



Understanding Views of Individuals who are Interested in or Affected by Autism Research: A Mixed Methods Study

Laura Foran Lewis, Caroline A. Mahoney, Julia R. Carbone, Melissa Houser, & Zeph

Disclosures

I have no actual or potential conflict of interest in relation to this presentation.

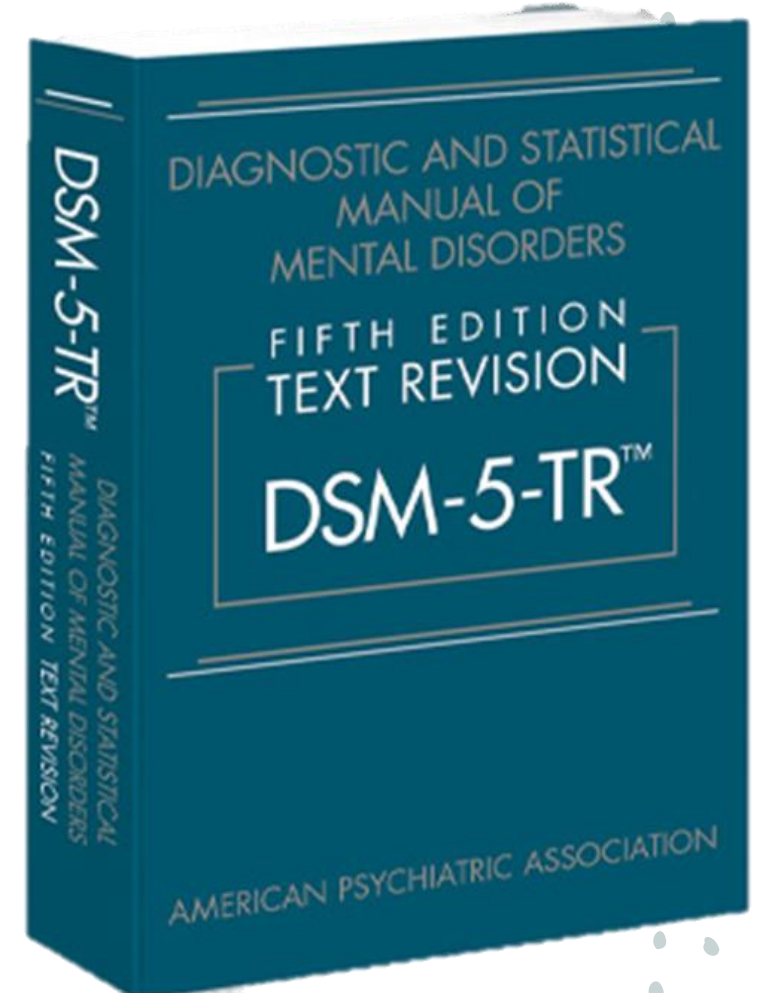


Positionality Statement



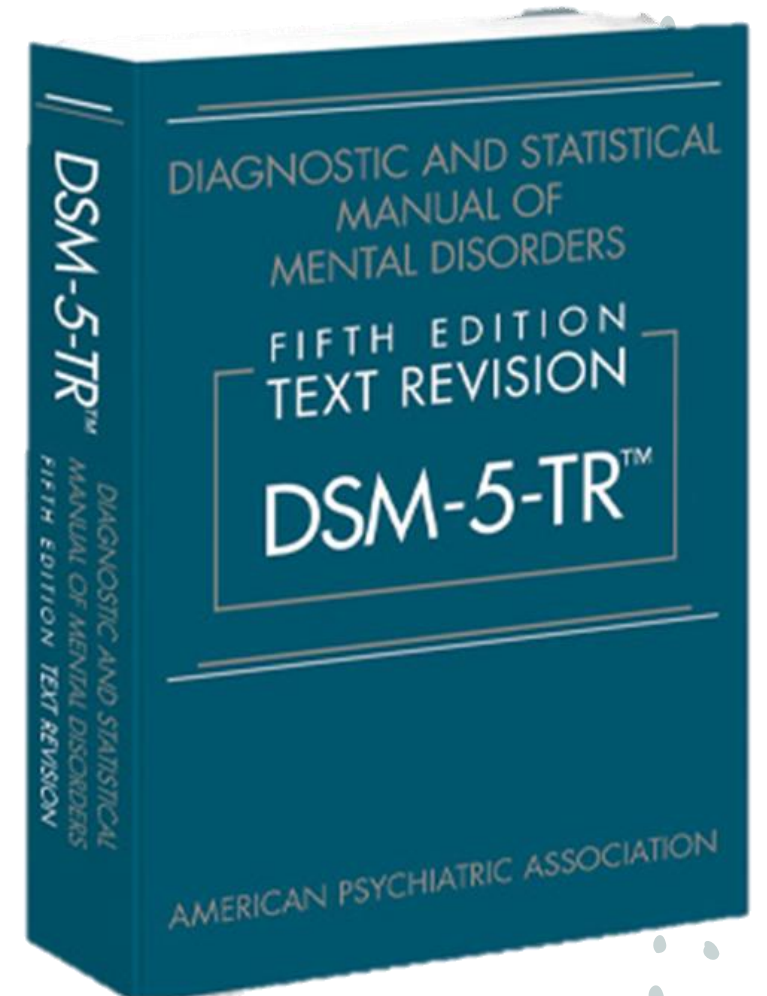
“Autism Spectrum Disorder”

- “Persistent deficits in social communication & social interaction”
- “Restricted, repetitive patterns of behavior, interest, or activities”
- “Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.”

