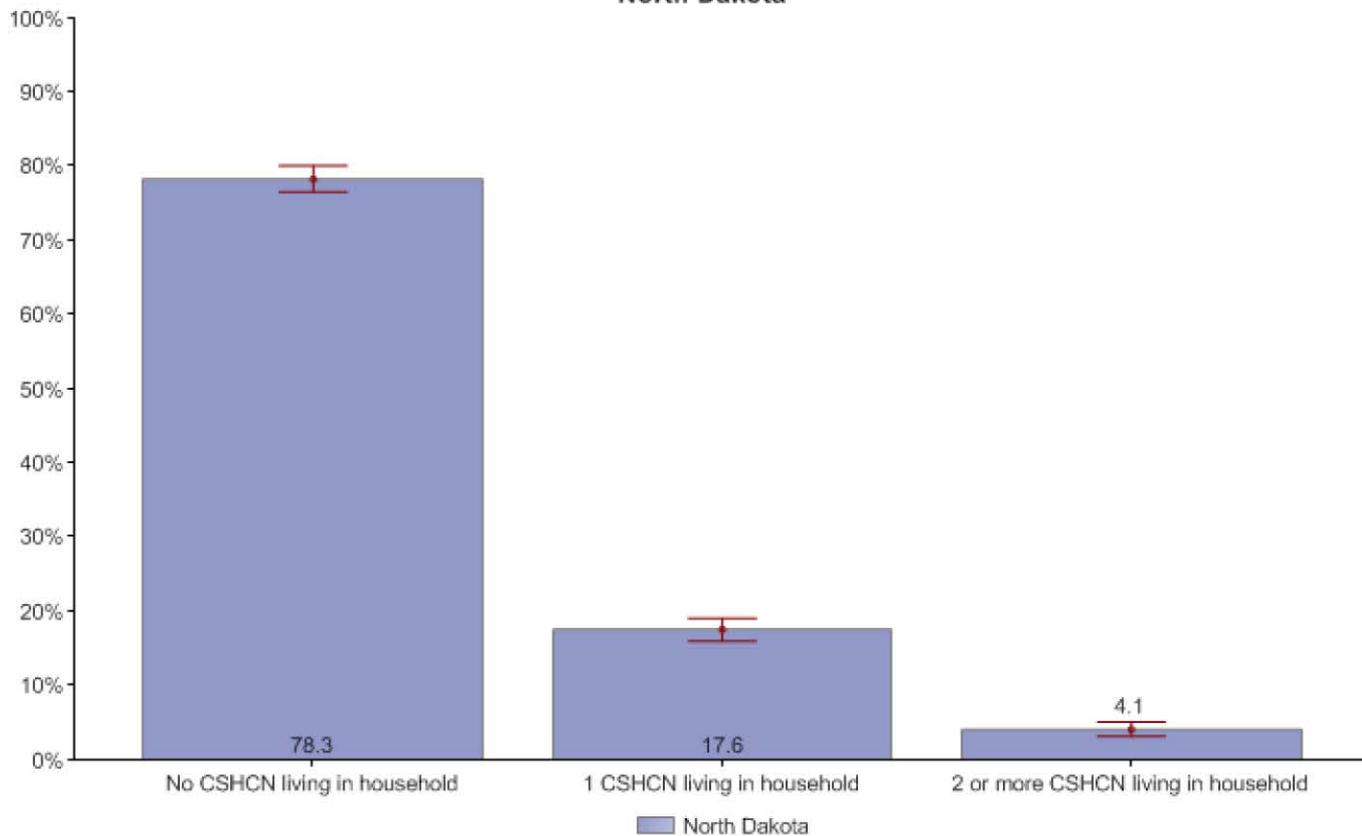
Children whose special needs include ongoing emotional, behavioral or developmental issues

Children 0-17 years

North Dakota



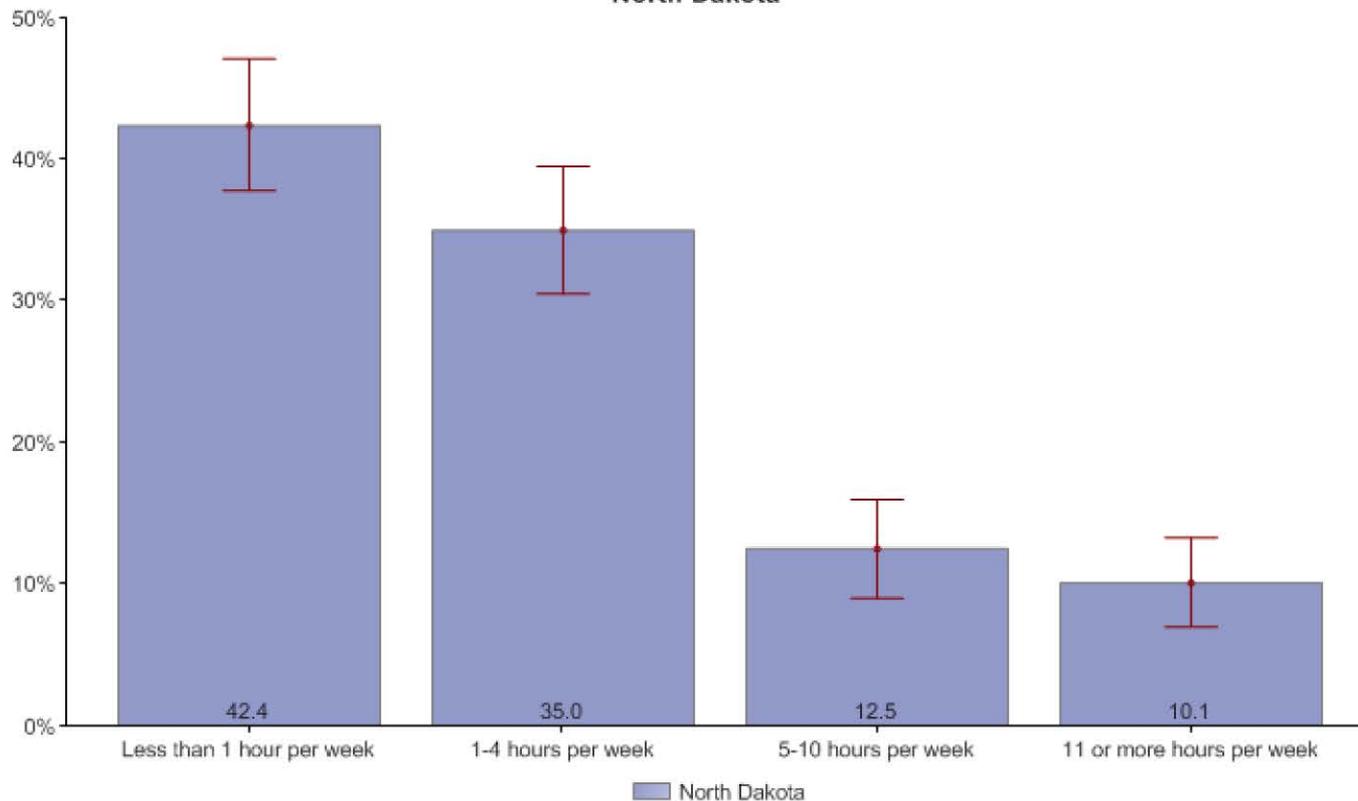
Number of children with special health care needs living in household
Households with children 0-17 years old
North Dakota



