

research snapshot

summarize | mobilize



What Should Autism Research Focus on? Community Views and Priorities From the United Kingdom

What is this research about?

The reported number of people affected by autism spectrum disorders (ASD) has increased dramatically over the past several decades. As a result, we have also seen a rise in international funding and research exploring the causes and effects of ASD. However, in the United Kingdom (UK), the authors note that the majority of the research funding is used solely in exploring the “basic science” of ASD (neural cognitive systems, genetics, and other risk factors). The current study aimed to understand what kinds of research were important to people with ASD and their families and compared this to the kinds of research currently being funded.

What did the researchers do?

They used focus groups, interviews and an online survey to understand:

1. participants’ knowledge of current ASD research in the UK
2. their views on ASD research funding in the UK
3. their priorities for future ASD research in the UK

There were 72 participants in the focus groups/ interviews, including adults with ASD, parents of children with ASD, practitioners and researchers. Additionally, 1,929 people from the ASD community

What you need to know:

More than half of ASD research funding in the UK between 2007 and 2011 went to the areas of biology, brain and cognition. Compared to this, little funding was used on researching effective services for people with ASD and their families (5% of the funding), on diagnosis (5%), on interventions (18%) or on societal issues (1%).

participated in the online survey.

What did the researchers find?

According to the participants of the survey and focus groups there was a clear mismatch between what was being researched and what was important to the people in the ASD community. Responses suggested that funding for ASD research in the UK should be more balanced across the major areas of interest (basic science, treatment/intervention, causes, services, diagnosis, societal issues). While they acknowledge that research in basic science is important, they are generally unhappy that there is little about how they can improve their daily lives.

How can you use this research?

The focus on basic science in research is a concern to many individuals with ASD and their families because they feel that it is not related to outcomes in areas such as education, health and social care.



Funders of research can use these findings to inform their decision making about the proportion of funding allocated across sectors, and by involving people with ASD in developing research goals and priorities. Doing this can maximize the outcomes and impact of research funding because research will be done in areas where those who live with ASD believe they are needed most. Overall, the ASD community can inform the path of future ASD research in the UK.

About the Researchers

Dr. Elizabeth Pellicano is the Director of the Centre for Research in Autism and Education at the Institute of Education.

Adam Dinsmore is the Evaluation Officer at the Wellcome Trust in London, UK.

Tony Charman is the Chair in Clinical Child Psychology at King's College London's Institute of Psychiatry.

Citation

Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, 18(7), 756-770.

Keywords

Autism community, Autism research, Decision-making, Priority setting

This research summary was written by Jordan Cleland 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