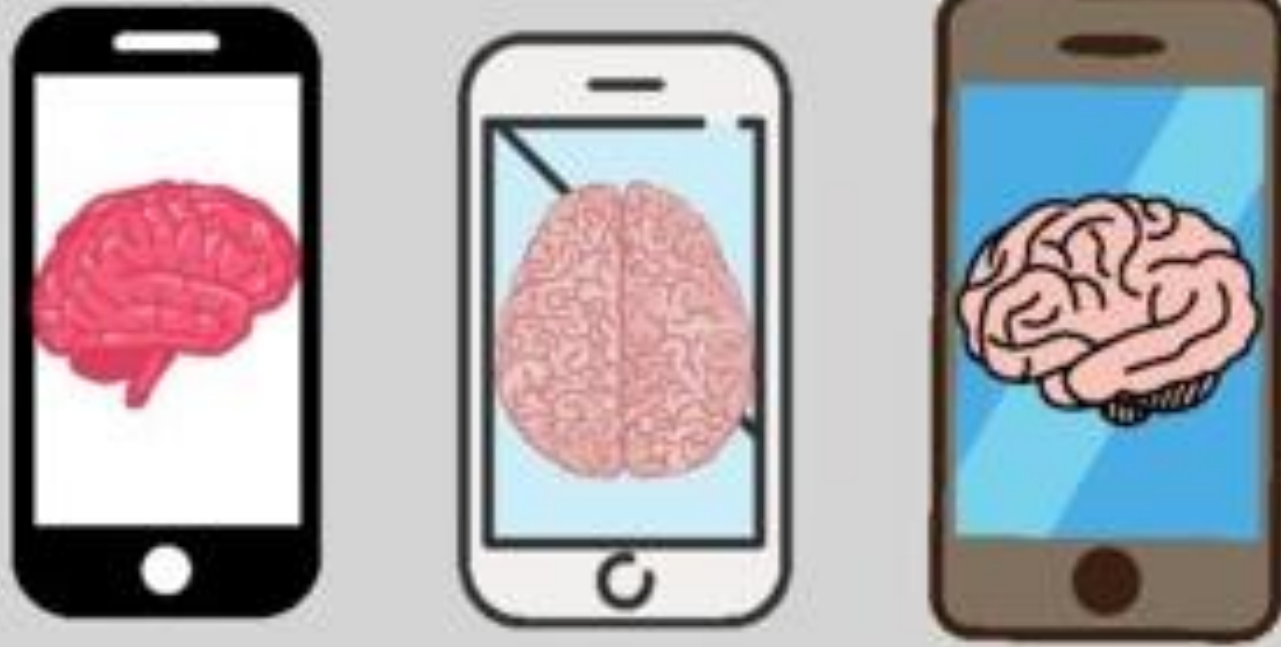


“Autism Spectrum **Disorder**”

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Neurodiversity Movement



All these brains have their own way of doing things. One isn't better than the other, they are different.

@more than one neurotype

Article

**'The line between
behaviour and**[Home](#) > [Handbook](#)

Neurodiversity

[Robert Chapman](#)Chapter | [First Open Access](#)**2452** Accesses |Part of the [Autism](#)

Abstract

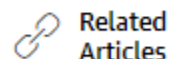
This chapter pro
movement, and
are appropriate
proponents, an
Analysis (ABA)—

More ▾

This Issue[Views 7,519](#)[Citations 13](#)[Altmetric 89](#)**Viewpoint**

July 11, 2022

At a Crossroads—Reconsidering the Goals of Autism Early Behavioral Intervention From a Neurodiversity Perspective

Geraldine Dawson, PhD^{1,2}; Lauren Franz, MBChB, MPH^{1,2}; S. Brandsen, PhD³[» Author Affiliations](#) | [Article Information](#)*JAMA Pediatr.* 2022;176(9):839-840. doi:10.1001/jamapediatrics.2022.2299Related
Articles

The neurodiversity perspective posits that each person has a unique brain and a unique combination of traits and abilities and asserts that many challenges faced by autistic individuals stem from a lack of fit between the characteristics of autistic people and society's expectations and biases. The neurodiversity movement is akin to a civil rights movement. Among its goals are reducing stigma, increasing accessibility, and ensuring that autistic

Purpose

To understand how individuals who are interested in or affected by autism research view autism research and what aspects of research are important to them

Methods

- Participatory action approach



Methods



Inclusion Criteria

- 18+ years
- Interested in autism research
- English speaking



Recruitment

- Online message boards
- Autism organization newsletters
- Social media



Data Collection

- Survey
- Open-ended questions about research values
- Close-ended questions to rate research topics they would like to see

Design & Data Analysis

Convergent Parallel Design

Descriptive & inferential statistics
(comparing Autistic vs. non-Autistic responses)

Reflexive Thematic Analysis
(Braun & Clarke, 2021)

