Access to Services and Supports for Children and Youth with Special Health Needs and their Families

ENSURING CYSHN AND THEIR FAMILIES HAVE WHAT THEY NEED TO THRIVE

Minnesota acknowledges that systemic racism and generational structural (social, economic, political and environmental) inequities result in poor health outcomes. These inequities have a greater influence on health outcomes than individual choices or one's ability to access health care, and not all communities are impacted the same way. All people living in Minnesota, including those with special health needs, benefit when we reduce health disparities and advance racial equity.

Current Landscape of Services and Supports for CYSHN in Minnesota

An estimated 222,109 children and youth in Minnesota (approximately 17.2 percent of children 0-17 years old) have special health needs, which includes a range of chronic physical, developmental, behavioral, and emotional conditions.[1] These children and youth may use a variety of services and supports, including (but not limited to) primary care, dental services, speech, occupational, and physical therapies, specialized child care, mental health counseling, respite care, specialized medical care and equipment, school-based services, other community-based services, and more.[2]

Unfortunately, it is not always easy or possible to access these crucial services. CYSHN and their families are more likely to report having forgone needed services compared to those without special health needs.[1] The more complex the needs of the child, the less likely they are to receive needed services. Families often forgo care due to challenges in accessing care, such as long waitlists or problems getting appointments, troubles with eligibility criteria, complex systems to navigate, a lack of support services for parents and other family members, child care availability and affordability issues, and transportation issues. Often, the greatest barriers to care are faced by those who identify as non-White, who live poverty, who live in rural areas, or who speak a language other than English.

Data from the 2018-2019 National Survey of Children's Health (NSCH) shows that only 14.1 percent of Minnesota CYSHN reported to have received care in a well-functioning system.*

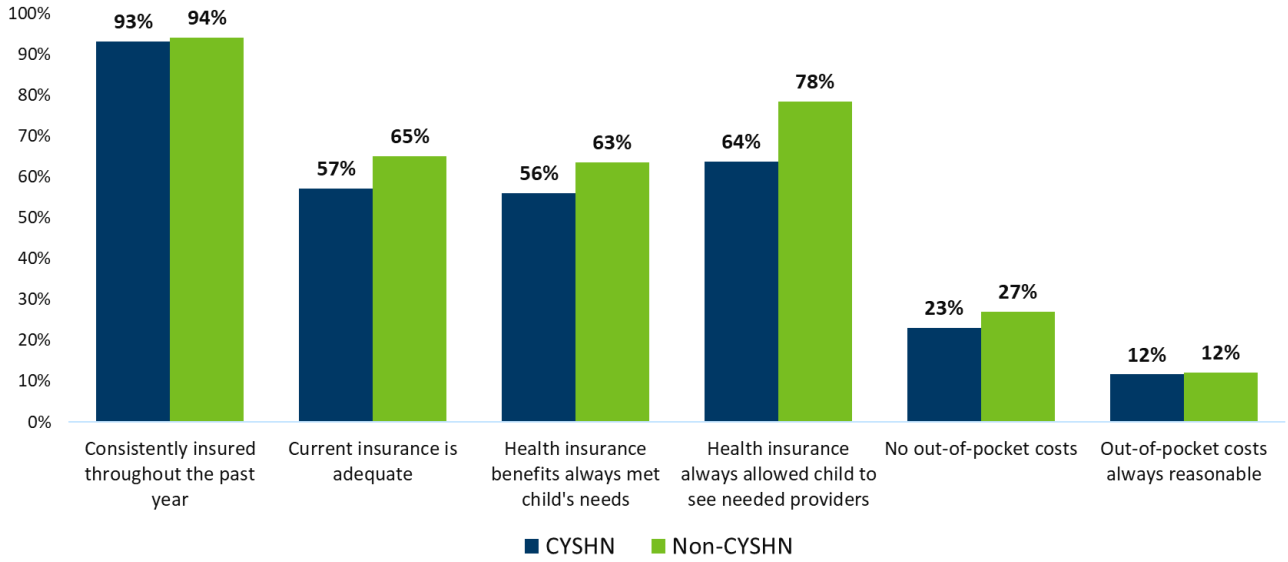
In Minnesota, many services for CYSHN are administered at the local level and differ between counties. This can make it difficult for families to know what services are available, if they are eligible for them, and how to access them.

