

research snapshot

summarize | mobilize



Understanding Healthcare Challenges of Adults with Autism

What is this research about?

Adults with autism generally have more unmet healthcare needs, use fewer preventive services, and are less satisfied with patient-provider communication than non-autistic adults. As a result, as individuals with autism transition from high school to adulthood, they use less medical and mental health services. This study examines factors that affect the success of healthcare interactions on three levels: challenges related to the patient's autism, the training and skills of the healthcare provider, and the navigability of the broader healthcare systems.

What did the researchers do?

The researchers used a Community-Based Participatory Research approach, which means that the research team included autistic individuals, their family members, and care providers, all contributed equally to the project's design, data collection, and interpretation. Thirty-nine participants gave vivid accounts of their experiences in an open-ended interview framework. Questions focused on both positive and negative healthcare experiences, perceptions about how autism affects care, and recommendations for improvement.

What did the researchers find?

There were common themes related to having a successful healthcare interaction at three different levels:

1. Patient-level factors included difficulties with communication, body awareness, organization, and

What you need to know:

Healthcare interactions are more successful when adults with autism receive the necessary accommodations and support, and respect for their autonomy. This largely depends on the provider's knowledge, attitudes, and skills, and the patient's ease in navigating the healthcare system.

comprehension, as well as sensory sensitivities and a need for consistency.

2. The main provider-level factor was the provider's limited knowledge about autism which led to incorrect assumptions about the patient's skills or needs.
3. System-level factors including the complexity and accessibility of systems, supporters, and facilities. Societal issues such as stigma, common myths about autism, and employment difficulties were also identified.

The participants gave several suggestions for how to improve care; the underlying theme was to "respect the way I need to communicate with you." Examples included dimming the lights, asking patients more specific questions, and ensuring providers have personalized information about their client's needs prior to the medical appointment. Another recommendation was to make resources and information available to patients to increase independence in system navigation and preparation for healthcare visits.

How can you use this research?

These findings demonstrate the importance of making healthcare interactions more successful for adults with autism. This can be accomplished with increased training in adult autism for care providers, as well as improved accommodation strategies and resources to increase patient independence. The team assembled a toolkit for providers and patients (found at autismandhealth.org).

About the Researchers

Cristina Nicolaidis (MD, MPH), a Professor of Medicine and Public Health at Oregon Health & Science University, and Dora Raymaker (PhD), of Portland State University, co-direct the Academic Autistic Spectrum Partnership in Research and Education (aaspire.org).

Elaisa Ashkenazy, a disability rights advocate and parent is the chair of the Community Council of AASPIRE, which includes Amelia Baggs, an autistic writer, W Cody Bosclair, a researcher at Oregon Health & Science University, and Stephen Kapp, a researcher at UCLA.

Katherine McDonald (PhD), a Psychology Professor at Portland State University, and Michael Weiner (MD, MPH), a health services researcher at Indiana, are part of the AASPIRE Academic Council.

Sebastien Dern is an undergraduate student in Developmental Psychology at Maastricht University in the Netherlands.

Citation

Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E. V., Kapp, S. K., Weiner, M., Cody Bosclair, W. (2015) "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. *Autism* 19(7), 824-831.

Keywords

Healthcare Systems, Autism, Adults, Participatory Research, Transition

This research summary was written by Mira Goldstein 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

Partners