Quantitative Data Collection and Analysis

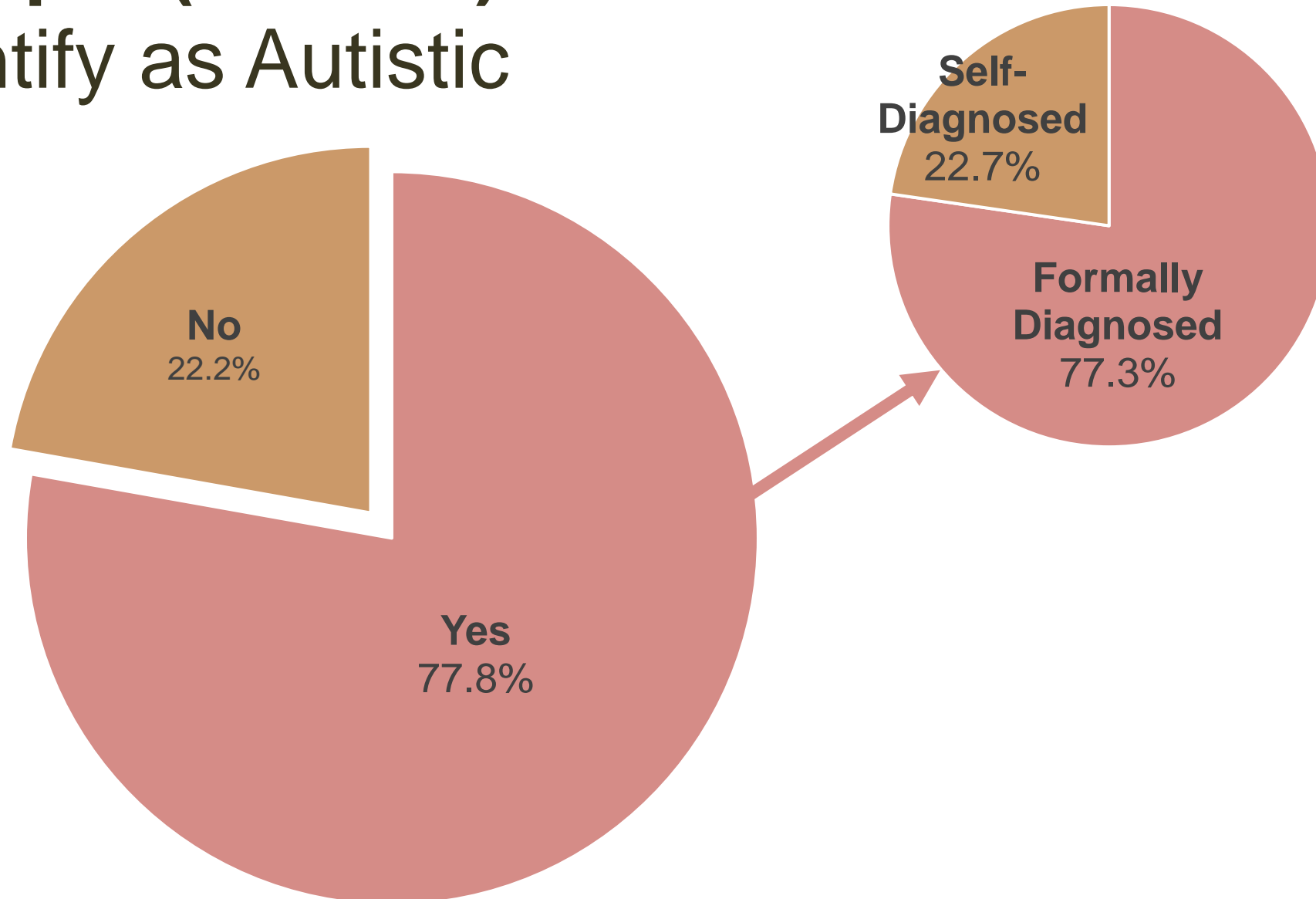
Qualitative Data Collection and Analysis