Indicator 14: CSHCN whose families spend 11 or more hours per week providing and/or coordinating child's health care

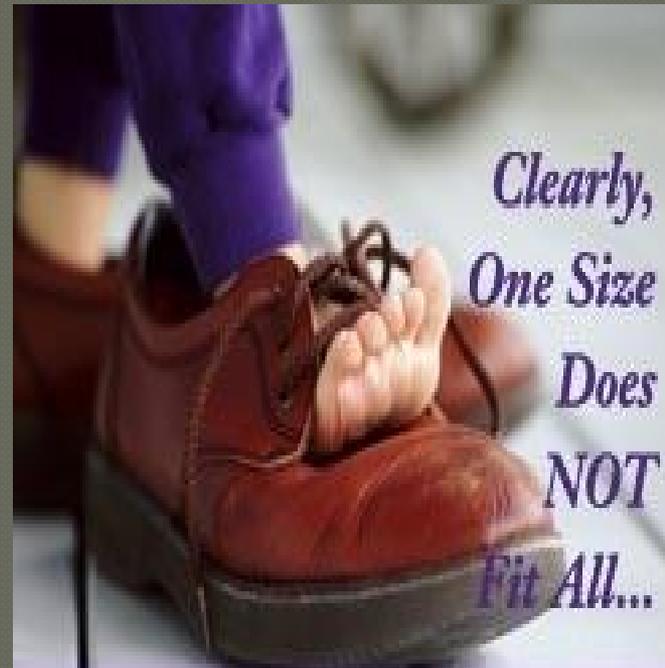
CSHCN age 0-17 years

North Dakota



FVND Purpose

- To assist families as they navigate public and private health systems, insurance plans and community resources



FVND Purpose

- To educate and assist families about how to access services and resources for their children and how to work with health providers

Examples: applications to services, where to begin connecting to resources

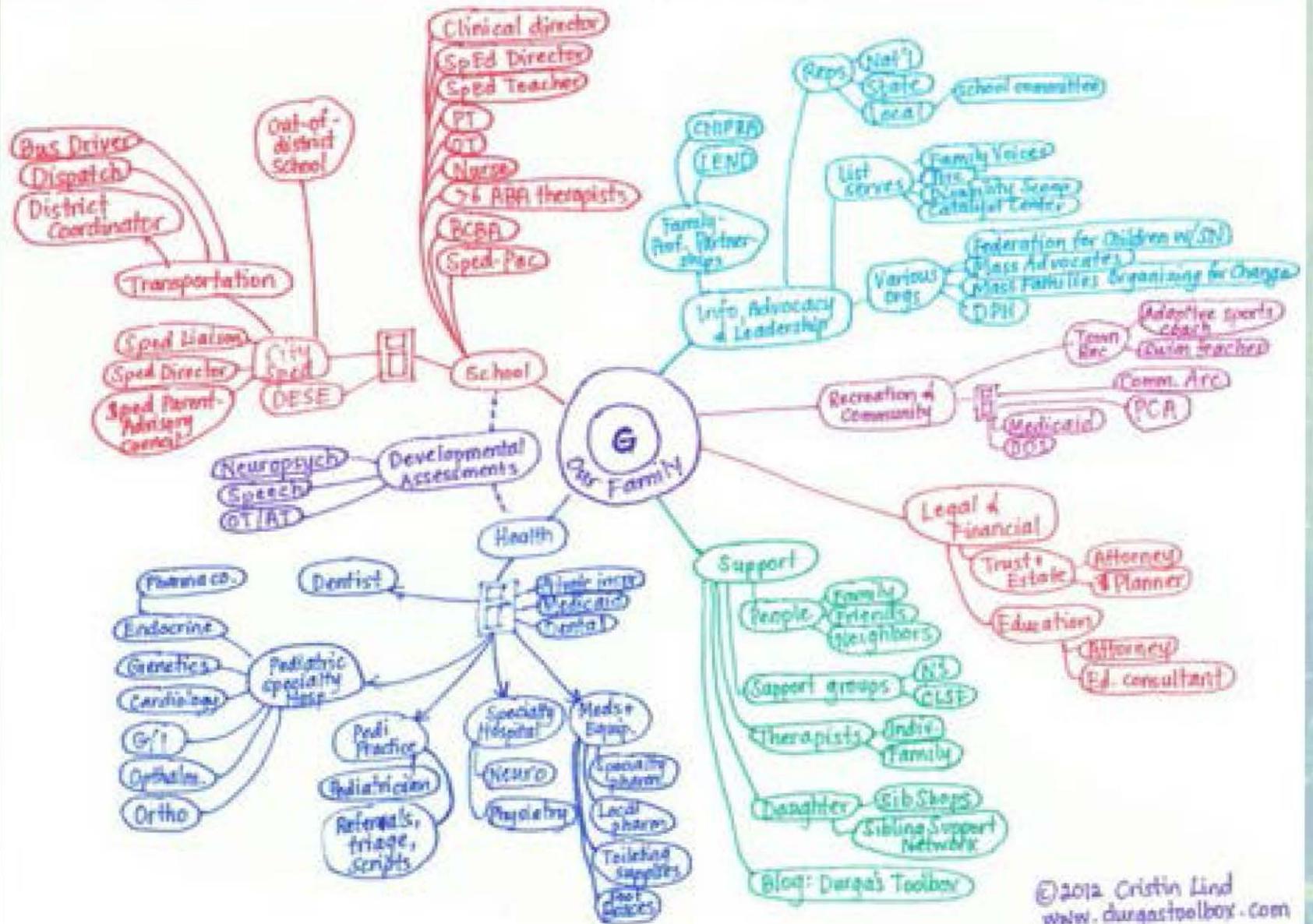
- To listen to families as they describe their encounters with systems and help guide them to possible solutions

FVND Purpose

- To promote discussion and linkages among families, providers, public and private entities, and government to better serve the health care and related needs of children and families in North Dakota

FVND Purpose

- To work with families, health care providers, public and private agencies, and advocacy or support groups to promote best practice of family-centered care and medical homes for children with special health care needs



Core Programs at FVND

Family Voices of North Dakota is part of a national grassroots clearinghouse for information and education concerning the health care of our children with special health needs.

