

The Service Needs of Women with Autism



Recent research shows that some women with autism may present differently than men. For example, some women may develop strategies to "mask" their social communication difficulties (e.g., hide behaviour that might be perceived as socially unacceptable or mimic others' social behaviour). However, we know very little about women with autism, especially about how these differences in presentation may impact their service needs. This study aimed to better understand the service experiences of women with autism.

What did the researchers do?

The researchers ran five focus groups (i.e., small group discussions) with 20 women with autism (ages 19-69 years). Participants were asked questions about the services they used, what services they needed but were unable to access, and their perceived barriers to care (i.e., what was preventing them from accessing the services they needed). The researchers coded transcripts of the discussions with a technique called thematic analysis, which identifies common themes or patterns across qualitative data.

What did the researchers find?

The researchers found 3 main themes: 1) Masking service needs; 2) (Mis)Communication with service providers; 3) Accessing appropriate services: "A constant struggle".

What you need to know:

Women with autism have many unmet service needs, particularly in the areas of mental health, residential, and vocational and employment supports. Many women perceive service providers as disregarding or misunderstanding their unique needs; increased awareness by researchers and service providers of the unique service needs of women with autism is needed.

Masking Service Needs. Many women felt that service providers often dismissed their service needs because they have subtler or less obvious autism symptoms than many men with autism. Several participants also described the negative emotional and physical consequences of "masking" their social and communication differences (e.g., feeling emotionally exhausted after social interactions).

(Mis)Communication with service providers. Participants spoke about their challenges communicating with different service providers, especially about sensory sensitivities and how they experience pain. Many women described medical professionals' lack of experience working with individuals with autism, as well as the positive difference it made when service providers took the time to listen to them and individualize their treatment accordingly.





Accessing appropriate services: "A constant struggle". Many women were unable to access services because they did not meet eligibility criteria (e.g., they were too old; they did not have intellectual disability); this was especially true for residential services. For some, transportation and the required paperwork were significant challenges to accessing appropriate services, and others identified a need for individually tailored supports. In particular, many women felt mental health services and employment supports did not adequately meet their individual needs.

It is important to take into consideration that this sample was not representative of all women with autism. The researchers note that future research should use larger, more representative samples to understand the experiences of women with autism with a range of abilities and of varied demographics.

How can you use this research?

Women with autism may present differently than men, and correspondingly have unique service needs. It is important for future research to focus on methods of improving professionals' awareness of these sex/gender differences and how to improve service provision for women with autism.

About the Researchers

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Citation

Tint, A., & Weiss, J. A. (2017). A qualitative study of the service experiences of women with autism spectrum disorder. Autism. doi:

10.1177/1362361317702561

Keywords

autism, women, service needs

This research summary was written by Ami Tint. This research was funded by the Canadian Institutes of Health Research (MOP 102677). Dr. Weiss is supported by the Chair in ASD Treatment and Care Research (Canadian Institutes of Health Research RN162466-284208 in partnership with Autism Speaks Canada, the Canadian Autism Spectrum Disorders Alliance, Health Canada, Kids Brain Health Network

(formerly NeuroDevNet) and the Sinneave Family Foundation.

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