

Autistic adults report significant shortcomings in their health care

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Researchers at Oregon Health & Science University (OHSU) have found that adults with autism, who represent about 1 percent of the adult population in the United States, report significantly worse health care experiences than their non-autistic counterparts.

"Like other adults, adults on the autism spectrum need to use health care services to prevent and treat illness. As a primary care provider, I know that our health care system is not always set up to offer high-quality care to adults on the spectrum; however, I was saddened to see how large the disparities were. We really need to find better ways to serve them," said Christina Nicolaidis, M.D., M.P.H., principal investigator and associate professor of medicine (general internal medicine and geriatrics) at OHSU.

The study, published in the *Journal of General Internal Medicine*, was conducted by the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE), an academic-community partnership where academic investigators, autistic adults and other community members work together throughout the project.

Nicolaidis and colleagues surveyed 209 autistic adults and 228 non-autistic adults through a secure registration system for <u>online studies</u>. Autistic adults reported greater unmet health care needs, higher use of the emergency department, and lower rates of preventive services such as Pap smears. They also reported poorer satisfaction with provider communication and lower comfort in navigating the health care system



or managing their health.

"While I am discouraged by the findings, I am also encouraged by the direct involvement of the autistic community in all parts of this project. In order to ensure research that is truly useful to autistic adults, it is critical to involve us directly in the process," noted Dora Raymaker, AASPIRE's community co-director.

The study also has important implications related to changes in the newly released Diagnostic and Statistical Manual of Mental Disorders (DSM-V), which combined Autistic Disorder, Asperger's Disorder, and Pervasive Developmental Disorder Not Otherwise Specified into one new category of Autism Spectrum Disorder. There has been considerable controversy over the new criteria, with some studies predicting a significant reduction in the number of people who will meet criteria, especially among those with Asperger's disorder or without intellectual disabilities.

"The existence of health care disparities in our sample, most of whom had diagnoses of Asperger's and/or high educational attainment, highlights the possible negative consequences of stricter criteria. Not having a diagnosis may deprive patients and their providers of insights, strategies, and accommodations to improve health care experiences," explained Nicolaidis.

Provided by Oregon Health & Science University

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