> *"Waiver programs are administered differently from county to county and the amount of money distributed differs by county. So, when we are providing support, it is very hard to say, 'This is what is available to you in your county,' because it is variable across counties." – Key Informant Interview, Carolyn Allshouse, Family Voices of Minnesota*

* A well-functioning system is one in which 1) children receive screening and are identified for needed intervention early, 2) families are partners in making decisions related to the child's care, 3) children have access to comprehensive primary care (medical home), 4) children have easy access to services, 5) children and families have adequate insurance and financing for supports, and 6) youth are adequately prepared to transition to adult health care.

Families may experience issues accessing care because they lack adequate health insurance. According to the 2018-2019 NSCH, around 46 percent of CYSHN in Minnesota did not have insurance coverage that was adequate to meet their needs, increasing from 40 percent in 2017-2018. CYSHN are less likely to have been consistently insured throughout the year and less likely to have insurance that is adequate (meaning it meets the child's needs, allows them to see needed providers, and has reasonable out-of-pocket costs) (see Figure 1).

Figure 1. Insurance Status Measures – Minnesota CYSHN vs. Non-CYSHN, 2018-2019



Data Source: National Survey of Children's Health (NSCH)

Many of the services that are required for CYSHN are often not covered by insurance plans, which means that families must bear the burden of cost, resulting in attempts to provide some services for their child at home or forgoing these services altogether.[3] Having insurance coverage is crucial for families of CYSHN; according to a recent study, cost was twice as likely to be named as a barrier to services for parents of uninsured CYSHN than insured.[2]

Around 17.5 percent of families of CYSHN had difficulty paying their medical bills in the past 12 months, compared to just 10 percent of non-CYSHN families, highlighting the importance of comprehensive health insurance coverage. In another study, CYSHN were twice as likely to live with caregivers who were experiencing high levels of financial stress. Additionally, 14.1 percent of families reported not changing jobs because they needed to maintain health insurance for their child, versus only 6.1 percent of non-CYSHN parents according to 2018-2019 NSCH data.

Families also face challenges accessing care because of a shortage of qualified professionals, especially with home health (i.e., home nursing and personal care assistance) and mental health services in the state. Reasons for these shortages include low pay, high staff/provider turnover, lack of early childhood mental health specialization, and limited providers in Greater Minnesota.[4]

Additional information about CYSHN health care utilization and access:[1]

- Around 21 percent of CYSHN have gone to the emergency department at least once in the past year, versus only approximately 17 percent of non-CYSHN.
- About 12 percent of CYSHN had a small or big problem getting referrals when needed, whereas only 1.2 percent of non-CYSHN had a small problem, and 0.9 percent had a large problem.

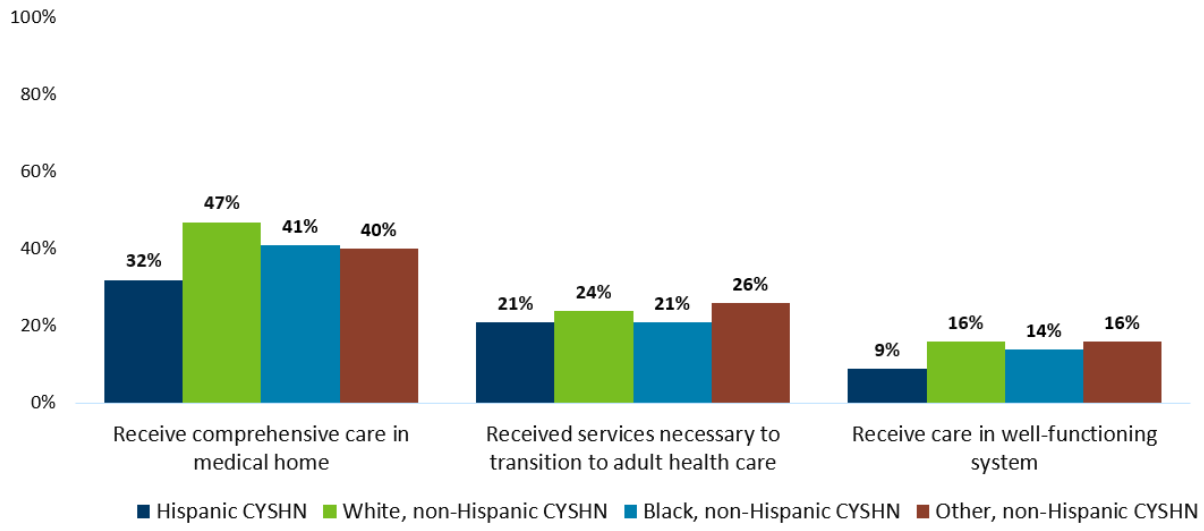
- Notably, nearly 9.4 percent of CYSHN reported not receiving family-centered care in the last year, while 11.1 percent of non-CYSHN reported the same.

