research snapshot summarize mobilize

Physician Perspectives on Providing Primary Medical Care to Adults with Autism Spectrum Disorder



The number of people being diagnosed with, and living with ASD has been rising over the last decade. There are many of barriers to gaining access to the healthcare system for these individuals. Particularly, the transition from pediatric to adult care is difficult, as some physicians are unwilling to accept adults with ASD as new patients. In this study, the authors wanted to understand the point of view of physicians who provide care to adults with disabilities. They were interested in why they began to serve this population, the challenges they face, their training, and their ideas for increasing the number of physicians who are willing and able to offer care to these individuals.

What did the researchers do?

The researchers conducted an in-depth case study of 10 health care professionals (9 doctors and one nurse) who served adults with ASD. They created an interview guide, asking specific questions about (1) the type of clinic they worked in; (2) their experience and background with ASD; (3) the physical environment and details about the care they provide; (4) care coordination; and (5) interactions with other medical providers and recommendations for increasing the number of adult providers willing to care for adults with ASD. The researchers conducted the interviews primarily on the phone, each lasting about 45 minutes.

What did the researchers find?

Many of the providers spoke about system level challenges to providing care to people with ASD, such as a lack of knowledge of services and supports, a lack of willing providers, a lack of financial

What you need to know:

The number of individuals with ASD moving into adult health care settings is increasing but many physicians are hesitant to take on these individuals as patients. The authors of this study spoke to healthcare providers who work with people with ASD to uncover some reasons for this hesitancy, as well as potential solutions to this issue.

compensation for the additional time, and for additional staff support. They mentioned other difficulties on the ground level, such as longer appointments, the complexity of family participation, and inaccessible physical space. Providers also mentioned that waiting rooms can be particularly challenging for patients with ASD, and difficulties communicating also influence the information the provider has to make decisions and outline subsequent treatments. In terms of training, overall, the responders had very little exposure to people with ASD, which made them feel less confident in their ability to serve them.

While there were clearly many barriers, the healthcare providers also spoke about solutions to these problems. The majority indicated that recognizing the additional time and resources through financial compensation would likely entice more healthcare providers to participate. On a practice level, they indicated that: (1) a list of community services for this population would be helpful and (2) planning appointment schedules (i.e. earlier in the day) to reduce wait times for patients on the autsim spectrum would reduce anxiety for them and others in the waiting room. It would also be helpful to have





facilitated communication between pediatricians and the physicians involved in adult care during the care transition. Lastly, a training priority would be to increase awareness of the needs and rewards for caring for these people among care providers. Training could include the understanding that physicians will encounter many of these patients as time goes on, and drawing on some of the parallels between people with ASD and other medically complex patients.

How can you use this research?

Given the growing amount of adults with ASD, this research provides a glimpse into the motivation for and barriers to providing health care service to these people. It can be used to inform physician training, accessible health care spaces, and policymaking.

About the Researchers

Maiji Warfield (PhD) is a Senior Scientist in the Heller School for Social Policy and Management at Brandeis University. Morgan Crossman (PhD) is a Research Assistant at the Starr Center on Intellectual and Developmental Disabilities at Brandeis University.

Jennifer Delahaye is a Clinical Program Manager at the Center for Child and Adolescent Health Research and Policy at the Massachusetts General Hospital in Boston. Emma Der Weerd is affliated with Harvard Medical School and the Massachusetts General Hospital.

Karen Kuhlthau (PhD) is an Assistant Professor in the Dept. of Community Health Services at Boston University School of Public Health and affliated with Harvard Medical School and the Massachusetts General Hospital.

Citation

Warfield, M.E., Crossman, M.K., Delahaye, J., Der Weerd, E., & Kuhlthau, K.A. (2015). Physician perspectives on providing primary medical care to adults with autism spectrum disorders (ASD). *Journal of Autism and Developmental Disorders*, *46*(7):2209-17.

Keywords

Autism Spectrum Disorder, Healthcare Transition, Youth, Adult, Medical Care

This research summary was written by Jordan Cleland and 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.

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 support was provided by York University.

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

Partners















