

Division of Specialized Care for Children

Healthcare Access and Quality as a Social Determinant of Health for Children and Youth with Special Healthcare Needs

Background

Access to health care as a social determinant involves how people interact with the healthcare system. It includes seeing a healthcare provider and the availability, affordability, and acceptability of healthcare services. It also includes early and timely screenings, access to medication, services, and healthcare-related communications.

Healthcare quality refers to how healthcare services are delivered to increase health outcomes by being effective, efficient, patient-centered, equitable, and timely. The goal of healthcare access and quality is to decrease the barriers that prevent people from improving their health. (See the [Agency for Healthcare Research and Quality website](#)) for more details. Limited access contributes to poor health outcomes and increased healthcare costs that disproportionately affect children and youth with special healthcare needs (CYSHCN).

Children and Youth with Special Healthcare Needs and Healthcare Access and Quality

[CYSHCN require additional services](#) to address chronic health conditions and maximize health, development, and wellness compared to their peers without a special healthcare need. These services can include specialized care such as medication, equipment, and therapy. Pediatric specialties are mostly concentrated in care centers in larger, metropolitan cities, which makes it difficult for families to access regularly due to long wait lists and distance.

CYSHCNs are dependent on their adult caregivers to access health care. [Families report their interactions with the access and quality of care](#) for their child as:

- often disorganized
- unaffordable
- stressful

Per the 2021-22 [National Survey of Children's Health](#), when comparing CYSHCN with their peers.

Compared to their peers, CYSHCNs and their families are:

- Seven times more likely to describe the child's health as fair or poor
- 10 times more likely to not obtain specialist care
- Two times more likely to be admitted to the hospital for at least one night
- Four times more likely to find it "very difficult" to get a referral to see a physician or receive services
- Four times more likely to not receive the health care that they needed
- 10 times more likely to feel frustrated in their efforts to receive for the child

This survey also highlights that in Illinois, **19%** of families with children with more complex health needs had to stop working or reduce their hours available to work because of their child's healthcare needs. In addition to the lost income, [*research finds families often encounter higher out-of-pocket expenses and challenges*](#) obtaining adequate insurance coverage. To learn more, read [*Economic Stability as a Social Determinant of Health*](#).

Importance of Medical Home for CYSHCN

The medical home model is a way of delivering high-quality, comprehensive healthcare to children. The [*American Academy of Pediatrics \(AAP\)*](#) defines a medical home as "a model of delivering primary care that is accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective to every child and adolescent." Learn more about the — Medical Home model on the AAP website.



Research from national, state, and local organizations has found that when a child has a medical home, they have the following benefits:

Health Care Costs	Quality of Care, Health Outcomes and Medical Needs	Family Satisfaction
<ul style="list-style-type: none"> • decreased hospitalizations • decreased visits to the emergency department • less out-of-pocket spending from families, especially those with public insurance • lower per-member per-month costs 	<ul style="list-style-type: none"> • increased access to preventive services • decreased outpatient sick visits • decreased rate of inappropriate antibiotics • improved health outcomes and health status 	<ul style="list-style-type: none"> • increased family satisfaction and positive parental experiences • increased ability for families to meet day-to-day demands of parenthood • decreased missed workdays for families • decreased parental worry

See the [*Overview of Data Related to the Pediatric Medical Home*](#) for more details.

Opportunities:

- Support initiatives to improve the implementation of the medical home model within child-facing programs that interact with CYSHCN.
- Support initiatives for the expansion of telehealth, school-based health programs, and home and community-based services
- Support and increase collaboration between programs that offer care coordination, resources, and referrals for CYSHCN to collaborate with families to empower their ability to deal with barriers with insurance, accessing healthcare services, and working with providers.
- Support workforce initiatives to increase the capacity of specialty providers and services, including behavioral health.

The Role of UIC's Division of Specialized Care for Children

Parents and caregivers of CYSHCN should have a strong support system.

DSCC is a statewide program that partners with Illinois families and communities to help CYSHCN connect to the services and resources necessary to reach their full potential. DSCC guides families through their child's journey with a medical condition and works with doctors, schools and community groups to create a seamless support system. Our staff works together with families to develop a plan of care that addresses a child's medical, social, behavioral, educational and financial needs. This process is called care coordination. It is free for all children with eligible medical conditions, regardless of their family's income level.

Find out more about the Division of Specialized Care for Children's programs and who we help on our website at dsccl.uic.edu. You can also contact us at dsccl@uic.edu or (800)322-3722.

This fact sheet and other information about SDoH are available at <https://dsccl.uic.edu/social-determinants-of-health-information-and-resources/>. DSCC last updated this fact sheet in March 2025.