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The Experience of Crisis in Families of Individuals with Autism Spectrum Disorders Across the Lifespan

What is this research about?

Families of children with an autism spectrum disorder (ASD) have higher levels of stress and are more at risk of experiencing crisis. The experience of crisis significantly impacts family functioning, causing parenting, marital and mental health issues.

This study focuses on three aspects of crisis: antecedents, behaviour and consequences. Antecedents are events that may lead to the onset of a crisis; behaviours are the events that occur during a crisis; and consequences are the outcomes of a crisis. This study also looks at the different components of crisis and how they vary based on the age of the child with ASD.

What did the researchers do?

Over two hundred individuals with a family member with ASD completed an online survey about their personal experiences of crisis. Participants were asked to provide any additional thoughts on the topic of crisis in a final, open-ended question. Researchers then divided the experience of crisis into three aspects - antecedent, behaviour and consequent - and then further divided into four age groups - elementary school, middle school, high school and adulthood – to look at the differences in experiences of crisis for families at different stages of development.

What did the researchers find?

For antecedents, the severity of presenting problems,

What you need to know:

At all stages of development, families of individuals with Autism Spectrum Disorders experience high levels of stress, which in turn can lead to crises for the family. By identifying what type of stressors a family may experience at certain stages, they can maximize the use of available services that would be most beneficial.

a need for services, and problems with service providers were common themes across all age groups. The majority of respondents indicated that services were unable to address the problems leading to crisis.

In terms of behaviours, families with a child in elementary school described the universal nature of crisis, where they believe that all families, regardless of ASD diagnosis, experience crisis. Families with children in middle school, high school and adulthood highlighted the constant, pervasive, and frequent nature of crisis.

Finally, families across all age groups reported the negative consequences of these stressors on family life and the mental and emotional health of all family members. Families with children in elementary and middle school described a lack of services whereas families with children in high school reported using emergency services to address these crises. Parents with children in adulthood were concerned about what was going to happen to their child after they have passed away and about the lack of programs and support systems for ASD adults.

How can you use this research?

By understanding the different challenges that arise at different developmental stages, programs can be developed to address the unique stressors associated with crisis throughout a child's development. The results of this research can be helpful for determining when families are most likely to use services and how they can benefit most from the services provided.

About the Researchers

Stacy White is currently enrolled in a doctorate program in psychology at Indiana University. She previously worked as a behavioural therapist for children with Autism. Her research interests include comorbid psychopathology and educational interventions in children with autism.

Dr. Yona Lunsky is an Associate Professor at the University of Toronto and the Research Head of the Dual Diagnosis Program at the Centre for Addiction and Mental Health in Toronto. Her research examines mental health needs of adults with intellectual disabilities. She is also involved in multiple projects that focus on training health care professionals who work with individuals with intellectual disabilities.

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This research summary was written by Carly Albaum 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.

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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