DEPARTMENT OF HEALTH

Transition

CHANGE FROM PEDIATRIC TO ADULT HEALTH CARE

Why It's Important

Adolescence is a period of rapid change, development, excitement, and sometimes fear and confusion. For youth with disabilities, chronic conditions, or other special health needs, this period is especially challenging as youth and families navigate the transition from childhood to adulthood along with chronic condition or disease management.[1] Health care transition is complex for those with chronic conditions; however, a successful transition lays the groundwork for successful, lifelong positive health outcomes.

Health care transition is the process through which youth move from pediatric to adult-centered health care. Health care transition forms the framework for healthy adult outcomes through appropriate, sufficient and successful access to necessary preventive and condition-specific adult care.[1] Transition planning should ideally start when the adolescent is 12 years old. Successful transition planning and completion can help an adolescent to independently and confidently manage their own health care into adulthood. Adolescents that receive transition services are more likely to have better continuity of care, which improves health outcomes, reduces complications, and decreases the cost of care. Transition to adult care is challenging for most adolescents but barriers such as inadequate insurance, complicated health needs, and lack of support from a pediatrician or other medical professional can make the process more difficult.

> *"I have depended on my child's pediatrician for everything, so receiving transition services makes me feel confident that my child will receive adequate care in the adult setting." – Focus Group Participant*

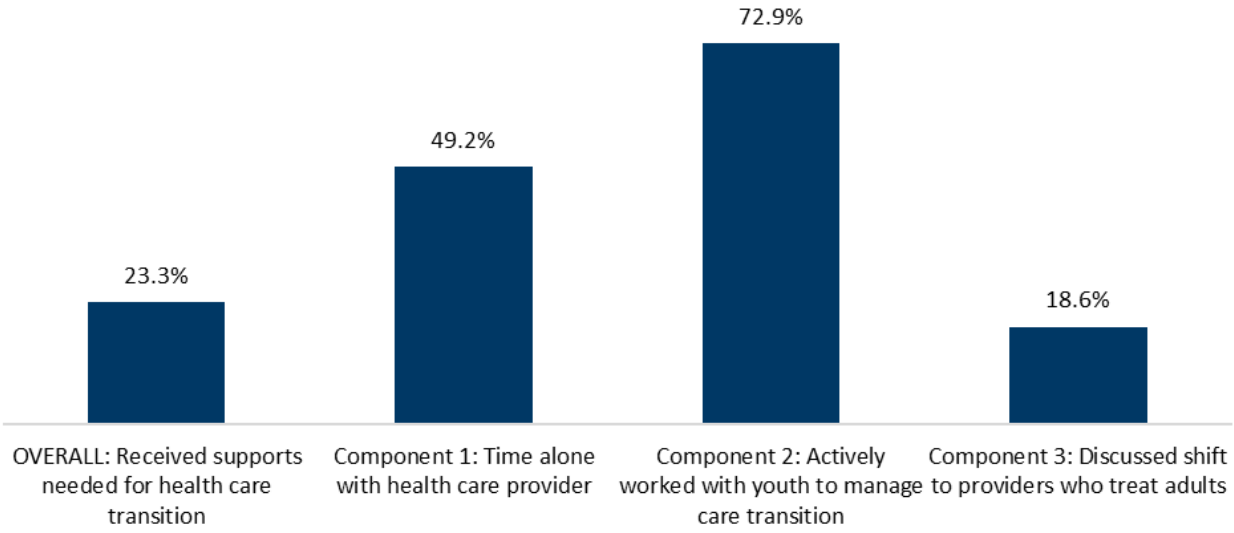
Although all adolescents benefit from transition services, those with special health needs often require more coordination for health care and other services. According to the 2017 National Survey of Children's Health (NSCH), about 17.5 percent or 224,026 children and adolescents under the age of 18 have a special health need in Minnesota.[2]

In Minnesota, fewer than 1 in 4 adolescents (23.3%) with a special health need reported receiving services needed for transition to adult health care, leaving an estimated 76.7 percent of adolescent in need of these services but not receiving them.[2]

Coordination of care, consultation, and communication between providers and care coordination services available can be additional challenges to transition care. Care coordinators play an important role in transition services by ensuring insurance is maintained, medical records are shared, and that adult health care providers have adequate knowledge of resources available to CYSHN.

> *"From the perspective of someone who's worked in pediatric hospitals all my life, the lack of effective "hand off" operations for most patients who are graduating from pediatric to adult health care is a HUGE problem – there's no funding to cover staff time to help the patients and families plan this, find a new doctor, visit that doctor, help explain the personal and family dynamics to the doctor."[1]*

Figure 1. Minnesota Youth with Special Health Needs Who Receive Supports to Transition to Adult Health Care, 2016-2017



Source: National Survey of Children's Health

Focus on Health Equity

Minnesota's youth with special health needs experience a wide range of disparities when compared to youth without special health needs. They have a higher percentage of parents who usually/always feel stress due to parenting and are more likely to have had two or more adverse family experiences. CYSHN are more likely to miss at least one week of school compared to non-CYSHN with 13.5 percent of CYSHN missing 11 or more days of school in a school year.

Barriers to accessing and receiving health care can also be influenced by race, ethnicity, socioeconomic status, educational attainment of parents or caregivers, and neighborhood of residence. CYSHN that live in rural areas experience barriers to accessing care in general and providers are less likely to have received training on transition care. There is also more likely to be a shortage of primary and specialty care providers that will accept CYSHN in rural areas.

Additional Considerations

Components of Transition

The 2016-2017 NSCH surveyed parents of 12 to 17 year old youth with special health needs on transition services. Transition services were measured through 3 components: 1) the doctor spoke with child privately without an adult in the room during last preventive check-up; 2) if a discussion about transitioning to adult care was needed it must have happened; and 3) the doctor actively worked with child to gain skills and understand changes in their health care. Youth were classified as receiving transition services if there was at least one valid positive response to this measure. Almost 70 percent of Minnesota parents reported that their child's health care provider has actively worked with their adolescent to help them gain skills to manage their healthcare and understand health care changes that happen at age 18. At their child's last preventive check-up, 46 percent of parents of CYSHN report that their child had the chance to speak with their health care provider privately. Only 17 percent of parents reported that the health care provider discussed the shift to providers who treat adults.

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

1. Minnesota Department of Health. (2019, July). White Paper on the Transition from Pediatric to Adult Health Care. St. Paul, MN: Minnesota Department of Health.
2. Child and Adolescent Health Measurement Initiative. 2017 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 [04/30/2019] from www.childhealthdata.org. CAHMI: www.cahmi.org.

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