Healthcare Use for Adults with Autism without Intellectual Disability

What is this research about?
Adults with Autism Spectrum Disorder (ASD) often have complicated care needs. We know that adults with ASD who live with their caregivers often use many different health services but we know very little about adults with ASD without intellectual disability (ID) who are often more independent. To better understand their needs, this study looked at the service experiences of adults with ASD without ID.

What did the researchers do?
The researchers surveyed 40 adults with ASD from across Ontario ranging in age from 18 to 61 years old. Participants were recruited from ASD support agencies and advocacy groups, and from email lists associated with these organizations.

Individuals completed an initial survey about their demographic, physical health, and mental health information. Then, they completed five brief bi-monthly surveys and a longer final survey 12 to 18 months later about their service use and satisfaction with services used. Participants also answered questions about barriers to service access that they encountered and completed a rating of psychological distress at the end of the study. All participants had the option of completing their surveys online, by telephone interview, or on paper; most preferred online surveys.

What you need to know:
Adults with ASD without ID often face challenges accessing appropriate, quality services to meet their needs, particularly those with complex medical and mental health issues. It is important to find ways to improve health care for this population who may become distressed if their needs are left unmet.

What did the researcher find?
The researchers found that beyond a family doctor, the most commonly used services were dentistry, individual counseling, and psychiatry. Adults with ASD who had medical problems experienced significantly more barriers to service use than those who did not, and those who had medical and mental health problems were less satisfied with services.

Additionally, participants who were less satisfied with the services they received across the study period were also more distressed at the end of the study. The researchers cautioned that their sample only included individuals with ASD without ID who were able to complete an online survey and the majority had high levels of education and lived in neighbourhoods with high average incomes. Therefore, these results may not generalize to all adults with ASD.
How can you use this research?
This research demonstrated that adults with ASD without ID have significant health care needs and use many different health services; however, they often encounter difficulty accessing effective care. We need to find ways of making health care services more accessible and easier to navigate for adults with ASD, particularly when a caregiver is not actively involved.

About the Researchers
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