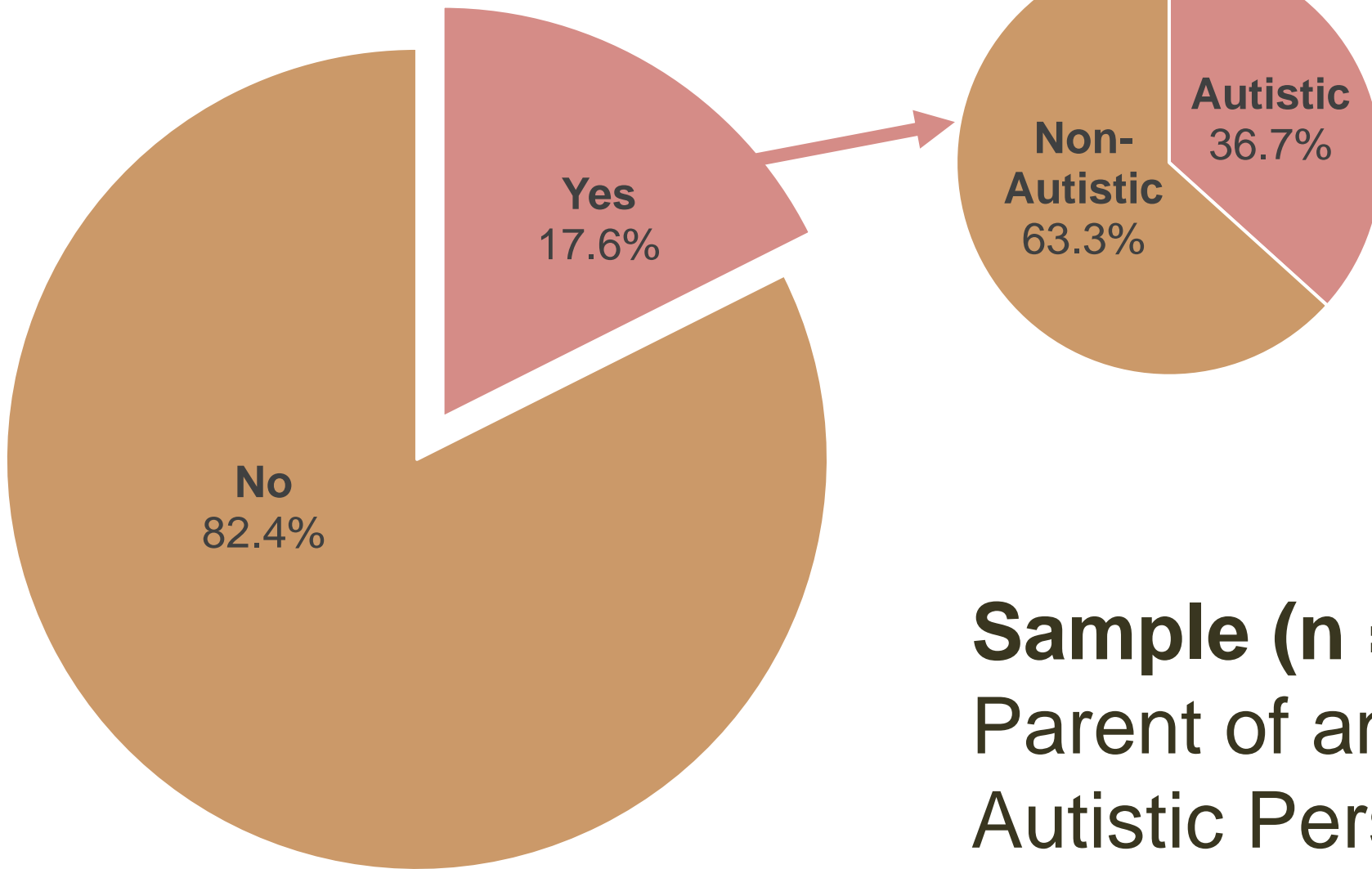
Compare or relate

Interpretation



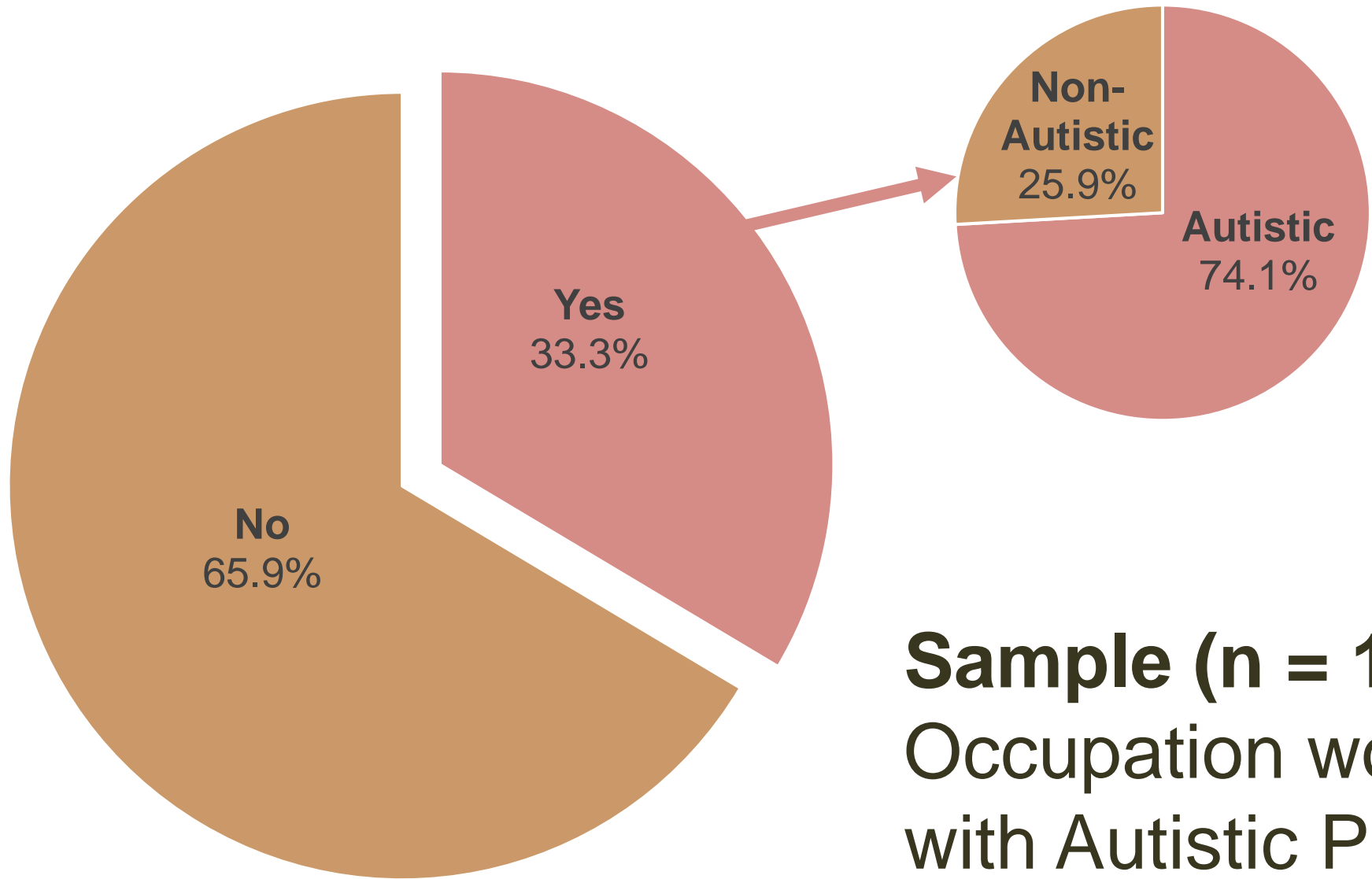
Sample (n = 174): Identify as Autistic





Sample (n = 174):
Parent of an
Autistic Person





Sample (n = 174):
Occupation works
with Autistic People

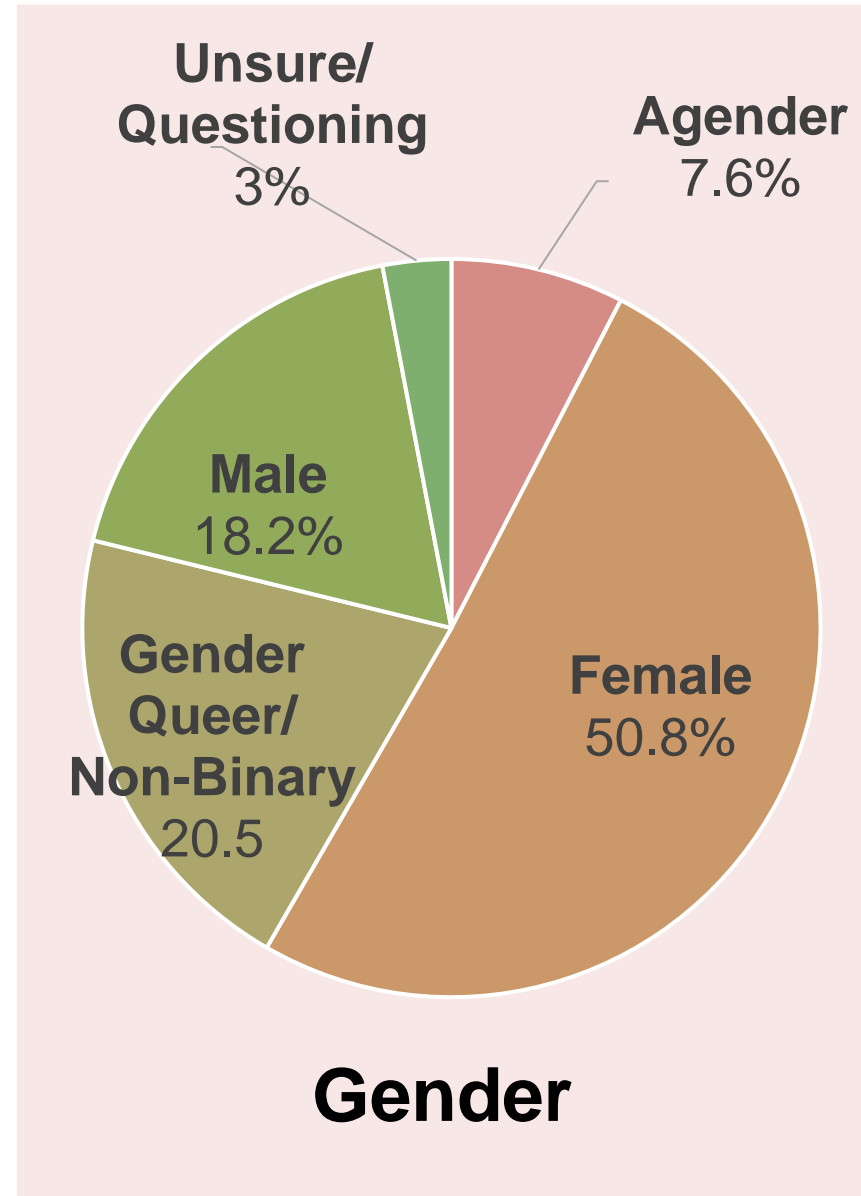


