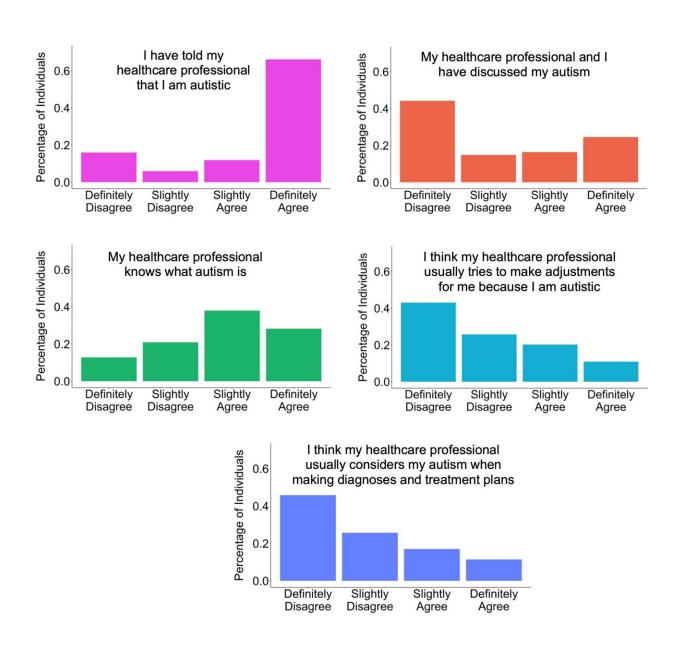


Study: Autistic individuals have poorer health and health care

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Autism-specific questions unadjusted distribution. Credit: Molecular Autism



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Autistic individuals are more likely to have chronic mental and physical health conditions, suggests new research from the University of Cambridge. Autistic individuals also report lower quality health care than others.

These findings, published in *Molecular Autism*, have important implications for the <u>health</u> care and support of autistic individuals.

Many studies indicate that autistic people are dying far younger than others, but there is a paucity of research on the health and health care of autistic people across the adult lifespan. While some studies have previously suggested that autistic people may have significant barriers to accessing health care, only a few, small studies have compared the health care experiences of autistic people to others.

In the largest study to date on this topic, the team at the Autism Research Centre (ARC) in Cambridge used an anonymous, self-report survey to compare the experiences of 1,285 autistic individuals to 1,364 non-autistic individuals, aged 16–96 years, from 79 different countries. 54% of participants were from the U.K. The survey assessed rates of mental and physical health conditions, and the quality of health care experiences.

The team found that autistic people self-reported lower quality health care than others across 50 out of 51 items on the survey. Autistic people were far less likely to say that they could describe how their symptoms feel in their body, describe how bad their pain feels, explain what their symptoms are, and understand what their health care professional means when they discuss their health. Autistic people were also less likely to



know what is expected of them when they go to see their health care professional, and to feel they are provided with appropriate support after receiving a diagnosis, of any kind.

Autistic people were over seven times more likely to report that their senses frequently overwhelm them so that they have trouble focusing on conversations with health care professionals. In addition, they were over three times more likely to say they frequently leave their health care professional's office feeling as though they did not receive any help at all. Autistic people were also four times more likely to report experiencing shutdowns or meltdowns due to a common health care scenario (e.g., setting up an appointment to see a health care professional).

The team then created an overall "health inequality score" and employed novel data analytic methods, including machine learning. Differences in health care experiences were stark: the models could predict whether or not a participant was autistic with 72% accuracy based only on their "health inequality score." The study also found worryingly high rates of chronic physical and mental health conditions, including arthritis, breathing concerns, neurological conditions, anorexia, anxiety, ADHD, bipolar disorder, depression, insomnia, OCD, panic disorders, personality disorders, PTSD, SAD, and self-harm.

Dr. Elizabeth Weir, a postdoctoral scientist at the ARC in Cambridge, and the lead researcher of the study, said: "This study should sound the alarm to health care professionals that their autistic patients are experiencing high rates of chronic conditions alongside difficulties with accessing health care. Current health care systems are failing to meet very fundamental needs of autistic people."

Dr. Carrie Allison, director of strategy at the ARC and another member of the team, added: "Health care systems must adapt to provide



appropriate reasonable adjustments to autistic and all neurodiverse patients to ensure that they have <u>equal access</u> to high quality health care."

Professor Sir Simon Baron-Cohen, director of the ARC and a member of the team, said: "This study is an important step forward in understanding the issues that autistic adults are facing in relation to their health and health care, but much more research is needed. We need more research on long term outcomes of autistic people and how their health and health care can be improved. Clinical service providers need to ask <u>autistic people</u> what they need and then meet these needs."

More information: Elizabeth Weir et al, Autistic adults have poorer quality healthcare and worse health based on self-report data, *Molecular Autism* (2022). DOI: 10.1186/s13229-022-00501-w

Provided by University of Cambridge

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