FVND is a state affiliate organization

We are a Health Information and Education Center for families and professionals, providing information and resources on healthcare, disability and chronic health illnesses and issues affecting children with special health care needs.

There is a Health Information and Education Center in each of the 50 states.

Core Programs at FVND

- FVND is also home to the ND Parent to Parent Program

Parent to Parent trains seasoned parents to be mentors to other families for emotional and information support

Seasoned parents go through training on support, communication skills, confidentiality etc.

Core Programs At FVND

Family Support in ND

Project Carson:

- Provides parent-to-parent informational and emotional support for families whose baby receives prenatal and just-at-birth diagnosis
- Began because of the stories from families who told about the lack of support in the areas of family support and linkage to community programs
- Covers families across the state of ND.

Core Programs At FVND

- Parent Leadership Institute- annually to assist families reach their next step in not only advocating for their own child but for others and to help them better understand the systems and how they work
- IN ADDITION TO ALL OF THE PROVIDERS and SERVICE SYSTEMS A FAMILY MAY HAVE TO DEAL WITH

There are many additional issues they may be dealing with

Financial

- ♥ QUALIFYING FOR PROGRAMS
- ♥ CO-PAYS AND PREMIUMS
- ♥ ONE WAGE EARNER
- ♥ SAVINGS????
- ♥ ASSETS
- ♥ FORMS AND MORE FORMS



Relationships

- ◉ NO TIME
- ◉ COMMUNICATION
- ◉ BLAMING
- ◉ COPING STRATEGIES AND ACCEPTANCE DIFFER
- ◉ CAN MAKE OR BREAK

Sibling issues

- ♥ UNINTENTIONAL NEGLECT
- ♥ HAVE TO GIVE UP “NORM”
- ♥ JEALOUSY
- ♥ ANGER
- ♥ HATE
- ♥ HURT
- ♥ HEALTH
- ♥ EMBARRASEMENT

Family issues

- ♥ GRANDPARENTS
- ♥ DOUBLE GRIEF
- ♥ OTHER FAMILY MEMBERS
- ♥ MISUNDERSTAND
- ♥ “If I can’t even get my family to understand that he has a disability and that it is not bad parenting and my fault, how will anybody else every understand?”

Physicians' and Parents' Ranking of Services

*Ranking

Service	Physicians	Parents
-Respite care	1	9
-Day care	2	21
-Parent support groups	3	3
-Help with behavior problems	4	10
-Financial information or help	5	2
-After-school child care	6	20
-Assistance with physical household changes	7	15
-Vocational counseling	8	6
-Psychological services	9	5
-Homemaker services	10	22
-Recreational opportunities	13	4
-Information about community resources	14	1
-Dental treatment	16	8
-Summer camp	19	7

What We Do

- Information, Education and Referral with 24/7 Toll Free line for families and providers
- Workshops for Families and Providers on a wide variety of topics such as:
Accessing Systems, Advocacy, Medicaid, Social Security, IDEA, How to get the most out your health visits, Paying the Bills, Partnering with Providers and many more....

What We Do

- Provide family input at policy meetings for systems change
- Weekly E-News, Quarterly newsletter, Big Tent, Facebook and website
- FVND has created many publications for families and providers and can be found on the web
- We have a wide variety of resource information for families and professionals. Videos, tapes, books etc.

Trainings

- FVND offers a wide variety of trainings to assist families and providers keep up to date with the ever changing system
- 1:1 trainings, group trainings and topical call trainings are available.

The Needs Increase Annually

Individual Contacts to FVND

Total Encounters	2010	2011	2012	2013	2014	2015
<i>Families</i>	2,052	2,321	2,411	2,467	2,584	2865
<i>Professionals</i>	1,186	1,387	1,619	1,766	2,061	2339

Staff

- Family Consultants:

2-Fargo (PT),

1 @ 16 HOURS, 1 @ 30 HOURS;

Grand Forks-1 (PT) @ 16 HOURS,

Bismarck-1 (FT),

Edgeley-1 (FT),

Williston-1 @ 10 HOURS (PT);

P2P Coordinator-1 (FT)

Staff

- Our needs and calls received indicate a need to full time staff in each region
- Original SB 2012 budget was for \$450,000 to be divided among Federation and FVND (\$225,000 for each organization)
At this level would have provided an increase to all staff to near FT and additional travel funds to meet with families and provide assistance.

Staff

- ◉ Received general fund dollars: \$75,000
- ◉ Added a Consultant in Dickinson (PT) @ 10 hours.
- ◉ Increase/maintain hours to existing staff
- ◉ Travel funds to do outreach/meet with families 1:1 in areas where there is no staff such as Minot and Devils Lake

In closing

- Data indicates that 86% of parents with children eligible to receive services are not aware of available programs. (ND Kids Count 2014) ***People cannot access what they do not know exists.*** (verified by study, see handout)
- We know and can identify as best practice that families thrive when supported by others with **lived experience**. That families build capacity, strength and confidence through support and coaching from another parent. (see handout)
- Active engagement with families through responsive listening from others who have walked in the same shoes assists families in a manner that allows them to receive services necessary to meet their family and child's needs.

In closing

- Families need to access services, in a timely basis. They may experience difficulty at times in communication with providers through various agencies, and not understanding how programs work.
- Families may often be told of one resource, but not necessarily the all of the resources needed. (Told about the slice of bread but not the entire loaf)
- Part of this may be that the provider has limited access and knowledge to what does exist.
- We find that many times providers know and are familiar with what is under the preview of their daily work, but may not have access or know the additional resources that may be out there. This leaves families to search for answers on their own and often feel alienated by the professionals who serve them when they discover other programs that may have assisted with their family's needs.

Thank you

- ◉ We thank this legislative body for recognizing the needs of families and the beginning to further assist them through this funding.

How to Reach Us for Questions

- You may reach us by phone:
- 701-493-2634 or 888-522-9654
- Fax: 493-2635
- E-mail: fvnd@drtel.net
- Web: www.fvnd.org

Who are Children with Special Health Care Needs?

Nearly 20,000 children in our state have some kind of special health care need and over 40% of these children have a health condition that limits their play and school activities.

This means 1 in 5 families within our state have children living with a special health care need and includes: physical, mental or emotional disabilities; others live with a chronic illness and many present a brief, but life-threatening medical problem.

