NORTH Dakota | Health & Human Services
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Children with Special Healthcare Needs Annual Plan

North Dakota Maternal and Child Health Priority Goal: Improve the system of care for children with special healthcare needs (October 1, 2026-September 30, 2027).

Children with Special Healthcare Needs (CSHCN) are defined as those who have, or are at an increased risk for, chronic physical, developmental, behavioral, or emotional conditions. Despite these challenges, it is imperative that children and youth with special healthcare needs are provided with the opportunity to lead fulfilling lives and thrive within a supportive system that addresses their social, health, and emotional requirements. This approach ensures their dignity, autonomy, independence, and active involvement in their communities. According to data from the 2023-2024 National Survey of Children's Health (NSCH), approximately 22% of children aged 0 to 17 in North Dakota are identified as having a special healthcare need.

The establishment of a medical home is crucial for all children, including those with special healthcare needs. A medical home is characterized as a model for delivering comprehensive, high-quality primary care that fosters collaborative partnerships among patients, clinicians, medical staff, and families. This model transcends the traditional confines of clinical practice, encompassing care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective.

Federally available data indicates that North Dakota is exceeding the national average of 40.1% for CSHCN aged 0 to 17 who have a medical home, achieving a rate of 48.2% in the 2023-2024 period. It is crucial to continue promoting and facilitating the integration of the medical home model throughout the healthcare system, as it appears to significantly contribute to the overall health and well-being of CSHCN. Key components of the medical home model include providing families with care coordination, a seamless referral process, family-centered care, and having a usual source of sick care.

Data from the 2023-2024 NSCH reveals that 62.7% of CSHCN in North Dakota received needed care coordination, exceeding the national average of 53.3%. However, there remains an opportunity for improvement in this area. Furthermore, 72.4% of these CSHCN did not have difficulty getting referrals when needed, compared to the national average of 70.4%. Additionally, 89.4% of CSHCN in North Dakota have family-centered care, which is above the national average of 81.6%. Next, the 2023-2024 NSCH

indicates that 86.5% of North Dakota CSHCN have a usual source of sick care, versus the national average at 81.8%. Lastly, according to the NSCH, the percentage of CSHCN, ages 0 through 17, who are receiving care in a well-functioning system in North Dakota decreased from 19.2% in 2022-2023 to 18.7% in 2023-2024. While this was a decrease, North Dakota is still above the national average at 13.7%.

The 2025 Needs Assessment identified a clear need for strengthened services aligned with the medical home model. When stakeholders were asked to select the single performance measure they believed should be prioritized for the CSHCN population, the medical home measure was the predominant choice, receiving 60% of responses. Based on these findings, the priority for the CSHCN domain is to enhance the system of care for children with special healthcare needs. The established goal is to increase the percentage of children, including CSHCN, who have a medical home from 55% to 60%, as measured by the NSCH, by September 30, 2030.

As noted previously, the medical home model consists of several key components. Because the planned strategies are designed to address multiple aspects of this model, medical home was selected as the overarching priority. Additionally, an Evidence-Based or Informed Strategy Measure (ESM) has been developed and will be implemented through targeted strategies aimed at achieving the established goals.

Title V staff recognize the essential role that education and outreach play in increasing awareness and promoting the utilization of available services for families and their children. To ensure families are informed about and able to access existing programs and supports, Title V staff plan to implement a series of targeted activities. Staff will collaborate with other MCH domain groups and established partners to encourage the use of available services and to highlight the importance of a medical home. This collaboration includes disseminating evidence-based materials that describe the medical home model and supporting partners in expanding their outreach to families. Additionally, planned strategies include providing funding to partners through contracts to deliver education and/or training to families on medical homes and care coordination. As a result, the selected ESM will measure the percentage of families served through family support contracts who receive education and/or training on medical home care coordination.

Second, Title V staff plan to attend and/or provide educational opportunities, such as disseminating resources at conferences and developing family resource toolkits, to help families understand the importance and functions of a medical home. Because MCH staff participate in a wide range of conferences that reach various target audiences, they intend to leverage these engagements to deliver education to families whenever feasible. Additional educational efforts may include serving on planning committees and presenting at conferences commonly attended by families. Finally, Title V staff will meet

with the Special Health Services Family Advisory Council one to two times per year to discuss medical home activities and gather feedback on improving the CSHCN system of care. Staff acknowledge the critical value of family input and are committed to providing multiple opportunities for families to share feedback and help shape strategies aimed at increasing medical home awareness.

Next, it is also essential to provide education to providers across the state, as their support and collaboration are critical to establishing effective medical homes for children. Title V staff will therefore implement targeted education and outreach efforts to assist providers in adopting and enhancing medical home practices within their settings. These efforts will involve a range of professionals, including healthcare providers, school personnel, and medical students, through multiple strategies. First, staff will allocate funding for projects or initiatives specifically focused on strengthening medical home components, with the goal of supporting organizations in integrating these practices. Next, staff will develop practical resources, such as referral toolkits for school nurses, multidisciplinary clinics, and medical students, to promote consistent and informed medical home practices. These toolkits will include evidence-based materials and information on commonly used programs and services for CSHCN, such as Early Intervention (Infant Development) and North Dakota Medicaid.

