

Listening to the Autistic Voice: Mental Health Priorities to Guide Research and Practice in Autism from a Stakeholder-Driven Project

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For which topic were research priorities identified?

autism

In which location was the research priority setting conducted?

North America - USA

Why was it conducted at all?

Autistic adults are significantly more likely to experience co-occurring mental health conditions such as depression and anxiety. Although intervention studies are beginning to be implemented with autistic adults to address mental health outcomes, little is known about what research autistic adults feel is needed, or what mental health outcomes are of value to them.

What was the objective?

to identify and ascertain autistic adult perspectives related to mental health practice and the specific mental health research priorities that emerge through this stakeholder-driven project

What was the outcome?

a list of 5 research questions

How long did the research prioritization take?

2 years

Which methods were used to identify research priorities?

focus group; meeting; survey

How were the priorities for research identified exactly?

Step 1: stakeholder meeting: to provide an opportunity for autistic adults and researchers to identify broad knowledge gaps about health and health care needs, to develop preliminary research priority areas, and to discuss strategies promoting engagement of autistics in co-developed research, breakout sessions: infographic posters: sticky notes to communicate preferred areas for future research, and group discussions. Step 2: survey: participants were asked to rank interventions. Step 3: focus groups: discussion of future research areas, using sticky notes to provide input on top areas for future research. Step 4: stakeholder meeting: to engage stakeholders in additional prioritization of areas and topics identified from the survey and focus groups, small group discussions and rankings

Which stakeholders took part?

Autistic adults, family members, researchers. Meeting: 37 participants: 17 autistic adults, 8 family members of autistic adults, 12 researchers or organizational partners, and 4 had unknown stakeholder roles. Survey: 136 participants. Focus groups: 26 participants: 10 autistic adults, 8 family members, 8 researchers.

How were stakeholders recruited?

Year 1 meeting: meeting was advertised through listservs of large autism advocacy groups and through email, Facebook, and in collaboration with Community Council members. Anyone was able to register and attend. Year 1 survey: Individuals were eligible to participate in the online survey if they were adults aged 18 years and older and if they reported a formal autism diagnosis or a self-diagnosis. The project team excluded caregivers of adults. Both purposive and convenience approaches were used for recruitment between August and December 2018. Purposive sampling was accomplished with Community Council and Project Team members sharing the survey link via online and social media posts with known autism groups and individuals. The project team used convenience sampling by posting the survey link on Facebook. Year 1 focus groups: Purposive sampling to recruit a sample of autistic adults across the lifespan and in different geographic areas was accomplished through identification of support groups serving autistic individuals in rural, suburban, and urban settings. Year 2 stakeholder meeting: The project team advertised the meeting through paid advertisements on Facebook and emailing known autism advocacy groups and contacts.

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.