

Largest ever study of autistic people's research priorities finds need for focus on mental health

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The largest ever study of autistic people's priorities has revealed a desire to focus research on mental health, post-diagnosis support and social stigma.

The majority of funding for autism research is currently spent on biological studies and on the search for treatments and a cure.

New research by the University of Stirling has found that [autistic people](#)'s priorities for research lie elsewhere.

More than 200 autistic people in Scotland were surveyed by psychology researchers based in the University's Faculty of Natural Sciences.

Quality of life

Dr. Monique Botha, a co-author of the study, said, "Most research tends to treat autistic people as a homogenous group, but it is important not to treat all autistic people as the same, and to acknowledge the other factors influencing autistic people's lives.

"The aim of this study was to work with autistic people, who live in Scotland, to understand what they want from autism research.

"We found that autistic people want applied research into diagnosis, [mental health](#), and topics which can enable a good quality of life.

"Autistic people who participated also highlighted a deep desire for the research that is done to either be led by autistic people, or be conducted in participatory ways alongside autistic people, because it's something that affects their lives."

Prior to this study, only one autistic person for every 11 non-autistic people in priority settings studies were asked about how they would like

funding spent in autism research.

Roadmap toward change

Lead researcher Dr. Eilidh Cage said, "Autistic people face diagnostic disparities and a lack of service the whole way through the diagnostic process. They are more likely to have mental illness and are more likely to die by suicide.

"They often do not qualify for services in the community, face higher rates of unemployment and underemployment, are more likely to be victimized—including by caregivers, peers, and romantic partners—and are more likely to drop out of or be excluded from education.

"This piece of research outlines a roadmap towards change which could be meaningful, but its impact is not limited to Scotland. As the single largest study of autistic people's priorities for autism research, it has the ability to influence research agendas across the U.K., and globally."

The Scottish Government is currently consulting on proposals for a Learning Disabilities, Autism and Neurodivergence Bill.

Dr. Botha added, "This research has the potential to influence the priorities that the Scottish Government sets for the next decade."

The [paper](#), "What are the [autism research](#) priorities of autistic adults in Scotland?" was published in *Autism*.

Cross-sectional survey

The research was conducted by the Striving to Transform Autism Research Together, Scotland (STARTS) group, a collaborative of

researchers and autistic people from across Scotland, led by Dr. Eilidh Cage, Dr. Monique Botha and Dr. Catherine Crompton (University of Edinburgh).

Together, they created a [cross-sectional survey](#). A total of 225 autistic people from almost all council areas in Scotland participated during May and June 2022.

The survey, which also included 50 autistic caregivers of autistic children, involved ranking and rating the importance of 25 different research topics.

The survey also asked participants to elaborate in open text boxes about any other topics that should be studied, and what questions should be studied based on their top three highest ranked topics.

More information: Eilidh Cage et al, What are the autism research priorities of autistic adults in Scotland?, *Autism* (2024). [DOI: 10.1177/13623613231222656](#)

Provided by University of Stirling

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