

Finding Support From Others: Why Do Parents of Children With Autism Join Support Groups?



Parents of children with Autism Spectrum Disorders (ASD) experience considerable distress. Parents who do not have access to formal supports for their child with ASD, like not having access to medical care or health information, can feel isolated and have poor physical and mental health. Parents often note that after they participate in support groups they feel less isolated, more emotionally supported, and learn important information about helpful services. Support groups also give parents a chance to connect with other parents going through the same situation and this support can help people cope with significant stresses.

What did the researcher do?

This study explored factors related to parent involvement in support groups and their experiences in the groups. The researchers used information collected through surveys from 1,005 families of people with ASD in Pennsylvania. Parents were asked about the quality and types of services they were using, their child's characteristics, as well as demographic characteristics, like their income, ethnicity, age, and location. The researchers compared parents who had participated in support groups to those who had never participated in support groups.

What you need to know:

Parents who participate in ASD support groups are more likely to have children with high needs, such as having sleep problems, language problems, or who harm themselves, than parents who do not participate in support groups.

What did the researcher find?

Two thirds of the families in this study participated in support groups for ASD. The parents who were part of a support group were more likely to be married, white, middle income, university graduates and living in a suburban area. Also, they were more likely to participate if their children were harming themselves, had problems sleeping or had serious problems with language. The doctor or clinician who originally diagnosed the child with ASD was often the person who referred the parents to the support groups.

How can you use this research?

The findings from this research can help parents to access support groups. Family doctors can play an important role in helping parents to





access support groups. In these support groups, families can support each other and share helpful information about how and where to access services. Future studies can try to explain why parents decide to participate in these groups.

About the Researchers

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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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