



# Autism Advocacy in Research

Kate Holman, Ella Semonian & Ali Cunningham Abbott, Ph.D.  
Lynn University



## Literature Review

- Autism is a neurodevelopmental difference accompanied by sensory sensitivities, autism is not measured linearly but by individual skills and deficits (Jones 2024).
- Autism awareness acknowledges the inequity the community faces but fails to progress toward inclusivity. Acceptance is essential for autistic people to feel valued in society (Lee et al., 2022).
- Autistic people can be portrayed as “unfeeling, robotic and one dimensional in the media” (Jones, Gordon & Mizzi, 2023).
- ‘Masking’ is an autistic person’s attempt to disguise or suppress their autistic traits in social settings to fit in better (Alaghband-Rad et al., 2023).
- To enhance social relationships and get proper treatment for their children with ASD, parents believe it is imperative to take on the role of advocate (Samsell et al., 2022).
- In addition to becoming specialists in the unique requirements of their own children and families, parents who take the time to educate themselves on how to manage all facets of ASD also frequently become experts in the diagnosis in general (Samsell et al., 2022).
- People who reported a high level of knowledge about autism had a more positive attitude towards the community (Lee et al., 2022).
- Always presume competence, someone who is unable to speak may understand everything around them (‘input’) but is unable to respond verbally (‘output’) (Sincile-Kira, 2014).
- Phenomenological research requires the researcher to formulate a hypothesis, collect and examine data to verify the hypothesis, and provide a response to the research question that can be followed and repeated in the future (Mahrer, 1983).

## Proposed Methods

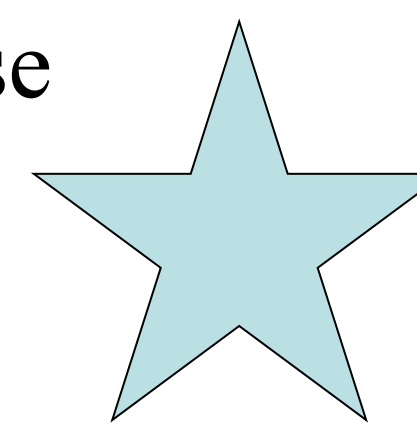
**Participants:** 100 members directly and indirectly affiliated with the autistic community, 25% of which must have an autism diagnosis by a professional.

**Measure & Procedure:** Qualitative self-report survey distributed via social media groups (Facebook & Instagram).

**Design:** Phenomenological qualitative research explores lived experience, answering questions that reflect self-reported experiences. Codes responses for themes.

## Research Questions

1. What advocacy measures do autistic people (those directly impacted) believe are most important?
2. What advocacy measures do people indirectly impacted by autism believe are most important?



## Sample Survey Questions & Materials

Questions included in the survey with responses from participants would be shared through an infographic. Responses provided on these examples reflect existing research.


QUESTIONS TO INCLUDE IN THE QUALITATIVE RESEARCH QUESTIONNAIRE

- “What do you wish people knew about autism?”
- “What are a few common misconceptions about autism?”
- “What is the most important part about being an advocate for autism?”
- “How can schools/facilities accommodate autism better?”
- “What would you like to see in a counseling or therapy session for an individual with ASD?”

Responses may be presented on several different infographics with quotes from community members.


REAL PEOPLE REAL RESPONSES

WHAT ARE A FEW COMMON MISCONCEPTIONS ABOUT AUTISM?



AUTISTIC PEOPLE DONT WANT FRIENDS

- \* Girls can not have autism
- \* Autistic people do not have social skills
- \* If you can't speak you can't listen
- \* AUTISM IS CURABLE
- \* There is 'high-functioning' and 'low-functioning' Autism
- \* Autistic people are always Violent




These are sample responses consistent with examples from existing literature.

AUTISM ADVOCACY

MENTAL HEALTH COUNSELING

- Give individuals with autism the language and power to advocate for themselves
- Become an advocate as a counselor
- Understand how each individual learns and processes information differently
- Provide more physically engaging work



SUGGESTIONS FROM COMMUNITY MEMBERS

- Work from a strengths based approach
- Communicate with caretakers of individuals with autism
- Less structured sessions with room to adjust to the individual's needs without judgement
- Provide all accommodations needed



These are sample responses consistent with examples from existing literature.

## Key Concepts

**Advocacy:** An individual or organization engaging in advocacy aims to sway choices made by political, economic, and social institutions. Advocacy is the action of endorsing a plan or cause (Samsell et al., 2022) which research is a part of.

**Psychoeducation:** Offers methods, techniques, and resources for monitoring and controlling symptoms as well as enhancing general health and quality of life. Empowers those impacted.

**Directly & Indirectly Impacted:** Directly impacted participants are autistic people and their family members. Indirectly impacted participants are members who are involved in the community such as teachers, counselors, advocates, doctors.

## Discussion

- This study provides a platform for those directly and indirectly impacted by autism to share insight from their own experiences and quotes selected to provide psychoeducation with the goal of creating a more inclusive and realistic approach to autism advocacy.
- The process of having a space to speak about authentic experiences is a therapeutic process for participants of the study.
- Commonly accepted stereotypes surrounding the autistic community negatively impact the lives of those with the disorder. This study is a unique and effective approach towards advocating to counteract stigma.
- Social media has become one of the largest forms of communication making it an accessible platform to collect data, psychoeducate and advocate.

## References



Available at this QR code