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Getting What You Really Want: Priority Service Needs For People With Autism In Canada

What is this research about?

People with autism have different symptoms and challenges depending on their health and their life stage and context which creates a broad range of services needed. Because of the variation in types of need, there is no “one size fits all” solution to address those needs. Since resources are limited, addressing the top pressing needs may help alleviate much of the burden and stress families face. In this study, the researchers examine the priority needs of people with autism in Canada and looked at factors that were related to meeting these needs.

What did the researchers do?

The researchers used an online survey that was distributed across Canada with the help of community organizations through the Canadian ASD Alliance. Participants in this study were caregivers of 3317 people with autism. From a comprehensive list of 23 services, they were asked what services they are currently getting as well as what their top 5 (most important) service needs were. Using a scale 0-5 out of 5, the researchers gave each person a priority service score that reflected how many of their top (or priority) service needs were currently being met. The researchers also collected clinical, sociodemographic and systemic factors that may be related to getting a higher or lower priority service score. Analysis was done in 5 age groups (preschool, under 4 years; elementary age,

What you need to know:

Top service needs change by age group. Over 30% of people did not receive services addressing any of their top 5 needs. Systemic factors, more than clinical factors, were related to receiving services that meet priority needs.

5-11; adolescence, 12-17; young adults, 18-24; and adults, 25 and older).

What did the researchers find?

Priority needs were more concentrated in the preschool and elementary age groups; variability in what people considered priority services diversified with age. Social skills programs were a top need in all the age groups, followed by activity-based and recreation programs as common needs across age groups.

Importantly, 30% of people did not get any of their identified priority services and only 8% received 4 or 5 of their top 5 service needs. The researchers found that younger age groups got more of their priority services than older groups. On average, preschoolers received the most priority services (1.9), going down to 1.6 services in elementary school age group and further decreasing in the older groups.

Systemic factors (e.g. government funding, ability to afford services, having services that were for caregivers themselves) were most commonly

related to getting priority services across the lifespan. For instance, caregiver of teens that had services for themselves were 1.4-1.8x more likely to have priority services. Families whose child was elementary age and had a household education level that was college-level or higher were 1.3-1.4x more likely to receive one more priority service than those who had less education. For adults, having an intellectual disability meant they were 1.4x more likely to receive one more priority service.

How can you use this research?

Individualized service planning across service sectors is required for this population as they age. Only a small proportion received services that address all their priority needs, indicating that there is a potential misalignment of services or that their need is not adequately addressed with what they are getting. Although clinical need can lead to specific clinical services, in general, systemic factors play the largest role in determining how many of a person's top 5 needs are met.

About the Researchers

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Keywords

Autism, Predictors, Service Need, Priority Services, Lifespan

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

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