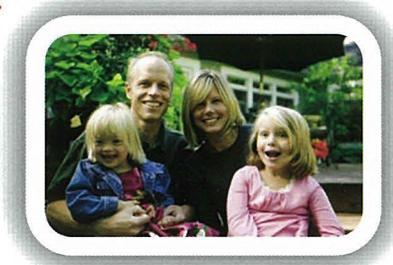
If you are the parent or caregiver of a child, youth or young adult with special health care needs you are not alone! Family Voices of North Dakota is available in all eight regions across the state. Contact us; we understand your concerns.



What makes Family Voices different?

Family Voices of ND is a parent led organization. All staff are parents of children with special health care needs and disabilities.

All services that are provided to your family are at NO cost to you!



For more information about Family Voices of North Dakota please contact us!

P.O. Box 163
Edgeley, ND 58433
1-888-522-9654
701-493-2634
fvnd@drtel.net
www.fvnd.org



As part of a grassroots national network, Family Voices of North Dakota is the Family to Family Health Information Center to help you navigate the complicated issues surrounding health care for your child or youth with special health care needs and/or disabilities.



KEEPING FAMILIES AT
THE CENTER OF THEIR
CHILD'S HEALTH CARE

What does Family Voices do?

Family Voices of ND:

- Provides families with tools to navigate systems and help make informed health care decisions.
- Provides leadership and brings the voice of families to health care programs and policies.
- Promotes family/professional partnerships.
- Offers opportunities to interact with policymakers, educates families about the legislative process and teaches advocacy skills.
- Hosts trainings, workshops and topical calls for parents and professionals.
- Provides support, encouragement and peer mentoring.
- Walks you through transition phases into adulthood.

Parent to Parent USA Program

Parent to Parent (P2P) matches families with children/youth with special health care needs/disabilities with a trained volunteer Support Parent who has had similar experiences.

P2P is a valuable source of assistance and information for parents because they can talk with an experienced parent who really understands.

Families often look to P2P for help and information such as:

- Resources
- Financial supports
- Similar experiences
- A listening ear



Member of the Parent to Parent USA Alliance,
Committed to Parent to Parent USA-Endorsed Practices

If you are looking for another parent to visit with, please call F V N D today

Project Carson

Project Carson offers support to new parents who receive a prenatal or at birth diagnosis. Project Carson's goal is to assure that families receiving a diagnosis have access to a support network of parents and organizations that understand the emotions, joys and challenges that come with the word diagnosis."



Our network of experienced parents can help you access supports that may be available to you such as:

- Financial Assistance
- Family Support
- Early Intervention Services for your child and family

To be referred to Project Carson, call 1-888-522-9654.

Supporting Families in North Dakota: Through the Lens of Lived Experience



Family Story

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

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

Supporting families involves the connection to another person who has also raised a child/youth with a special health care need and/or disability and who has a shared life experience. This connection assures that families get resources and services in ways that are respectful, relevant, and honor their unique choices and perspectives so that they can make informed decisions to achieve the best possible outcomes for their children and/or youth.

Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. As family members, we nurture, protect, and influence each other. Families are dynamic and are cultures unto themselves, with different values and unique ways of realizing dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Each family has strengths and qualities that flow from individual members and from the family as a unit. Our families create neighborhoods, communities, states, and nations.

Developed and adopted by the New Mexico Legislative Young Children's Continuum and New Mexico Coalition for Children, June 1990.



Family Driven

Family-driven means families have a primary decision making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory and nation. This includes:

- Choosing supports, services, and providers;
- Setting goals;
- Designing and implementing programs;
- Monitoring outcomes;
- Participating in funding decisions; and
- Determining the effectiveness of all efforts to promote the mental health and well-being of children and youth.

Osher, Osher, & Blau, 2006

Fidelity is trust, accountability, and predictability across the systems of care between all stakeholders within an established and accepted practice. Families of children and youth need fidelity from the people in their lives; teachers, providers, support team, and others. The expectation of fidelity to family driven or centered practices is a fundamental value in family support.



Background

There are an estimated 27,000 children and youth with special health care needs and another 23,000 children and youth with an emotional, behavioral, or mental health condition in ND; 13,000 of these children receive special education.

Research and experience shows that there is much more to meeting the needs of children and youth with

special needs than those services offered by providers. Most services are provided according to guidelines that dictate the eligibility, type of service, and access. Because of this, families of children and youth with special needs often serve in a variety of roles to ensure the well-being of their children and youth, such as care management, transportation services, social support, socialization,

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

Further...

Researchers and leaders across the nation agree that key to this support is:

- Connections** to others who have lived experience in successfully navigating the system of care for their own child or youth;
- Access** to formal and informal information and resources that are family and youth driven/centered and culturally responsive; and
- Family and youth **choice** based upon their interpretation of that information.

advocacy, medical treatment, therapies, and other necessary services. And, because family caregivers are generally the primary and/or sole caregivers to their children and youth with special needs, their own physical, mental, and emotional health and wellbeing can impact how they provide that care. As a result, parents of a child or youth with special needs may also experience increased stress, guilt, blame, or reduced self confidence in parenting, which can divert attention from other aspects of family functioning. In turn, this can effect the physical, mental, and emotional health and wellbeing of all of their children and youth.

Each component is essential as the foundations of family and youth driven/centered care and support. Family driven/centered care assures the health and well-being of children and their families through a respectful family professional partnership. Family driven/centered means that families have a primary decision-making role in the care of their children, as well as in the policies and procedures governing care for all children in their community, state, tribe, territory, and nation. Family-driven/centered care is the standard of practice which results in high quality services.



Current State of Supporting Families

Historically, until the past decade, families, youth, and consumers of services had to fight to secure a place at the decision-making table, and typically served in a volunteer advisory capacity. Later, some were paid a "stipend" to cover childcare costs, travel related expenses, and income lost due to missed work. As organizations and individuals became more experienced and skilled, and as programs and service providers saw the value of ongoing support, some agencies contracted with family run organizations and leaders as providers of lived experience, peer to peer support for families of children and youth with special needs. States and their communities have taken the task of developing sustainable support as a critical component to the provision of a continuum of services for families of children and youth with special needs. Many are offering funds and resources for family run organizations to provide support services.

Using representatives from lived experience populations has been on an upward evolutionary process for over three decades. Federal, State, and private funding sources require family, consumer, and youth representatives and a shift towards a more family, consumer, and youth driven approach to serving vulnerable populations. Aside from organizational and funding requirements, the inclusion of a lived experience representative to provide family support has multiple benefits.

Across the Country

In **Arkansas** a community based, family run organization was awarded a contract from the state to provide peer to peer home visiting for targeted families of young children at risk for special needs. The organization was given enough funding to train the trainers of home visitors, hire and supervise home visitations, and to manage the program within nonprofit business practices.