CYSHN and their families living in poverty or rural areas often face the greatest barriers to care. Disparities in access to health care exist among CYSHN living in rural areas versus urban areas in Minnesota. Rural CYSHN typically face additional barriers in receiving health and support services that their urban counterparts do not encounter. These include fewer options for services available locally and the need to travel long distances to receive care due to lack of services or limited availability of condition-specific care.

Racial Justice and Access to Services and Supports for CYSHN and their Families

National-level data shows disparities between CYSHN of different races on several systems indicators related to access to services and supports. According to the NSCH, compared to non-Hispanic Black and Hispanic CYSHN, non-Hispanic White CYSHN were more likely to have received care in a comprehensive medical home, received services necessary to transition to adult health care, and received care in a well-functioning system (see Figure 2). In addition, Black and Hispanic CYSHN are more likely than White CYSHN to be uninsured and to have inadequate insurance.

Figure 2. Systems Indicators for CYSHN, by Race/Ethnicity



Data Source: National Survey of Children's Health (NSCH)

While national data on inequities among CYSHN can help identify the gaps in access to services and supports that exist for certain subgroups of CYSHN, inequities may differ from one state to another. However, it is difficult to report on important differences in access to services and supports due to data limitations. Though the National Survey of Children's Health is a primary data source for CYSHN, Minnesota is unable to conduct sub-analyses at the state level, even when combining data years, due to small sample sizes.

Though data limitations exist, we do know that there are strong connections between racism and ableism that lead to barriers to care and ultimately poorer outcomes. It is important to understand how racism and ableism are linked and how that impacts Black, Indigenous, and People of Color (BIPOC) with disabilities/special health needs.

"Racism and ableism are often thought of as parallel systems of oppression that work separately to perpetuate social hierarchy. Not only does this way of looking at the world ignore the experiences of people of color with disabilities, but it also fails to examine how race is pathologized in order to create racism. Meaning that society treats people of color in specific ways to create barriers, and these poor conditions create disability. The concept of disability has been used to justify discrimination against other groups by attributing disability to them." – Isabella Kres-Nash[5]

COVID-19 Pandemic: Access to Services and Supports for CYSHN and their Families

During March 2020, MDH conducted a five-question survey of partner organizations to assess the impact of the COVID-19 pandemic on families of CYSHN and on the organizations that serve them. The over 100 respondents provided information on how the pandemic is impacting families and organizations. Of note, our partners reported profound impacts on the mental and emotional health of families and CYSHN, which is likely due to some of the following issues:

- Increased feelings of social isolation or feeling separated from their friends and families.
- Difficulty accessing needed services/care for their child.
- Lack of educational supports available for children with disabilities to successfully participate in distance learning.
- Loss of income or other financial concerns due to unemployment or caregiving concerns for children.
- Concerns around stigma and discrimination against their child with a disability.
- Concerns over their basic needs being met due to some of the issues described above.

Additionally, organizations themselves expressed concern about being able to continue to serve families of CYSHN during and after the pandemic.

Strategic Planning Description

The Division of Child and Family Health (CFH) in partnership with stakeholders conducted a comprehensive assessment of the health and well-being of Minnesota's maternal and child health populations – including women, mothers, fathers, caregivers, children and youth (including those with special health needs), families, and communities. Following the prioritization of unmet needs, access to services and supports for CYSHN and their families was selected as a top priority for Minnesota.

In order to advance maternal and child health outcomes and health equity, CFH acknowledges that we need to work together in authentic, collaborative, and innovative ways. CFH continued to engage stakeholders by implementing a community-focused process to set and implement strategies to address the priority needs using Strategy Teams. We have only begun this work and know there is still much work to do. The outcome of this process helped form a statewide strategic plan that guides work on improving maternal and child health systems going forward.

Vision for the Future

We strive for a Minnesota where children and youth with special health needs (CYSHN) and their families receive all needed services and supports in family-centered, strengths-based, and culturally responsive ways. We also strive for communities where CYSHN and their families feel supported and connected.

