

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

ENSURING ALL KIDS AND FAMILIES HAVE WHAT THEY NEED TO THRIVE

Why It's Important

In Minnesota, 17.7 percent of children and youth (ages 0-17) have special health needs, which includes a range of chronic physical, developmental, behavioral, and emotional conditions.¹ These children and youth depend on a variety of services that are provided not only by the health care system, but by other systems, as well; these services may include dental, specialized therapies, counseling, medical equipment, special education services, community-based services and more.²

Unfortunately it is not always easy or possible to get these services. Only 15.8 percent of children and youth with special health needs (CYSHN) were reported to have received care in a well-functioning system, which includes family partnership, having a medical home, early screening, adequate insurance, easy access to services, and preparation for adult transition.¹ For CYSHN who access services at a greater amount and frequency than those without special health needs, having access to services and supports is even more crucial.

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

While there are many different services and supports that CYSHN and their families access, this data story is focused on health insurance, health care access, education, child care, and respite services.

Health Insurance

Despite more people being insured in the United States over time, almost 30 percent of the families of CYSHN who responded to the National Survey of Children’s Health (NSCH) said that their insurance coverage wasn’t adequate to meet their child’s needs.¹ 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.⁴ 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

Compared to about 10 percent of non-CYSHN families who had trouble paying their health care bills, 15 percent families of CYSHN had difficulty during the past 12 months paying their medical bills, highlighting the importance of comprehensive health insurance coverage.^{1,5} In another study, CYSHN were twice as likely to live with caregivers who were experiencing high levels of financial stress. Additionally, 11.7 percent of families reported changing jobs because they needed to maintain health insurance for their child, versus only 5.1 percent of non-CYSHN parents.¹

Health Care Access

Costs affect access to health care but there are other barriers that CYSHN face in receiving health care as well. In the 2016-17 NSCH, 8.5 percent of CYSHN in Minnesota did not receive health care that they needed.¹ In addition to costs, reasons for forgoing health care included eligibility, availability, problems getting an appointment, transportation and child care issues, and health care offices not being open.

Another major issue facing families of CYSHN is that their child's insurance is not accepted by all providers.

"There are not many clinics that accept state insurance in our area and the ones that do have a high patient volume so the wait to get an appointment can be months. More clinics need to start taking state insurance so that everyone can get good quality care!" – Needs Assessment Discovery Survey Respondent

Another aspect of health care is home health services; however significant barriers can exist in accessing these services. One of the most prominent barriers is a shortage of direct support professionals to provide home health care, often due to low pay and high turnover.⁷ In a recent report by the Department of Human Services, the main service gap identified by caregivers of children with mental health conditions in Greater Minnesota was a workforce shortage, including issues such as recruitment and retention.

Additional information about CYSHN health care utilization and access:¹

- Around 26 percent of CYSHN have gone to the emergency room at least once in the past year, versus only approximately 16 percent of non-CYSHN.
- Almost 10 percent of CYSHN had a small or big problem getting referrals when needed, whereas only 2.8 percent of non-CYSHN had a small problem, and 0 percent had a large problem (interpretative limitations)
- Notably, nearly 16 percent of CYSHN reported not receiving family-centered care in the last year, whereas only 9 percent of non-CYSHN reported the same.

Education

The special education system, which is governed by federal law, can be complex and difficult to navigate when it comes to accessing services.

"Working with the education system to provide a rich and quality academic experience for my son presents a whole new set of challenges in raising a child with special healthcare needs. Just like every other large system we must navigate, the education world comes with a whole new set of rules, regulations, confusing acronyms, and attitudes about the "best" way to support my son with special healthcare needs. I often find myself trying to convince my son's educational team that we should partner together to find ways to support my son's needs. In education, I am constantly reminded of what he can't do and his delays. It breaks my heart to know that many professionals in this field think so little of my child and his abilities. He is a bright, charismatic, and compassionate boy who truly enhances the lives of those around him...as does any child!" – Parent of a child with special health needs

In Minnesota around 36 percent of CYSHN were receiving services under a special education or early intervention plan.¹ Parents have communicated frustration with navigating services via schools, with challenges ranging from ensuring inclusion of their child to receiving appropriate referrals and services.

“After two years of working with my son's IEP team to find ways for him to be fully included in the general education class, he finally gets to eat lunch in the cafeteria with his 3rd grade friends rather than sitting at a separate table. My son and his peers need to be together learning and growing side by side. It breaks my heart that I, as a parent have to work this hard to even get an inclusive lunch experience for my son.” – Parent of a child with special health needs

Child Care

Children and youth with special health needs may require different supports and services when it comes to child care, which can make finding a provider difficult.

“There is also a lack of affordable child care for families. Many families pay more than their mortgage for child care, [and] paying less often leaves families using sub-par child care or putting children in risky situations. The programs available have a long wait or have limited income restrictions.” – Title V Needs Assessment Discovery Survey Respondent

Respite Services

Access to respite services is another crucial support that families of CYSHN require, but often it can be difficult to obtain. A study from the Department of Human Services found that 23 percent of caregivers of children and youth with mental health conditions feel that respite is a service they need but are not able to get; this was the most needed service identified.

“[For unmet needs in the community], in my opinion as a parent of a child with special needs, [it's] qualified staff (PCA, caregiver, respite) to give families a break. My child has a waiver that would cover respite if we could find a qualified provider to depend on. For now, we are overwhelmed by behaviors and the inability to take our eyes off of our child.” – Title V Needs Assessment Discovery Survey Respondent

Focus on Health Equity

Disparities in access to health care also 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 typically encounter. These include less options for care, less services being available, lack of adequate transportation, and the need to travel long distances in order to receive care due to lack of services or limited availability of condition-specific care.

Additional Considerations

It is difficult to report on important differences in care coordination due to data limitations. The National Survey of Children's Health is the primary data source for CYSHN, but the Minnesota Department of Health is unable to conduct sub-analyses, even when combining data years, due to small sample sizes.

Important Note on Equity and Intersectionality

The Minnesota Department of Health's Title V Needs Assessment team acknowledges that structural (social, economic, political and environmental) inequities can result in poor health outcomes across

generations. They have a greater influence on health outcomes than individual choices or a person's ability to access health care, and not all communities are impacted in the same way.

All people living in Minnesota benefit when we reduce health disparities.

We also acknowledge that the topic addressed in this data story does not exist in isolation – which is important to remember as we do needs assessments and as we start thinking about how we approach solutions. In addition to the needs themselves being intersectional, there are also intersecting processes and systems through which power and inequity are produced, reproduced, and actively resisted.

Citations

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