



Health Care Transition Services for Youth on the Autism Spectrum

Findings from the Life Course Outcomes Research Program



Comprehensive health care is important for all children, especially those with complex conditions and special health care needs. Children on the autism spectrum often have complex medical needs that require special consideration when choosing a health care or service provider. Families often also need help in navigating the change from pediatric to adult health care as their child ages. Health care transition is a process that helps children

seamlessly transition to health care as an adult and is often delivered within the medical home.

What is health care transition?

Health care transition (HCT) is the individualized process of providing lifelong, comprehensive health care as a child becomes an adult.¹ HCT should be patient centered, based on the needs of the individual patient, with a goal of maximizing life-long functioning and potential.

The American Academy of Pediatrics (AAP) says that HCT should include:

1. Discussing the shift from a pediatric provider
2. Discussing changing health care needs as an adult
3. Identifying how to keep or get new insurance as an adult
4. Being encouraged to take responsibility for personal health care

Why is health care transition important in ASD?

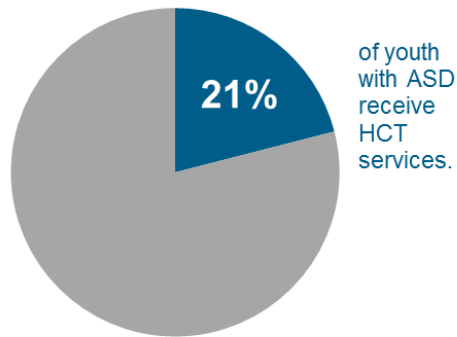
Fifty percent of youth with autism spectrum disorder (ASD) have a co-occurring medical condition that requires regular medical attention.² Of youth with ASD age 15-17, 60% have at least two conditions in addition to ASD.³ Because of the number of youth with ASD, the health care and specialty needs of individuals with

ASD, and the frequency with which other health conditions co-occur, the population of youth with ASD is vulnerable to insufficient health care services and unmet need for care and specialty care. This expands beyond childhood, as ASD is a lifelong disorder. According to our analysis of the National Survey of Children with

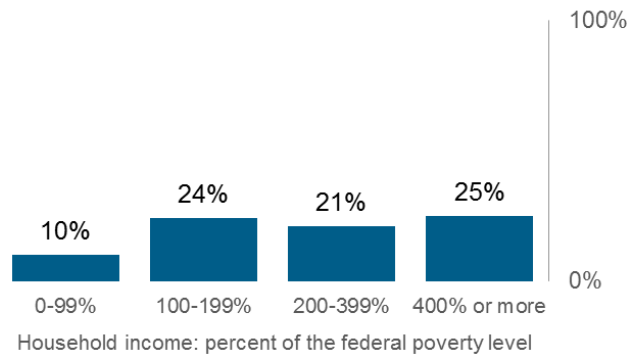
Special Health Care Needs 2009/10, around 70% of youth with autism have a primary care doctor who only treats children. This makes health care transition important because when the child becomes an adult, he or she will have to change doctors.

Who receives health care transition services?

Only 21% of youth with ASD receive HCT services compared to 40% of youth with other special health care needs.



Youth from households below the federal poverty level are less likely to receive HCT services than youth at other levels of household income.



We analyzed data from the NS-CSHCN and found that among families with youth with ASD between the ages of 12-17, 21% met the criteria for receiving HCT services. This is much lower than the 40% of youth with other special health care needs who received HCT

services. Youth who came from households with incomes less than the federal poverty level less often received HCT services than youth from households above the federal poverty level.

How do we know?

Data for this brief was taken from the 2009/10 National Survey of Children with Special Health Care Needs (NS-CSHCN). Learn more about the data at www.childhealthdata.org.

Sources:

1. Medical Home Initiatives for Children with Special Needs Project Advisory Committee. American Academy of Pediatrics: The medical home. *Pediatrics*. 2002; 110(1):184-186.
2. Cheak-Zamora, N. C., Farmer, J. E., Mayfield, W. A., Clark, M. J., Marvin, A. R., Law, J. K., & Law, P. A. (2014). Health care transition services for youth with autism spectrum disorders. *Rehabilitation psychology*, 59(3): 340. Chicago
3. Roux, Anne M., Shattuck, Paul T., Rast, Jessica E., Rava, Julianna A., and Anderson, Kristy, A. National Autism Indicators Report: Transition into Young Adulthood. Philadelphia, PA: Life Course Outcomes Research Program, A.J. Drexel Autism Institute, Drexel University, 2015.



Life Course Outcomes
Research Program

The Life Course Outcomes Research Program is building a base of knowledge about the things other than clinical interventions that promote positive outcomes for people on the autism spectrum and their families and communities.

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