Race

- Asian or Pacific Islander: 3%
- Black or African Descent: 2%
- Native American or Alaskan Native: 1%
- White: 87%
- Multi-racial or Biracial: 3%
- Race not listed: 4%

Ethnicity

5% Hispanic or Latino/a/x



Age

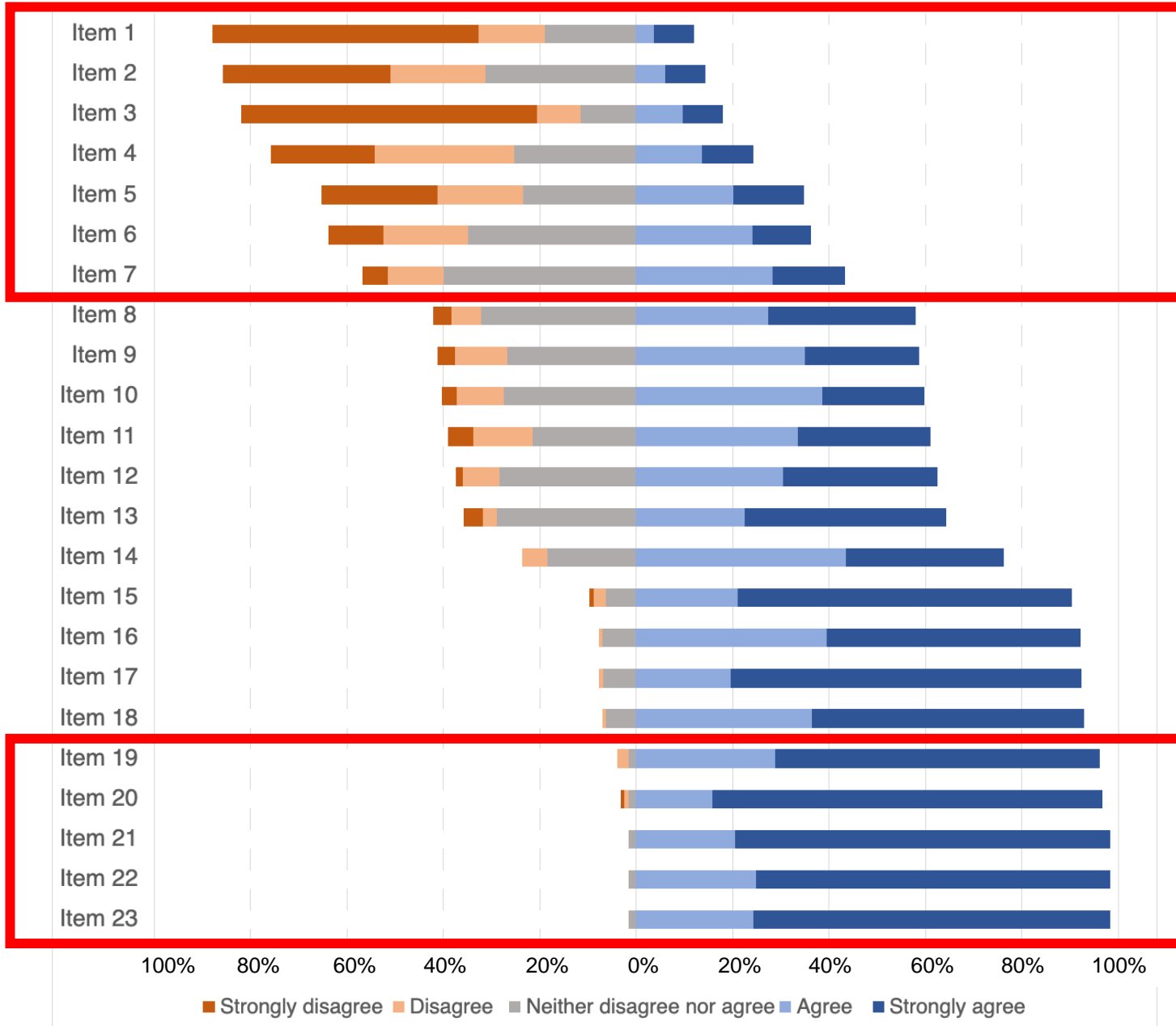
$M = 34.8$ years ($SD = 14.3$)

