

# 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,

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*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.*

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### 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

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