In **North Carolina**, the statewide, family run organization for children and youth with mental health needs received a large, state contract to hire, train, and supervise Family Support Specialists with lived experience across the state to work with providers and ensure a family driven approach to service delivery and evaluation.

Lived Experience

The term “lived experience” has been used to characterize consumer and family members whose experiences are likely to match up to individuals currently receiving services. The term can be used to describe the first-hand accounts and impressions of living as a member of a group, such as those who have used mental health services, families who have been involved in the child welfare system or families who received services through a federal or state program. The core concept of supporting families is based upon an embedded lived experience and a peer to peer approach. One or more of the following might describe an individual with lived experience:

- A parent, family member, caretaker who has raised or is raising a child or youth with special needs;
- Willing to share life experiences in a positive manner;
- Has been involved in and understands multiple service delivery systems;
- Can separate both the good and bad experiences and use them to improve the system response to the families they serve;
- Can use experiences to help other families move beyond perceived limitations;
- Can transfer knowledge to build the capacity of the families served/supported;
- Builds their knowledge of systems through interactions with different families and their needs;
- Has an understanding of where and how to get answers regarding identified needs; and
- Persistence in securing necessary resources and information.

Guiding Principles of Supporting Families

The following Guiding Principles were developed to serve as a foundation for supporting families across the state with special needs.

- **Lived Experience:** Support evolves from lived experience, where families have access to persons familiar with the road who understand the questions, worries, joys, heartache, and celebrations that are a part of the journey;
- **Coactive Navigation:** Families build their capacity, confidence, and strength through support and coaching from another parent who can share their experiences when traveling new paths with their child’s or youth’s diagnosis.
- **Meaningful Connections:** Families build their capacity, confidence, and strength in navigating systems through active support and coaching from another parent.
- **Active Engagement:** Responsive listening and translation is provided through shared experience and serves as a vital component to assist families in a manner that allows them to receive the services necessary to meet their authentic needs.
- **Critical Partnerships:** The system promotes and models family-professional partnerships as a predictable aspect in establishing family identified needs and services.
- **Unbiased Respect:** ALL support recognizes and builds on the strengths of each family member and respects their choices, culture, and beliefs in an impartial and nonjudgmental manner.
- **Sense of Belonging:** Families have peers with similar experiences standing with them as they identify and use their natural networks to promote a sense of belonging.
- **Ongoing Sustainability:** Adequate efforts and resources are identified and available to ensure the continuity and longevity of supporting families for the duration of need.

Supporting Families: A Sampling of Services

Some of the supporting families services that could be offered to families and the systems that serve them includes:

- Serving on care planning teams with families;
- Building the capacity of families to identify and express their needs;
- Advocating and sharing information on the needs of families;
- Developing or editing material that builds the knowledge, capacity, and skills of families;
- Creating special programs or activities to meet family needs;
- Evaluating the program’s response to the principles of family, consumer, and youth driven-centered;
- Creating and collecting satisfaction surveys;
- Discussing with families their specific needs and guiding them to resources;
- Serving as a trainer for in-service trainings;
- Representing the families served on workgroups, taskforces, and/or interagency councils;
- Reviewing program policy to ensure sensitivity to the needs and experiences of families served;
- Creating and facilitating family advisory committees;
- Serving as an family advocate or voice at service planning meetings; and
- Serving as a peer mentor to those served when partnering with professionals or navigating the system of care.

Recommendations

In light of the previous discussion, the following recommendations emerged from the group.

- **Families must have access to organizations that represent the lived experience through:**
 - Referrals to supporting family organizations by all child and youth serving agencies and programs within a specified period of time;
 - Systems that use available evidence based, parent to parent models and family driven principles to connect families; and
 - Family run organizations that provide family support through a memorandum of agreement and within the guiding principles of this paper.
- **Support to families must be accessible on all levels of planning, treatment, and evaluation and feature the following:**
 - Statewide coverage without gaps;
 - Transparency that allows families to make choices on what will work best for them;
 - 24/7 availability;
 - Family driven and centered approaches;
 - Opportunities to access culturally competent support that is respectful and responsive to their own beliefs, values, and customs; and
 - Adequate provisions for urgent and emergency support needs.
- **Families are engaged and have opportunities to build their skills as a parent of a child or youth with special needs through:**
 - Agencies and programs that are committed to assisting family run organizations in identifying families that could benefit from additional training and support;
 - Utilization of family run organizations and their expertise to develop and manage training programs for families that are responsive to their identified needs;
 - Annual trainings within the state to build the leadership capacity of families; and the
 - Availability of a formal career ladder for families with lived experience through a rigorous training and certification program.
- **Family support is viewed as a critical and professional service to the well-being of families of children and youth with special needs and demonstrated through:**
 - An examination of the extent to which current supports are aligned with these principles;
 - Ongoing opportunities for funding and resources to ensure that family run organizations have the capacity to sustain the support they offer;
 - Family leaders have regular opportunities to meet with the Governor, policymakers, and agency management to discuss and review the state of the state in family support;
 - During budget discussions, family support will be considered as a viable alternative to more costly interventions;
 - Regular, consistent, and predictable funding from the state; and the
 - Recognition that program management does not constitute family support in itself.

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

A.L. North Dakota

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Next Steps

In an effort to promote the principles and intent of this paper and promote the fidelity of supporting families, we have agreed to the following next steps:

1. Development of a short and long term strategic plan that will outline goals, activities, outcomes, and accountability;
2. Meet with stakeholders and policymakers to establish direction and resource options to finance and sustain family support;
3. Work collaboratively to align our organizations with responsibilities; and
4. Create memorandums of agreement between organizations to minimize competition, repetition, and confusion.



Changing the future,
one family at a time

Contributors

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Executive Summary

North Dakota Family Support; Sharing Through the Lens of Lived Experience

Research and experience indicates that there is much more to meeting the needs of children and youth with special needs than those services offered by providers. Most services are provided according to strict funding guidelines that dictate the eligibility, type of service, and access; leaving huge gaps to fill in the pursuit of the wellbeing of children and youth with special needs and their families. Meeting the unique and diverse needs of families and their children and youth with special needs can only be accomplished by maximizing contributions of all stakeholders. Family leaders from across North Dakota gathered to discuss how to maximize the capacity of the system and families they serve and their role in targeted support activities that promote the well-being of children and youth with special needs. Through intense strategic planning, the group emerged with a definition, guiding principles, recommendations, and next steps that they feel are critical components of elevating the focus on ensuring and improving the well-being of children and youth with special needs and their families.

