

research snapshot

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Caregiver Burden For Parents of Individuals With ASD: Differences Across Intellectual Functioning

What is this research about?

As children with autism spectrum disorder (ASD) age, they often lose supports that they used as children. Many young adults remain highly dependent on their family members. Caring for an individual with ASD is associated with a high level of caregiver burden including: distress, anxiety, depression, demoralization, and loss of personal freedom. This study explores the relationship between caregiver burden and a number of parent, child, and service system characteristics in Canada.

What did the researchers do?

The authors examined child, parent, and system variables for 297 parents of youth with ASD. Children with intellectual disabilities (ID) made up 55% of the sample. Most of the individuals with ASD (98%) were living with their family. The parents filled out a questionnaire online or by mail. The authors measured caregiver burden, child factors, parent factors, and aspects of service system use.

What did the researchers find?

In this study, levels of caregiver burden were high – a result that is consistent with previous studies. Even in Canada, the high cost of services was related to caregiver burden. The severity of ASD symptoms, internalizing problems, externalizing behaviour, medical problems, and parent age all predicted high caregiver burden. These predictors

What you need to know:

Those who care for individuals with ASD often face greater burdens. The factors contributing to these burdens differ based on the intellectual ability of the individual with ASD.

varied according to the child's level of intellectual functioning. Internalizing problems and externalizing behaviours affected the amount of burden on parents of children with ASD and ID, but this was not the case for parents of children with only ASD. Mental health issues are common in individuals with ASD without ID, so the authors wondered if it could be the severity of the behaviours rather than the type that have this effect.

The inability to pay for services was more of a burden for parents of those without ID, which may have to do with government funding regulations. High functioning individuals with ASD are often underserved because they do not qualify for some services and families are then left to pay out of pocket.

How can you use this research?

Appropriate services and supports are needed to address child and service factors to reduce caregiver burden. There is a gap in financial aid that many people with ASD may face. Services could be tailored to fill this gap for families in need.



ASD
Mental Health

About the Researchers

Vanessa Vogan, Johanna Lake, & Yona Lunsky are associated with the Centre for Addiction and Mental Health and University of Toronto.

Jonathan Weiss, Suzanne Robinson, & Ami Tint are associated with York University.

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Keywords

Autism Spectrum Disorder, Intellectual Disability, Caregiver Burden, Canada, Mental Health, Parents, Service System.

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.

The Chair is funded by the Canadian Institutes of Health Research in partnership with Autism Speaks Canada, the Canadian Autism Spectrum Disorders Alliance, Health Canada, NeuroDevNet and the Sinneave Family Foundation. Additional funds from the Spectrum of Hope Autism Foundation and support from York University.

For more information, visit the Chair in Autism Spectrum Disorders Treatment and Care Research website at asdmentalhealth.ca

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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