Country of Residence

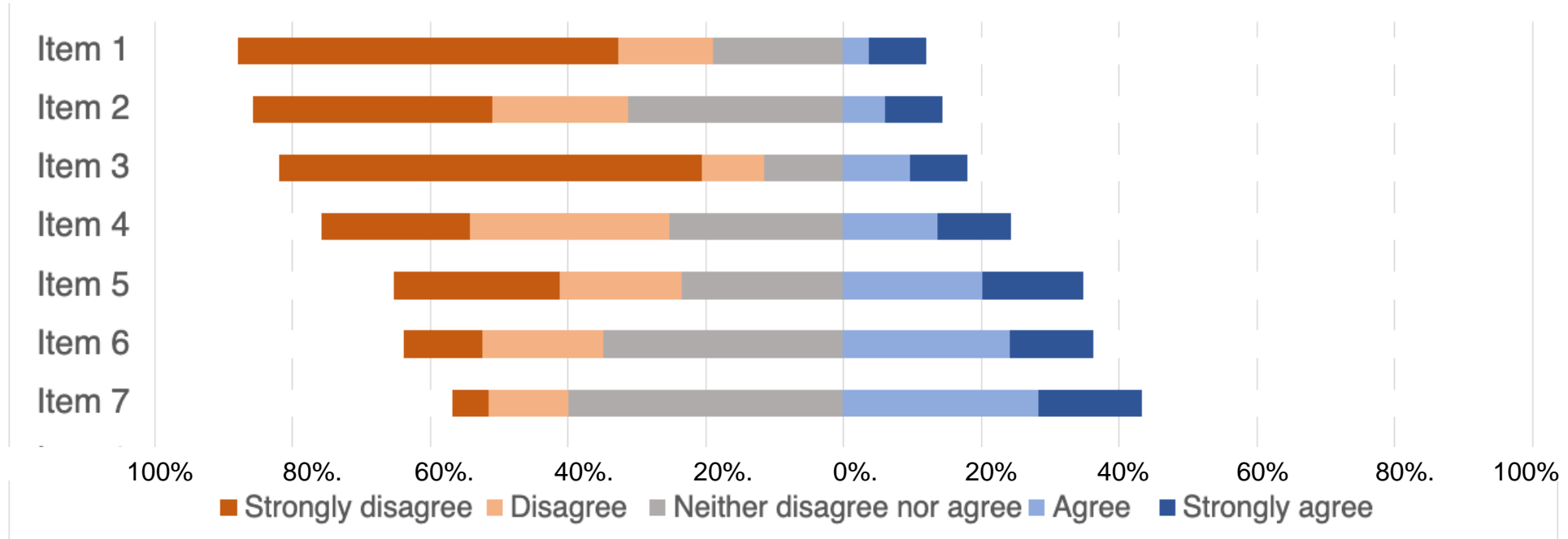
- 16 countries represented
- United States: 66%
- UK: 12%
- Canada: 9%

(n = 174)

I would like to see more research that...



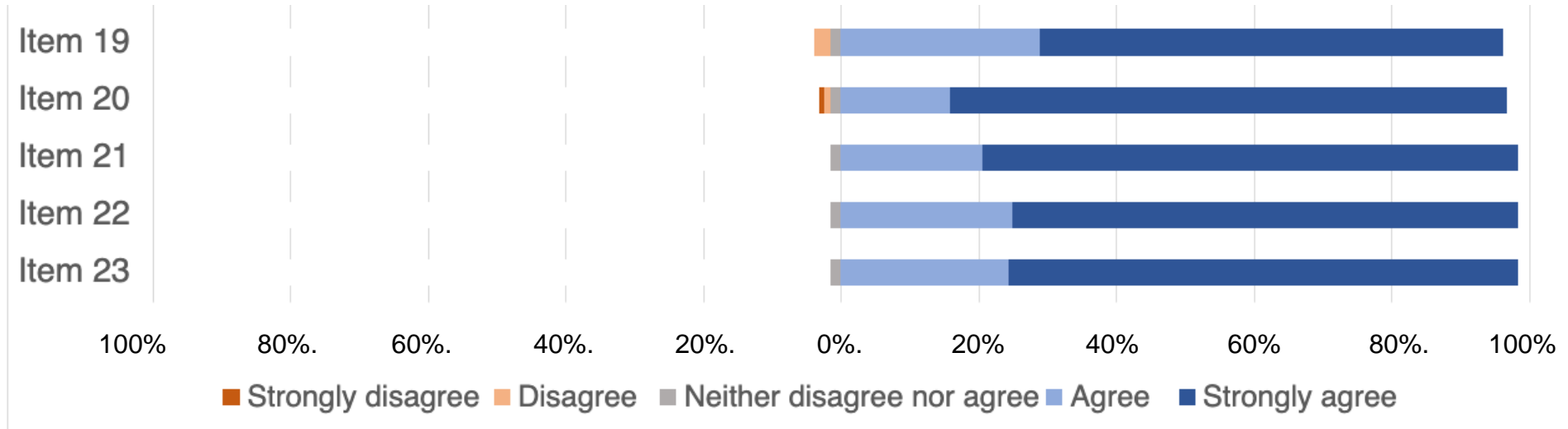
I would like to see more research that...