Additionally, Title V staff will collaborate with the Primary Care Office (PCO) to disseminate information regarding access to rural health providers. Due to North Dakota's rural nature, many families face challenges accessing care close to home. Recruiting providers in small rural communities is difficult, creating barriers to timely and specialized care. To help address this issue, staff will work with the PCO to share information with potential providers about loan repayment opportunities available to those willing to practice in rural areas. Finally, Title V staff will continue strengthening collaboration with North Dakota Medicaid to align efforts related to provider education and outreach. Staff have recently participated in discussions with the Centers for Medicare and Medicaid Services (CMS) and North Dakota Medicaid, and have held several meetings focused on improving partnership related to care coordination for CSHCN, Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), and provider education on Medicaid services. These conversations will continue as North Dakota Medicaid receives EPSDT guidance from CMS following their virtual visits. Furthermore, as additional details emerge regarding North Dakota's Rural Health Transformation Program, Title V staff will explore new opportunities for coordination with state-level partners working toward similar goals and outcomes.

Engaging family and community partners is essential to strengthening the system of care for CSHCN. Family-led support organizations, in particular, play a critical role in providing families and partners with information on key topics such as the medical home model. The Special Health Service Unit (SHS) maintains strong partnerships with

several of these organizations, which offer leadership, advocacy, and direct support to families. Four prominent partners include Family Voices of North Dakota (FVND), Pathfinder Services of North Dakota, the Federation of Families, and Designer Genes. Additional statewide organizations also offer valuable support to specific populations, including families involved in Early Intervention and individuals with Down syndrome, autism, or hearing loss.

SHS will continue to ensure that families and family support organizations are meaningfully represented on various workgroups and advisory bodies, such as the Newborn Screening Advisory Council, the SHS Family Advisory Council (FAC), and the SHS Medical Advisory Council (MAC). Members of the MAC were actively engaged in developing the CSHCN Action Plan and provided critical insight and feedback throughout the process. Title V staff also plan to apply for the MCH Strategic Partnership Skills Institute to further strengthen their strategic partnership competencies.

North Dakota priorities and activities for CSHCN align with family and child well-being and quality of life, access to services, and financing of services.

Providing families with opportunities to achieve optimal health will remain a priority across programs and services by promoting access to healthcare for all children, including CSHCN. Translation services will be available to any child participating in an SHS program to help reduce language barriers. Additionally, travel assistance may be offered through a contracted healthcare organization for families who must travel long distances to access multidisciplinary clinics. A variety of multidisciplinary clinics, including those focused on asthma, metabolic disorders, cleft lip and palate, and neurodevelopmental concerns, will continue to be available to children at no cost. This multidisciplinary approach reduces the number of separate appointments a child must attend and enhances care coordination and communication among providers and families. To further strengthen family engagement and ensure the work being conducted for CSHCN remains meaningful, family involvement on the FAC will continue to be prioritized. The application for families interested in joining the Council is available on the SHS website to ensure equal access to participation.

Family and child well-being, along with activities aimed at improving quality of life, will also be advanced through a range of strategies. As noted above, SHS coordinates the FAC, where families of CSHCN serve as equal partners in decision-making and strategic planning for Title V initiatives. Strong partnerships with family support organizations will also be maintained. SHS supports and promotes a variety of FVND initiatives, including the Leadership Institute for families, Extended Learning calls, and the Family-to-Family support network.

Ensuring that CSHCN and their families have reliable access to services is essential to supporting their overall health and well-being. Core medical home components, such as care coordination, play a central role in Title V efforts. Staff maintain strong working relationships with numerous state and local programs to help ensure that access to services does not become a barrier for families. Established referral systems help verify that children are connected to all programs and supports for which they are eligible. Common referral pathways for CSHCN include Early Intervention, Right Track, North Dakota Medicaid, FVND, the North Dakota Association for the Disabled, and the Newborn Screening Long-Term Follow-Up program. Additionally, Title V will continue to fund multidisciplinary clinics across the state to address gaps in care and ensure that CSHCN are closely monitored and receive all necessary evaluations and treatments.

Lastly, financing of services will be integrated into North Dakota's strategies to support CSHCN. SHS administers a Financial Coverage Program in accordance with North Dakota Century Code, Chapter 23-41 that serves as a payer of last resort for eligible children, helping to offset medical expenses when no other coverage is available. This program will continue to be offered and regularly evaluated for effectiveness. In addition, Title V staff and the SHS Medical Director, a practicing pediatrician, will participate in North Dakota Medicaid Medical Advisory meetings to discuss potential program updates based on the evolving needs of CSHCN. As noted previously, Title V staff will continue providing care coordination services, including for dual-eligible children, to ensure they maintain adequate insurance coverage. Staff will also continue offering families resources and referrals related to insurance options, including the SHS Healthcare Coverage Options Resource Booklet available on the SHS website, as well as referrals to Early Intervention and North Dakota Medicaid.

In summary, North Dakota remains committed to advancing the system of care for CSHCN and their families. SHS recognizes the critical importance of medical homes and will continue working to expand education, knowledge, and resources that improve access to coordinated, family-centered care. Collaboration among stakeholders, including healthcare providers, state partners, community organizations, and families, will be essential to achieving these goals. North Dakota strives to ensure that all children and their families have the support they need to live full, healthy lives, thrive in their communities, and grow into healthy adults.