

Autism & Other Special Health Care Needs: Healthcare Transition Survey Results

In the fall of 2019, Ohio's Interagency Work Group on Autism ([IWGA](#)) conducted a survey of young adults with autism and/or other special health care needs (i.e., diabetes, epilepsy, cancer, etc.) who had recently exited high school.

The IWGA previously shared [results](#) related to transition from school to employment or further education. In this publication, we focus on healthcare transitions -- moving from pediatric care to adult care. While Ohio's response rate was low, data from the IWGA survey aligns with national findings, such as low rates of healthcare transition planning, and

Thanks to everyone who took time to respond. The information will be used to further the work of the IWGA.

Health Status

Children with developmental disabilities are more likely than typically developing children to:

- have a poor health status.
- have two or more overnight hospitalizations, experience delayed treatment, and have one or more unmet healthcare needs.
- Children with autism had nearly four times higher odds of unmet health care needs compared to children without disabilities
- Children with other disabilities had nearly two times higher odds of unmet health care needs.

Transition Planning

- Only 15% of youth with and without special health care needs receive transition planning assistance from their health care providers.

Youth with autism were:

- less likely to complete healthcare transition activities and tasks compared to individuals with other mental health/behavioral/developmental disabilities.
- less likely to consult with their doctor regarding healthcare transition.

What works?

- Children who received care consistent a "medical home" reported fewer unmet health care needs; experienced less delayed treatment; and were significantly less likely to report poor health outcomes.
- Youth with special health care needs who had care coordination and a written plan were more likely to transition to adult care.

Resources

[Family-to-Family Health Information Centers](#) (F2F HICs) are family-staffed organizations that assist families of children and youth with special health care needs and the professionals who serve them. F2F HICs provide support, information, resources, and training around health issues. Ohio's F2F is based within the University of Cincinnati, University Center for Excellence in Developmental Disabilities (UC UCEDD).

[Got Transition](#)/Center for Health Care Transition Improvement is a cooperative agreement between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health.

Research

1. Karpur, A., Lello, A., Frazier, T., Dixon, P. J., & Shih, A. J. (2019). Health Disparities among Children with Autism Spectrum Disorders: Analysis of the National Survey of Children's Health 2016. *Journal of autism and developmental disorders*, 49(4), 1652-1664.
2. Lebrun-Harris, L. A., McManus, M. A., Ilango, S. M., Cyr, M., McLellan, S. B., Mann, M. Y., & White, P. H. (2018). Transition planning among US youth with and without special health care needs. *Pediatrics*, 142(4), e20180194.
3. Prokup, J. A., Andridge, R., Havercamp, S. M., & Yang, E. A. (2019). Healthcare Disparities between Children with Developmental Disabilities and Typically Developing Children in Ohio. *Child Indicators Research*, 12(2), 667-687.
4. White PH, Cooley WC; Supporting the Health Care Transition From Adolescence to Adulthood in the Medical Home. *Pediatrics*. 2018;142(5):e20182587
5. Zablotzky, B., Rast, J., Bramlett, M. D., & Shattuck, P. T. (2020). Health Care Transition Planning Among Youth with ASD and Other Mental, Behavioral, and Developmental Disorders. *Maternal and Child Health Journal*, 1-9.

Got Transition: Six Steps

Got Transition has identified six steps to help youth (and their families) get ready for health care as an adult.

1. Discovering: learn about your provider's approach to transition
2. Tracking: know your own health information
3. Preparing: learn to manage your own health care
4. Planning: get ready for adult health care
5. Transferring: make the change to an adult provider
6. Completing: provide feedback

You can take their [quiz](#) to see if where you're at. The site also includes:

- videos of youth managing their own care.
- skills checklists and other tools to help with self-management of care.
- transition related questions for youth and families to use with healthcare providers.
- a list of "must have" papers and sample medical summary and emergency care plan.
- stories from youth and their families.
- ideas about how to share health information with family and friends.
- resources on guardianship and supported decision making.
- information on finding and accessing adult care.