

research snapshot

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Experiences Of Youth With ASD Making The Transition To Adult Healthcare

What is this research about?

Youth with ASD have major difficulties transitioning into the adult healthcare system. The communication and sensory challenges and the usual requirement that caregivers are less involved when the patient is an adult, alter their ability to interact with the health care system. This is important to address since relatively more of these youth have additional medical and psychiatric conditions – which require specialist care. Transition services that help patients move into adult care are available but few people with ASD receive those services. This study examined the perspectives of caregivers on how youth transitioned into the adult health care system and whether specific factors were related to receiving transition services.

What did the researchers do?

The researchers surveyed 183 caregivers of youth with ASD, aged 2-13 years old, identified using registry data at ASD clinics. Participants identified which health care transition services were received from a list. If it was received, they reported if they were satisfied with that service. If the service was not received, they were asked if they would have liked to have it. In addition, there were questions related to barriers to getting services. Finally, clinical measures around ASD severity, presence of common health and function challenges, special accommodations needed during health care visits, as well as sociodemographic data such as caregiver education, income and marital status were collected.

What you need to know:

Most youth with ASD are very satisfied with services they receive to help their transition into adult healthcare but these services aren't used by many. More than half of the caregivers report that they don't have enough information about transition plans by the time the youth in their care turns 18.

The researchers analyzed whether demographic or health-related outcomes were related to receiving services.

What did the researchers find?

The researchers found that only 60% of the sample received any transition services, even though the sample had high levels of health care access (averaging 8.8 visits per year). Only 3% had a written transition plan, 7% had support in finding an adult primary care physician, and 9% had a written medical summary. Most respondents wanted services they did not get (73%-92%) and those who did receive services, reported they were very satisfied with those services (89%-100%).

In terms of obstacles in their transition, 51% reported a lack of information about transition plans; 31% had difficulty with finding primary care with ASD knowledge.

Surprisingly, the only factor that related to getting transition services was if the youth had depression



(2.7 times more likely). ASD symptom severity and youth age were not related.

How can you use this research?

There is a need to provide better health care transition services for youth with ASD. Different predictors of transition services received in youth with ASD across studies, suggest that all youth should be targeted and not specific subgroups (not based on income, health status etc.). To address barriers, resources, such as toolkits for families, will help with the lack of information, and ASD training and education for clinicians will help with availability of suitable care providers.

About the Researchers

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Citation

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This research summary was written by Dr. Jonathan Lai 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

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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