

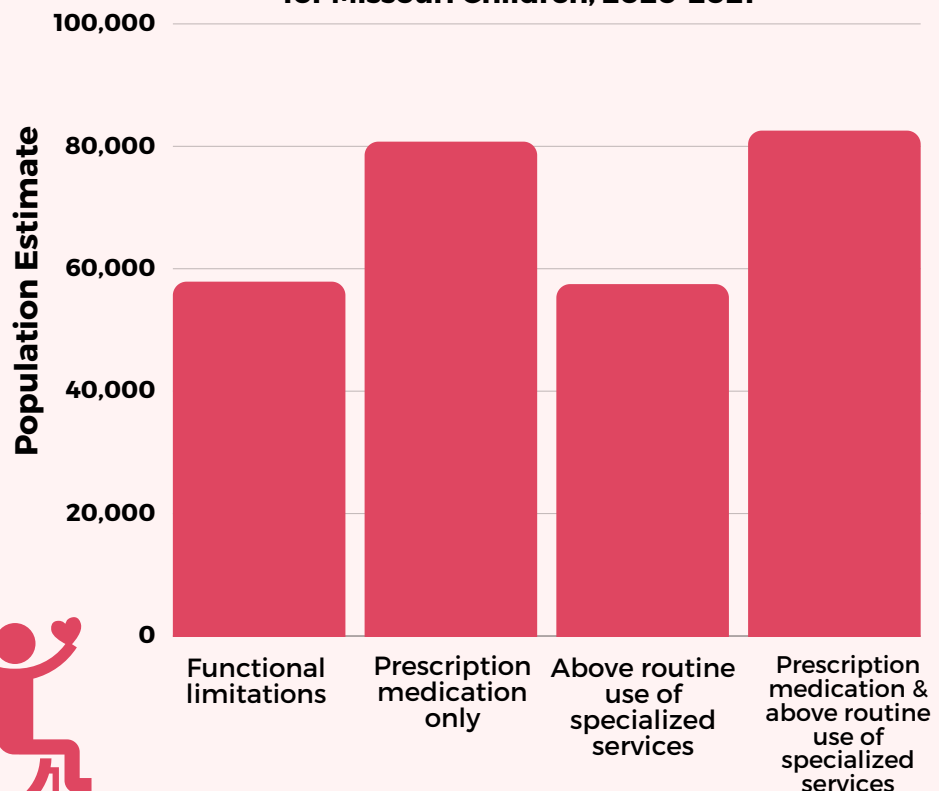


Missouri Title V Facts: **Children & Youth with Special Health Care Needs**

Background

The term “children and youth with special health care needs” refers to a diverse population of individuals with chronic conditions, medical complexities, or emotional or behavioral conditions. These conditions may reduce with age or medical or behavioral interventions, or may represent lifelong medical impact for the child and their family. These children often benefit from services and supports beyond that required by an average child. These supports are not¹ exclusive to the health care system, but may include associated systems such as mental health, transportation assistance, additional medical supplies and more. In Missouri, 20% of youth aged 0-17 have special health care needs, representing nearly 280,000 individuals. Timely identification of special health needs, through regular health care visits or developmental screening, has the potential to significantly impact outcomes for members of this population. The Title V Maternal and Child Health Block Grant program focuses on two major roles for programs addressing the needs of CYSHCN: supporting medical home development and utilization (including issues surrounding access to care), and supporting systems to transition CYSHCN to adult care.