Strategies to Address the Access to Services and Supports for CYSHN and their Families

The CYSHN Strategy Team identified strategies to address and improve access and supports for CYSHN and their families. In addition to developing the strategies identified below, the Team also created a framework from which all strategies are built. In all strategies, we aim to:

- **Meet families where they are**, in person and family-centered and culturally-responsive ways.
- **Ensure all materials developed are made fully-accessible**, meaning they are in plain language, meet the standards as laid out in the Americans with Disabilities Act, and are presented in a format that best meets the needs of the intended audience.
- **Ensure CYSHN and families are equal partners at the table** in developing, implementing, and evaluating programming.
- **Collaborate across state agencies** to ensure coordinated and consistent messaging and terminology.
- **Remain data-driven in our efforts**, using both evidence-based and promising practices and evaluating the effectiveness and return on investment in programming.

Below is a summary of Minnesota's strategies to improve access and supports for CYSHN and their families. To learn more see the entire Minnesota Title V Maternal and Child Block Grant Application and Annual Report.

Strategy A. Enhance Centralized Resources to Improve Knowledge of Services and Supports

The first strategy aims to enhance coordinated, centralized resources (including online resource directories and local public health agencies) where families can learn about and gain access to services through a "no-wrong door" approach by:[†]

- Coordinating online resource directories with interagency partners and assessing the effectiveness of the current directories, specifically Disability Hub MN™, Help Me Connect, CYSHN Navigator, and Autism Portal.
- Working with local public health (LPH) to provide assessments and follow-up focusing specifically on MDH's Newborn Child Follow-Up, Early Hearing Detection and Intervention (EHDI), and Birth Defects Programs.
- Enhancing Interagency Relationships.

Strategy B. Build the Capacity of Communities by Cultivating Knowledge and Improving Collaboration

Minnesota will also support capacity-building within communities by cultivating knowledge and improving collaboration. We will build capacity through:

- Facilitating the Pediatric Care Coordination Community of Practice.
- Funding parent-to-parent support through the Family Support and Connections Grant Program and the Early Hearing Detection and Intervention (EHDI) Program Parent-to-Parent Support.
- Supporting Workforce Trainings on Insurance and Financing.

[†] No-Wrong Door Approach: Families can get connected to services and supports no matter which organization/centralized resource they contact.

- Convene the Community Forum for Children and Youth with Special Health Needs and Disabilities (CYSHN/D).
- Responding to and rebuilding after the COVID-19 pandemic.

Strategy C. Construct a Competent and Well-Compensated Workforce

Families may have trouble accessing needed care for their child because of the shortage of qualified, competent professionals who are available to serve CYSHN. While workforce shortages can occur for many reasons, a primary concern in Minnesota is the lack of compensation provided to the direct service professionals who typically serve CYSHN, such as personal care assistants, in-home nurses, and child care providers. This lack of compensation can oftentimes be due to a lack of reimbursement available for services provided. Addressing this need in the workforce will be done by:

- Partnering with Minnesota's Medical Assistance (Medicaid) Program.
- Partnering to improve financing of needed services through advocacy efforts on current and upcoming policy.

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[1] Child and Adolescent Health Measurement Initiative. 2018-2019 National Survey of Children's Health (NSCH) data query. Data Resource Center for Child and Adolescent Health supported by Cooperative Agreement U59MC27866 from the U.S. Department of Health and Human Services, Health Resources and Services Administration's Maternal and Child Health Bureau (HRSA MCHB). Retrieved from www.childhealthdata.org. CAHMI: www.cahmi.org.

[2] Rosen-Reynoso, Myra, et al. "Disparities in Access to Easy-to-Use Services for Children with Special Health Care Needs." Maternal and Child Health Journal, vol. 20, no. 5, 2016, pp. 1041–1053.

[3] Walker, Ashley, et al. "Predictors of Coordinated and Comprehensive Care Within a Medical Home for Children with Special Healthcare (CHSCN) Needs." Frontiers in Public Health, vol. 6, 2018, p. 170.

[4] Cooney, V. "Long-Term Care Division Learns of Workforce Shortage." Minnesota House of Representatives. 2019. Retrieved May 2019 from https://www.house.leg.state.mn.us/SessionDaily/Story/13461.

[5] Kres-Nash, I. "Racism and Ableism." Retrieved March 2021 from https://www.aapd.com/racism-and-ableism/.

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