Definition of Supporting Families

Supporting families involves the connection to another person who has also raised a child/youth with a special health care need and/or disability and who has a shared life experience. This connection will assure that families get resources and services in ways that are respectful, relevant, and honor their unique choices and perspectives so that they can make informed decisions to achieve the best possible outcomes for their children and/or youth.

Guiding Principles

The following Guiding Principles were developed to serve as a foundation for supporting families across the state with special needs.

- **Lived Experience:** Support evolves from lived experience, where families have access to persons familiar with the road who understand the questions, worries, joys, heartache, and celebrations that are a part of the journey;
- **Coactive Navigation:** Families build their capacity, confidence, and strength through support and coaching from another parent who can share their experiences when traveling new paths with their child's or youth's diagnosis.
- **Meaningful Connections:** Families build their capacity, confidence, and strength in navigating systems through active support and coaching from another parent.
- **Active Engagement:** Responsive listening and translation is provided through shared experience and serves as a vital component to assist families in a manner that allows them to receive the services necessary to meet their authentic needs.
- **Critical Partnerships:** The system promotes and models family-professional partnerships as a predictable aspect in establishing family identified needs and services.
- **Unbiased Respect:** ALL support recognizes and builds on the strengths of each family member and respects their choices, culture, and beliefs in an impartial and nonjudgmental manner.
- **Sense of Belonging:** Families have peers with similar experiences standing with them as they identify and use their natural networks to promote a sense of belonging.
- **Ongoing Sustainability:** Adequate efforts and resources are identified and available to ensure the continuity and longevity of supporting families for the duration of need.

Recommendations

The following recommendations emerged as critical components of advancing family support across the state.

- *Families must have access to necessary connections* through organizations that represent the lived experience, including referrals to supporting family organizations by all child and youth serving agencies and programs within a specified period of time; the use of evidence based, parent to parent models and principles to connect families; and family run organizations will provide family support through a memorandum of agreement and within the guiding principles of this paper.
- *Family support must be made accessible on all levels* of planning, treatment, and evaluation and minimally feature statewide coverage without gaps; transparency that allows families to make choices on what will work best for them; 24/7 availability; family driven and centered approaches; opportunities to access culturally competent support that is respectful and responsive to their own beliefs, values, and customs; and adequate provisions for urgent and emergency support needs.
- *Families are engaged and have opportunities to build their skills* as a parent of a child or youth with special needs through agencies and programs that are committed to assisting family run organizations in identifying families that could benefit from additional training and support; utilization of family run organizations and their expertise to develop and manage training programs for families that are responsive to their identified needs; annual trainings within the state to build the leadership capacity of families; and availability of a formal career ladder for family support providers through a rigorous training and certification program.
- *Family support is viewed as a critical and professional service* to the well-being of families of children and youth with special needs and demonstrated through an examination of the extent to which current supports are aligned with these principles; ongoing opportunities for funding and resources to ensure that family run organizations have the capacity to sustain the support they offer; family leaders have regular opportunities to meet with the Governor, policymakers, and agency management to discuss and review the state of the state in family support; during budget discussions, family support will be considered as a viable alternative to more costly interventions; regular, consistent, and predictable funding from the state; and the recognition that program management does not constitute family support in itself.



Next Steps

In an effort to promote the principles and fidelity of sound family support to ensure the wellness of North Dakota's families of children and youth with special needs, we will develop a short and long term strategic plan that will outline goals, activities, outcomes, and accountability; meet with stakeholders and policymakers to establish direction and resource options to finance and sustain family support; and work collaboratively to align our organizations with responsibilities.

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In Search of an Answer

***Listening and Responding:
North Dakota Survey of
Agencies Serving Children
and Youth with Special
Health Care Needs***

In Search of an Answer Listening and Responding:

North Dakota Survey of Agencies Serving Children and Youth with Special Health Care Needs

A report of the Family Voices of North Dakota qualitative interview results to help identify the experiences that families may face as they search for resources, information, financial support, emotional support, and access to services.



Thank you to the families and professionals who provided their time and expertise on this project:

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FVND was started in 1996 and became a State Chapter formally sanctioned by National Family Voices, Inc. in the first quarter of 2001. FVND aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities. Through our national network, we provide families tools to make informed decisions, advocate for improved public and private policies, build partnerships among professionals and families, and serve as a trusted resource on health care.

The FVND Health Information and Education Center:

- Assists families as they navigate public and private systems, including health systems and insurance plans;
- Provides assistance to families in accessing services and resources for their children and how to partner with providers and caregivers;
- Listens to families as they describe their encounters with systems and helps guide them to possible solutions;
- Works with families, health care providers, public and private agencies, and advocacy or support groups to promote family-centered care and medical homes for children with special health care needs; and
- Promotes discussions and linkages among families, providers, managed care programs, and government to better serve the health care and related needs of children and families in North Dakota.

ND Parent to Parent Project:

- Is a statewide network of parents supporting families of children with developmental delays, disabilities, and special health needs;
- Offers emotional support and information;
- Acts as a valuable resource to families;
- Offers assistance in learning the necessary skills to help parents face the challenges of raising their child;
- Offers moral support and encourages parents to feel comfortable and optimistic about the future; and
- Is dedicated to supporting families at their most challenging times and to celebrating each new victory.

As a component of these services, FVND offers leadership institutes, training, workshops, and resource development. They also participate as a major partner on the local, state, and national levels in system transformation, facilitating a responsive system of care for children and youth with special health care needs (CYSHCN) and their families based upon a family-centered approach.

FVND Health Information and Education Center funding is provided by a grant from the US Department of Human Services' Health Resources and Services Administration, Maternal and Child Health Bureau and the North Dakota Department of Health (Title V, Children's Special Services) and ND Parent to Parent Project funding is provided by the ND State Council on Developmental Disabilities.

“We who have children with special health care needs have learned patience, joy and resilience which come from the lessons our children have taught us. Through them our lives have been enriched, learning from those lessons and sharing them with those who also have devoted their lives, partnering with parents and providers in each step. Family Voices of ND is an important connection for families not only to connect with one another but in assisting them in accessing vital information”

D. Feist

Listening and Responding:

North Dakota Survey of Agencies Serving Children and Youth with Special Health Care Needs



Over the past eleven year, Family Voices of North Dakota (FVND) has utilized a qualitative interview system to gather information regarding the capacity of the system of care for families of children and youth with special health care needs (CYSHCN) to help identify the experiences that families may face as they search for resources, information, financial support, emotional support, and access to services.

This effort serves as a bridge to a better understanding of what is working well for families, barriers that families encounter, a celebration of successes and models of excellence, and opening a dialogue regarding the identified challenges that families may be facing. This paper highlights background information (including population, about FVND, about family-centered care, and need), study design (including intent and proposed outcomes, potential uses, and methodology), overall results (including data collection results, description of the response and respect scale, and interpretation), and FVND recommendations for use of results to improve the capacity of the system to be responsive to the needs of families of children and youth with special health care needs as they navigate their care and support options.

