

Understanding Stakeholders' Views on Autism Research: A Mixed Methods Study

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Purpose & Background:

In recent years, the goals of autism research have shifted due to the emergence of the Neurodiversity Movement. Autistic self-advocates have challenged the dominant research narrative that focuses on “treatment” and “cure,” and instead are calling for research that embraces neurodiversity as part of one’s identity. It is unclear whether stakeholders feel that their perspectives are represented in current autism research. The purpose of this convergent parallel mixed methods study was to understand how various stakeholders view autism research and what aspects of research are important to them.

Methods:

A participatory action approach was utilized to carry out this research, in which autistic representatives were members of the research team and were involved in research design, data collection, data analysis, and interpretation of findings. Recruitment notices were shared on online message boards, autism organization newsletters, and social media. A sample of 174 autism stakeholders participated in a survey to understand their perspectives on autism research. Participants included autistic people (77.8%), parents of autistic people (17.6%), individuals who work in an occupation with autistic people (33.3%), and others interested in autism research. Open-ended qualitative responses were analyzed using reflexive thematic analysis. Quantitative responses were analyzed using descriptive statistics and independent samples t-test to compare autistic versus non-autistic responses. Qualitative and quantitative data were compared to determine agreement. Trustworthiness was ensured through triangulation of data collection and analysts, reflexive journaling of all researchers, and thick description of findings.

Results:

Seven themes were identified from the qualitative data. Themes indicated that participants value: 1) involving autistics on the research team, 2) centering autistic voices, 3) improving quality of life, 4) supporting neurodiversity, 5) debunking the cure narrative, 6) considering intersectionality, and 7) conducting high quality research. Quantitative data supports these themes. Compared to non-autistic participants, autistic participants were significantly less likely to want to see research that seeks to prevent or cure autism. Non-autistic participants were significantly more likely to want to see research that includes parents of autistic people on the research team, focuses on autistic children, and aims to improve the quality of life of parents of autistic children.

Discussion/Conclusion:

Findings indicate that autistic people support a shift in research away from a focus on prevention, treatment, and cure and towards a focus on the autistic experience, including ways to improve quality of life outcomes across the lifespan.

Nursing Implications:

The goal of this study is to offer guidance for future autistic research that supports what stakeholders want to see in research. Researchers should engage with the autistic community and involve autistic voices in the research process.