



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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