

Brief Report: A Survey of Autism Research Priorities Across a Diverse Community of Stakeholders

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For which topic were research priorities identified?

autism

In which location was the research priority setting conducted?

North America - Canada; North America - USA

Why was it conducted at all?

Over the last two decades, research has identified and begun to explain the etiologic and phenotypic heterogeneity of autism (de la Torre-Ubieta et al. 2016; Georgia des et al. 2014). Increases in public and private/non-profit research funding have been an important part of promoting autism research advances. Understanding the wide range of needs and desires of people that are directly affected by autism, including persons on the spectrum and families, as well as providers (clinicians and educators) and researchers, is important in setting priorities regarding autism research funding.

What was the objective?

to clarify the value and importance of broad lines of scientific inquiry and specific content areas relevant to autism science funding

What was the outcome?

a ranking list of 4 research areas

How long did the research prioritization take?

June 2017 - August 2017

Which methods were used to identify research priorities?

survey

How were the priorities for research identified exactly?

Step 1: survey: asking seven substantive questions with potential relevance to the broader autism community: What should be the core mission of Autism Speaks Science? (To discover the causes of autism? To increase our understanding of the biology of autism? To improve our ability to screen, identify and track autism throughout the life span? To develop, evaluate and/or improve interventions for autism and related challenges or conditions?) Should funding of basic science be part of the core mission of Autism Speaks? Should funding of applied science be part of the core mission of Autism Speaks? Please rate the level of importance of the following research topics to Autism Speaks Science? What products or improvements would positively impact the lives of individuals and families affected by autism? How important is it for Autism Speaks to be involved in funding studies that move research findings into clinical practice or communities? To what degree do you feel it is important to fund the development of young scientists?

Which stakeholders took part?

Persons with autism, family members of a person with autism, researchers and clinicians. 6004 participants.

How were stakeholders recruited?

Survey link was distributed through numerous outlets, including the non-profit foundation's website, its social media platforms, and via an Interagency Autism Coordinating Committee meeting presentation.

Were stakeholders actively involved or did they just participate?

Stakeholders were mere participants of the research prioritization process; they were not actively involved in the process.