| | |
|---|--|
| 1 | Explores ways to prevent autism |
| 2 | Uses person-first language |
| 3 | Explores ways to treat or cure autism |
| 4 | Explores things that increase people's chances of being autistic |
| 5 | Explores ways to decrease symptoms of autism |
| 6 | Includes parents of autistic people on the research team |
| 7 | Focuses on autistic children |



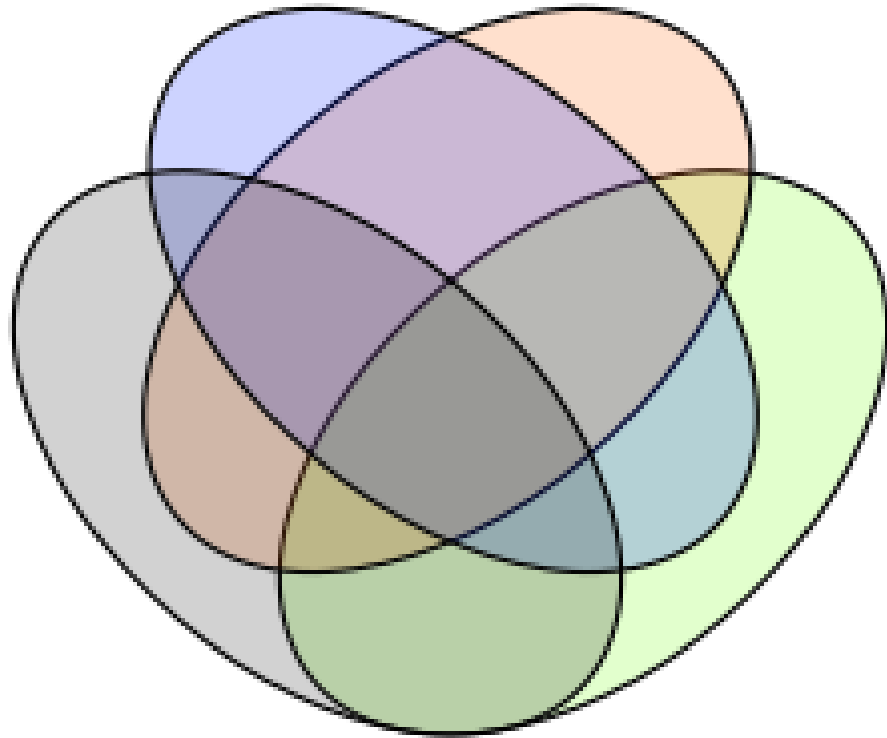
I would like to see more research that...



| | |
|----|---|
| 19 | Explores ways to manage physical health challenges that commonly co-occur with autism (e.g. gastrointestinal disorders) |
| 20 | Explores the perspectives of autistic people |
| 21 | Aims to improve the quality of life of autistic people |
| 22 | Explores ways to support autistic people in meeting life goals (e.g. living independently, maintaining employment) |
| 23 | Explores ways to manage mental health challenges that commonly co-occur with autism (e.g. depression, anxiety) |

Qualitative Themes

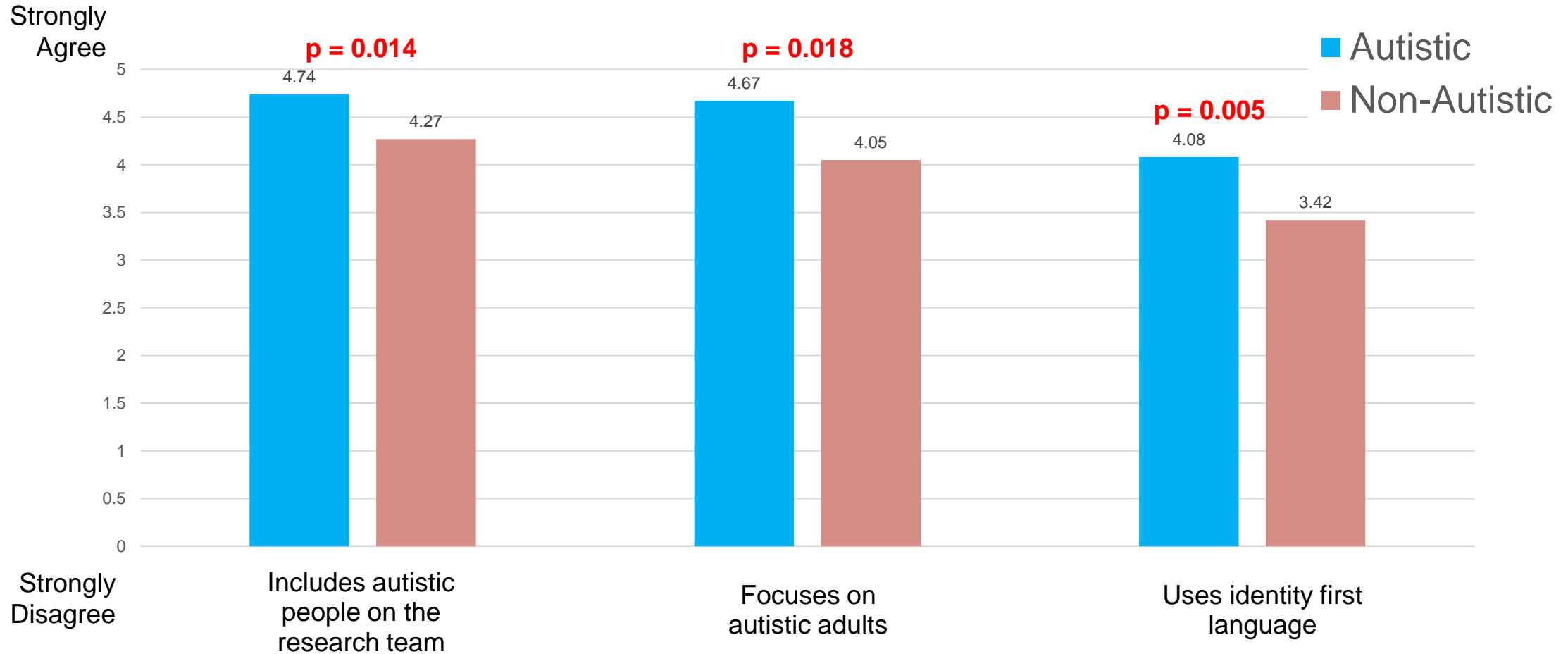
Participants valued:



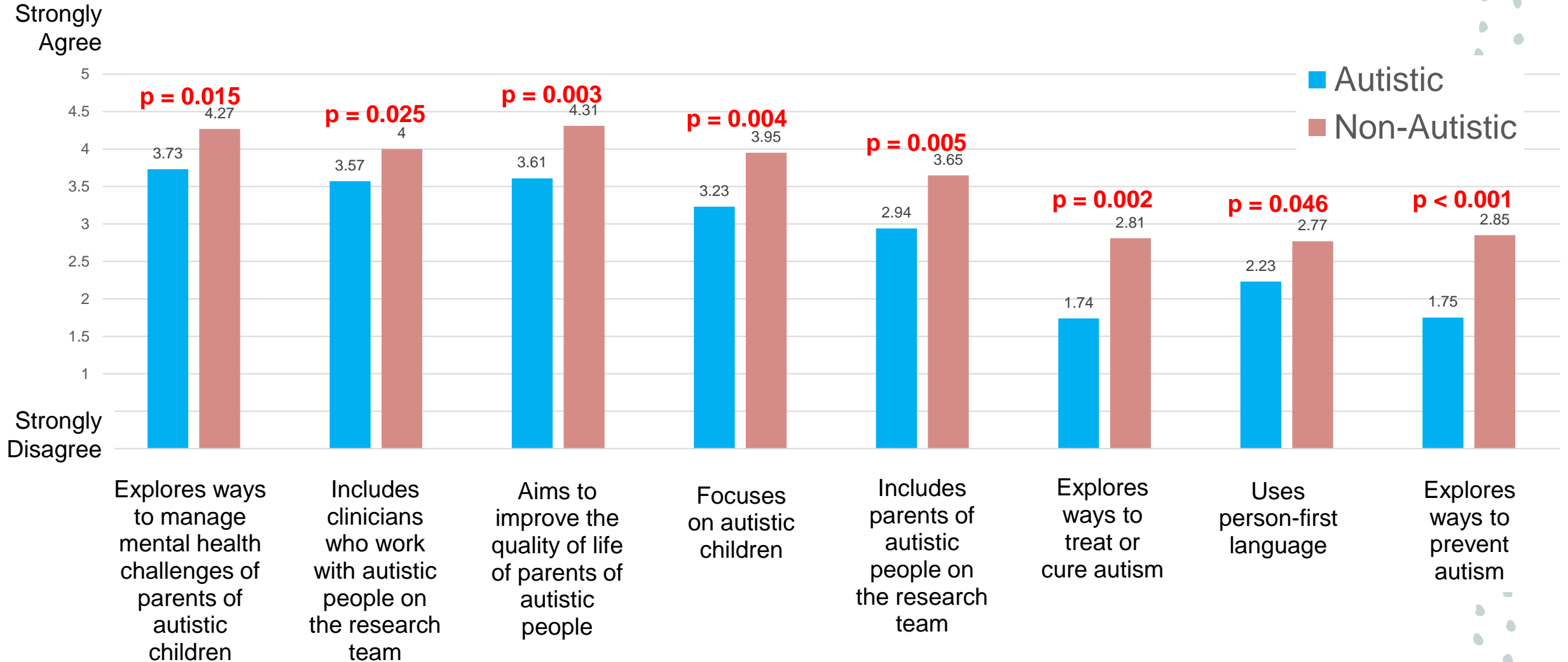
- 1) Involving Autistic Partners on the Research Team
- 2) Centering Autistic Voices
- 3) Improving Quality of Life
- 4) Supporting Neurodiversity
- 5) Debunking the Cure Narrative
- 6) Considering Intersectionality
- 7) Conducting High Quality Research



Research Topics Preferred by Autistic Participants



Research Topics Preferred by Non-Autistic Participants



Conclusions & Implications

- Autistic participants support a shift in research:
 - Away from a focus on prevention, treatment, & cure
 - Towards improving quality of life across the lifespan
- Need for further research on perspectives of BIPOC autistic community
- Call for increased engagement with the autistic community during research
- Importance of centering autistic voices



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