

# research snapshot

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## Difficulties Transitioning From Pediatric to Adult Care: The Voices of Youth With Autism and Their Caregivers

### What is this research about?

Many youth with autism spectrum disorder (ASD) also have developmental disabilities or other medical conditions, which make them more likely to rely on the healthcare system as they age. These youth are at a higher risk of polypharmacy (more than one prescription at a time), multiple health problems, mental illness, and behavioural problems when they are transitioning to adulthood. A smooth transition is very important to successful adulthood. Youth with ASD may use health care transition (HCT) services as they are transitioning from pediatric to adult health care. Typically, access to HCT services is in short supply and often underutilized by families. This study gathered information from youth with ASD and their caregivers through group discussions to understand their use of, and opinion on, HCT services.

### What did the researchers do?

Participants were recruited to focus groups through flyers and emails sent to families who attend clinics that serve youth with ASD. Youth were able to participate if they were between 15 and 25 years of age, had an ASD diagnosis, and had some verbal ability. The youth and their caregivers participated in separate group discussions where the researchers asked questions like, “What kinds of health-related preparations are you making to help your child get ready for adulthood?” or “What conversations would you like to have with your doctor to help you become

### What you need to know:

Youth with ASD and their caregivers face a rocky transition when moving from pediatric care to adult-centered healthcare. This study finds that many youth are not aware of how to navigate the health care system; they do not understand the transition process or the role healthcare providers play. Caregiver’s experienced added stress and worries about the rapid changes, the loss of relationship with trusted providers, and the loss of guardianship of their child.

an adult?” The researchers used a qualitative data analysis approach and identified themes in the discussions.

### What did the researchers find?

Youth and caregivers both indicated that health was critical in their lives and took up a lot of their time (e.g., managing medication schedules, visits to health care providers). While they discussed some positives of health care visits, many participants spoke about negative experiences. Parents discussed the loss of relationship with the former pediatric health care provider. They said they feel overwhelmed, frightened, and frustrated by this rapid process, especially because change and trust-building is difficult for some youth with ASD. Caregivers also talked about a general lack of education and sensitivity about ASD among care providers. This is especially difficult

when transitioning from a pediatric doctor who understands their situation to a adult-care doctor who does not. Lastly, many parents were concerned about losing guardianship of their children. After youth turn 18, parents are no longer able to communicate with their child's health care provider. In the youth group discussions, they focused on their confusion and anxiety around the role of the various medical providers. Many were unsure what each provider did, and they had little direct communication with their doctors as a result. The youth were split when it came to feelings about managing their medical lives independently. Some were eager to take more responsibility, while many preferred their caregivers to be in charge.

### How can you use this research?

This research provides greater insight into how youth with ASD and their caregivers perceive the transition from child to adult healthcare. This research can be used to help develop procedures to better serve this population.

### About the Researchers

The researchers are from the Department of Health Sciences, School of Health Professions at the University of Missouri in the United States.

### Citation

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### Keywords

Adolescence/youth, Autism, Caregiving, Health Care Transition

This research summary was written by Jordan Cleland for the Chair in Autism Spectrum Disorders

Treatment and Care Research. This research summary, along with other summaries, can be found on our [blog](#) and at [asdmentalhealth.ca/research-summaries](http://asdmentalhealth.ca/research-summaries)

### About the Chair

The Chair in Autism Spectrum Disorders Treatment and Care Research is dedicated to studying ways to improve the mental health and well-being of people with Autism Spectrum Disorders (ASD) and their families in Canada.

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For more information, visit the Chair in Autism Spectrum Disorders Treatment and Care Research website at [asdmentalhealth.ca](http://asdmentalhealth.ca)

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