“Instead of depending on case workers and teachers deciding what was a need for our family, give us the choice of what our family needs and allow us to pick and choose, with assistance, what we think we need.”



Background

Children and youth with special health care needs (CYSHCN) have been defined federally as children or youth with or at risk for chronic physical, developmental, behavioral, or emotional conditions who also require health and related services beyond what is needed by children generally. This definition includes children with:

- Disabilities
- Chronic illnesses and conditions
- Health related educational and behavioral problems



Based on the information from the National Survey for Children with Special Health Care Needs (CSHCN) provided to North Dakota's Children's Special Health Services (CSHS), 12 percent of North Dakota's children (about 17,500) have a special health care need compared to 14 percent nationally. Survey data indicate that the prevalence rate of special health care needs in ND is 6 percent for children ages 0-5, 15 percent for children ages 6-11, and 15 percent for youth ages 12-17, and is 14 percent for males and 10 percent for females.

The data show that CSHCN families experience an economic impact; 18 percent of these families had someone in the family who had to quit their job, not take a job, or greatly change their job due to problems with child care for their child in the past 12 months and 19 percent experienced financial problems due to their child's health needs.

About Family-Centered Care

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

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

- Families and professionals work together in the best interest of the child or youth and the family. As the youth grows, they assume a partnership role.
- Everyone respects the skills and expertise brought to the relationship.
- Trust is acknowledged as fundamental.
- Communication and information sharing are open and objective.
- Participants make decisions together.
- There is a willingness to negotiate.

"We were alone, and I SEARCHED for resources and made calls and went to meetings and filled out paperwork. I spent more than two years searching for help, including at social services, and they never even told me about CSHS. Very sad and frustrating at how much money and stress it could've saved our family. Accessing existing programs should be a simple, streamlined process."

Based on this partnership, family-centered care:

- Acknowledges the family as the constant in a youth's or child's life.
- Builds on family strengths.
- Supports the child or youth in learning about and participating in his or her care and decision-making.
- Honors cultural diversity and family traditions.
- Recognizes the importance of community-based services.
- Promotes an individual and developmental approach.
- Encourages family-to-family and peer support.
- Supports youth as they transition to adulthood.
- Develops policies, practices, and systems that are family-friendly and family-centered in all settings.
- Celebrates successes.



Sources: 1) National Center for Family-Centered Care. *Family-Centered Care for Children with Special Health Care Needs*. (1989). Bethesda, MD: Association for the Care of Children's Health; 2) Bishop, Woll, and Arango (1993). *Family/Professional Collaboration for Children with Special Health Care Needs and their Families*. Burlington, VT: University of Vermont, Department of Social Work; and 3) Family-Centered Care Projects 1 and 2 (2002-2004). Bishop, Woll, and Arango. Algodones, NM; Algodones Associates.

The Needs of CYSHCN in North Dakota

The 2009 North Dakota CSHS Family Needs Assessment and Block Grant Report indicate that families varied greatly in their knowledge of community services and programs they can access. Specifically the report showed that:

- 45 percent of families did not always receive needed information from their child's doctor or other health care provider.
- 51 percent of families did not feel comfortable in their knowledge of health care financing and the various systems.

Over the past decade, national surveys have indicated that families who are informed are better decision makers for their CYSHCN. The Health Care Experiences of Families of Children with Special Health Care Needs conducted by the Heller School at Brandeis University and Family Voices also confirmed this family need. Research shows that family and child health outcomes improve dramatically when they can consistently access accurate and quality information in a timely manner.

"I found it very hard to learn about services for children with special healthcare needs. I was always given the run around and always had to wait for answers. For new families I would suggest sending out a packet of information containing information for all services available and support groups for families dealing with a child with special healthcare needs."

As a reality check to assessment and survey indicators, families who have contacted FVND via phone or in person shared their lack of health care information and knowledge and available resources in ND. In addition to problems accessing medical and community based resources, families reported difficulty in locating information that is easily understood for diagnosis and treatments of their children, and in understanding public and private insurance benefits and limitations.

Study Design

Intent and Proposed Outcomes

The intent of this project was to help identify the experiences families of children and youth with special health care needs may face as they search for resources, information, financial support, emotional support, and access to services. The project sought to identify what was working well and how that was influencing the family capacity to access information. Barriers encountered by families serve as real life examples of specific challenges faced by families as they navigate the system of care for CYSHCN.

Potential Uses

The survey can enhance family capacity to seek and access appropriate services for their CYSHCN by providing a snapshot of the strengths and challenges within the information navigation trail. It will serve as a base for identifying and celebrating success and beginning a dialogue to identify barriers that families may face. The information will be used to identify areas for FVND to work as an organizational partner with the system of care to effectively improve the capacity of families to navigate, locate, and access appropriate services and supports.

Methodology

The methodology of this initiative had several stages, each serving as a progressive way of gathering information that would meet the anticipated outcomes and assist organizations, families, and systems to better meet the needs of CYSHCN.

STAGE	DESCRIPTION
Targeting Programs:	Using traditional avenues of information seeking by families, FVND developed a database of organizations and agencies across ND that serve CYSHCN to call in search of resources and information.
Notification of survey:	Before the survey was conducted, a letter was sent to administrators of the main agencies that were going to be called to let them know about the upcoming survey.
Scenario:	A family scenario was created to serve as the purpose of the call and a consistent way of soliciting information, resources, and referrals.
Seeking information calls:	A parent caller, using the scenario and acting as a parent seeking information and resources, called agencies, organizations, and providers in the database with the scenario.
Data collection:	The parent caller documented each call individually by noting the responses she received from each person (at each agency). The caller also rated each call on both responsiveness and respectfulness, based upon a subjective scale and interpretation from the vantage point of a parent of a CYSHCN.
Aggregate findings:	The responses were collated into an Excel database.
Rating responses:	A group of individuals from across the state rated each agency on a scale of 1-5, based on the data and indicated if the agency was responsive and respectful.
Disseminate information:	The results and information were shared at meetings with agency directors and partners.

