

research snapshot

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Parent's Own Perception of Providing Care and Access to Services for Their Child with Autism

What is this research about?

Many parents of adolescents and adults with Autism Spectrum Disorder (ASD) report feeling unsure about how to access services and find the right kind of care for their children. Their children often have complicated care needs requiring many services. This study looked at how well parents thought they were able to access and provide care (i.e. their perceived 'self-efficacy') to their sons or daughters with ASD.

What did the researchers do?

The researchers surveyed 324 parents of adolescents and adults with ASD from across Ontario. Participants were recruited from ASD support agencies and advocacy groups, and from email lists associated with these organizations.

Individuals with ASD ranged in age from 12 to 25 years old (averaging 16 years old). Parents were asked about their demographic information, their child's health, how difficult they found it to access and afford services, and their level of caregiver burden. Parents also answered questions about their self-efficacy regarding accessing services for their children.

What you need to know:

Lower parent self-efficacy is related to having an older child, being an immigrant, experiencing more barriers to service access, and caregiver burden. It is important to take these factors into account to ensure all parents are able to successfully access supports for their children with ASD.

All participants had the option of completing their surveys online, by telephone interview, or on paper; most preferred online surveys.

What did the researcher find?

The researchers found that, on average, parents reported a moderate level of self-efficacy; however, some parents experienced very low self-efficacy, and others, very high. Lower self-efficacy was related to having an older child, being an immigrant, experiencing more barriers to service access, and caregiver burden.

The researchers note that their sample was recruited through community service and advocacy agencies, and largely through online efforts. This could mean that the findings may not generalize to those who are not affiliated with community agencies and/or do not have access to the Internet.



ASD
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How can you use this research?

Given the crucial role that parents often play in the lives of individuals with ASD across the lifespan, it is important that service providers support the efforts of parents to provide and access care. Interventions that aim to support parents or improve parents' engagement with the service system need to consider several factors, including child and parent demographics, service access barriers, and level of parents' caregiving burden.

About the Researchers

Yona Lunsky, Ph.D., C.Psych, is a clinician scientist in the Adult Neurodevelopmental Services at the Centre for Addiction and Mental Health and the University of Toronto, in Toronto, Ontario.

Melissa Paquette-Smith, MA, is a graduate student in the department of Psychology at the University of Toronto.

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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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