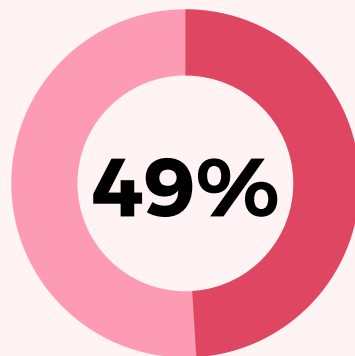
**Specific Types of Special Health Care Needs
for Missouri Children, 2020-2021**





Medical Home

The American Academy of Pediatrics (AAP) specifies that a medical home includes seven essential features: it is accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective. A medical home has many identified benefits for children with and without special health needs. Medical homes can improve identification of disabilities and developmental issues, and they encourage care coordination both vertically and horizontally.³ In 2020-2021, among CYSHCN, those with more complex health needs were less likely to have a medical home (44%) than those with less complex health needs (60%).² Medical home access for CYSHCN is impacted by the same social determinants that affect access to care in general, including parental income, education, and insurance adequacy.⁴



of Missouri youth with special health care needs received care through a system that met medical home criteria.

Transition to Adult Care

Health care transition is the process of moving youth from pediatric to adult-centered health care. Successful transition should equip young adults with or without special health needs to manage their own health care, ensure access to necessary preventive care and specialty care, improve health literacy, and secure continuity of required services.⁵ This period is particularly important for CYSHCN, who may experience greater medical complexity, enhancing the need for increased coordination of health services to meet their medical needs. As CYSHCN age, they need support from their health care, educational, and social service systems to successfully transition to adulthood. For example, they may need assistance to move from school to work or post-secondary education, from pediatric care to adult health care, and/or from family dependency to self-sufficiency. The National Survey of Children's Health measures health care transition of children aged 12-17 years primarily through three components, asked of the parents:

- 1) Whether a doctor spoke with the child privately during the most recent preventive checkup or well-child visit;
- 2) A doctor worked actively with the child to gain skills to manage their own health care;
- 3) That a discussion about health care transition occurred if it was required. In 2020-2021, 22% of adolescents with special health care needs received transition services, compared to 20% of non-SHCN adolescents.²



Barriers to Care

Barriers to accessing and receiving health care can be influenced by race, socioeconomic status, educational attainment of parents or caregivers, geographic location, and other factors.⁶ Beyond differences in the availability of preventive, generalist, and specialist care, CYSHCN that live in rural areas experience barriers to accessing additional services such as respite care, home health services, and special education.⁷

1 in 7

families with a child with special health needs reported having problems paying for any of this child's medical or health care bills.



Data Source: National Survey of Children's Health, Health Resources and Services Administration, Maternal and Child Health Bureau. <https://mchb.hrsa.gov/data/national-surveys>

References

1. Association of Maternal and Child Health Programs, et al. (2017). Standards for systems of care for children and youth with special health care needs: Version 2.0. Lucile Packard Foundation for Children's Health. Retrieved from: <https://www.lpfch.org/publication/standards-systems-care-children-and-youth-special-health-care-needs-version-20>.
2. Child and Adolescent Health Measurement Initiative. 2020-2021 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). www.childhealthdata.org. Accessed July 26, 2022.
3. Stille C, Turchi RM, Antonelli R, Cabana MD, Cheng TL, Laraque D, Perrin J, Academic Pediatric Association Task Force on Family-Centered Medical Home. 2010. The family-centered medical home: Specific considerations for child health research and policy. *Academic Pediatrics* 10(4):211-217.
4. Walker, I., McManus, M. A., & Fox, H. B. (2011). Medical home innovations: where do adolescents fit. Washington, DC: Natl Alliance Adv Adolesc Heal Rep, 7.
5. Toomey, S. L., Chien, A. T., Elliott, M. N., Ratner, J., & Schuster, M. A. (2013). Disparities in unmet need for care coordination: The National Survey of Children's Health. *Pediatrics*, 131(2), 217-224.
6. Abdi, F. M., et al. (2020). Children with special health care needs face challenges accessing information, support, and services. *Child Trends*. Retrieved from: <https://www.childtrends.org/publications/children-with-special-health-care-needs-face-challenges-accessing-information-support-and-services>.
7. Mattson, G., et al. (2019). Psychosocial factors in children and youth with special health care needs and their families. *Pediatrics*, 143(1), e20183171. Retrieved from: <https://pediatrics.aappublications.org/content/143/1/e20183171>.