Overall Results

The results yielded good responses from a variety of programs and agencies that were genuine in their willingness to help and find information, care about the situation, follow up by email, and emulate an overall desire to cover the needs of the family. Specific “helping” behaviors included:

- Referrals to county offices
- Referrals to FVND and other family support agencies
- Offers to make calls on behalf of the family
- Willingness to check back to see how they were doing
- Follow up emails
- Active listening

Some responses and behaviors that were not found helpful included:

- Multiple “baton tosses”; passing the parent caller on to other programs and services
- Referrals to other programs that were not knowledgeable or helpful
- Not referring to their own agency’s programs
- Offering websites, but not asking if the family had internet access
- Offering information without the contact information
- Using incorrect names such as “Human Resource Center” instead of “Human Service Center”
- “Good Luck” wishes when they were unable to assist

Number of programs called	215
Number of calls completed (sometimes spoke with multiple individuals within the same program)	324
Number with wrong 800#	8
Number with wrong local number	13
Number disconnected	14
Number totally unreachable	15
Number answering to a different name	11
Number rated as responsive	235
Number rated as respectful	146

Response and Respect Scale

1. Not responsive or respectful; gave no information or help on where to go or what to do.
2. Somewhat responsive or respectful, but not both; gave no information or help on where to go or what to do.
3. Responsive and respectful, offered some information, but it was not the best or was lacking in contact information
4. Responsive and respectful, gave information, but did not give all needed information (both parent support and other needs)
5. Responsive and respectful, gave correct information on who to call or connect to or what to do.

Table 2. Rating Results

1 – Worst	65
2	73
3	44
4	26
5 – Best	7
Rating average	2.2

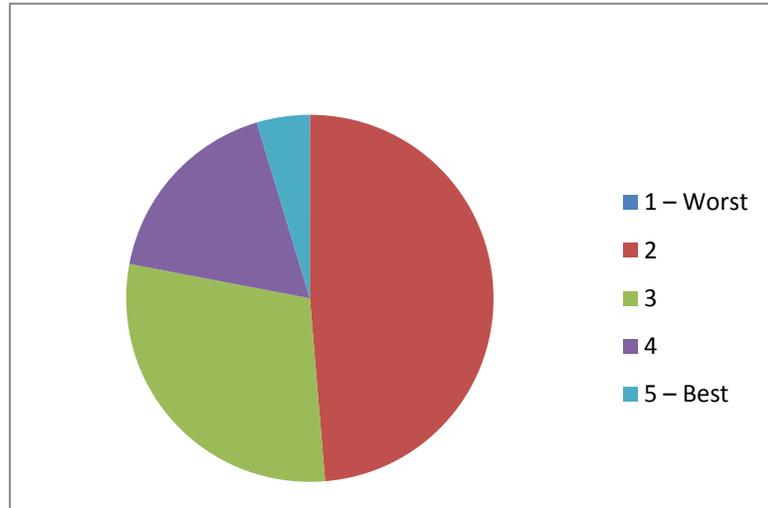


Figure 1: Response and Respect Results

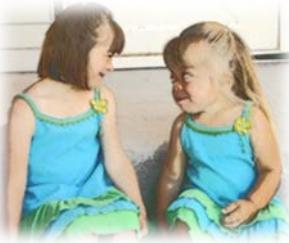
Interpretation

A review of the outcomes of this exercise indicate that there are locations, agencies, and programs that are well prepared to assist families when they turn to them in search of resources, information, and assistance. Some seemed to be inclined to assist, regardless of whether it was a population that they were responsible for helping or not. Several, albeit a small number, seemed to be prepared and well organized in their approach to assisting over the phone. Because of the many barriers to communication and understanding inferred by phone conversations, those that were considered respectful are to be applauded.

While there is no current national standard to help us determine whether an average state rating of 2.2 is adequate, we feel strongly that we would like to see this number improve. This project also highlighted the plight of families as they blindly stumble through the system of care in search of resources, information, and assistance for their CYSHCN. The study suggests that there was an abundance of wrong numbers, disconnected numbers, and a general lack of available resources without “digging” from one level within a program to another. There is an obvious lack of knowledge of the system of care in general by many programs and service agencies – sometimes within their own program. The “loop” of information had many missing links such as a failure to ascertain the capacity and resources of families to follow the suggested resource or failure to offer the contact information. First contact employees (those who answer the phone) may have created a barrier by not stating the program name appropriately or not offering a clear and concise description of what they could offer families of CYSHCN.



FVND Recommendations



Transformation of the health care system for CYSHCN will be dependent upon ensuring that families have accessible, accurate, family centered and culturally competent information. With the Family to Family Health Information Center and ND Parent to Parent Project, FVND recognizes their role and responsibility in working in collaboration with other partners to create an accessible and accurate information system for families. Recommendations that warrant follow up include the following.

Training that facilitates:

- Information sharing and cross training within an agency on the various programs, including the full scope of the agency, not just a specific program.
- Orientation and ongoing training for all front line/first contact staff, such as operators, receptionists, or outreach workers.
- Cross training and sharing of information and resources between agencies, programs, organizations, and service providers within the state's communities.
- Staff that are trained on accessing family support partners, such as FVND.
- Utilization of FVND training on family-centered practices and encourage agencies to have FVND staff present at staff meetings, trainings, and conferences.

Partnerships that:

- Encourage networking opportunities between agencies and service providers.
- Promote statewide information and resource partnerships that will promote consistent and predictable methods for sharing information that ensure service agencies, programs, and organizations can be responsive to the requests and needs of families and their CYSHCN.
- Ensure that agencies and programs include families and youth on advisory boards and committees.
- Provide families with information on FVND and other family organizations with all referrals.

Tools that promote:

- Quality improvement for monitoring and improving the information and resource system.
- The use or development of a shared database of information for families and providers with accurate contact information.
- The utilization of data from family support partners such as FVND to evaluate program and agency effectiveness in supporting families.

Accountability that will:

- Identify and use regular "check points" between critical partners within the CYSHCN system of care to identify gaps in the provision of information and resources.
- Lead to a strategic plan for a family centered and culturally and linguistically competent approach to addressing the needs of families.
- Assure that family support partners such as FVND are included in the planning, implementation, and evaluation of the information and referral system.
- Utilize FVND as an outside evaluator of the information and referral system.
- Continue to discuss available opportunities for family support organizations to provide information regarding family perspective in accessing services and support.

FVND Next Steps

As an immediate response, FVND will meet with state agency directors to review the survey, results, discuss recommendations, and explore partnership opportunities for improving information and resource access. After meeting with state agency directors, FVND is prepared to follow up with staff and present the results and discuss approaches to improve family access to information and resources.

FVND is working on a “North Dakota Roadmap” to begin addressing the information gaps experienced by families. We invite partners from across the state to join in this endeavor and other approaches to develop the capacity of the health care and information system to be more responsive to the requests for information and services of families of CYSHCN.

Finally, FVND is invested in the vitality of this survey and its potential to expand the capacity of families to access accurate information and support. We will continue to seek resources to support the survey each year, hoping to document improvements in information, support, service, and resource access for CYSHCN and their families.

