



Unheard voices

A systematic literature review of studies using self-report methods to gather the perspectives of Autistic adults with intellectual disability



Research Centre
for Autism Practice



Research team

Dr Vicki Gibbs, Aspect Research Centre for Autism Practice (ARCAP)

Dr Abbey Love, ARCAP

Dr Ru Ying Cai, ARCAP

Dr Chris Edwards, ARCAP

Dr Mustafa Al Ansari, ARCAP/La Trobe University



Working in partnership

The research team included an Autistic researcher who provided input in all stages of the research life cycle including design, recruitment, data collection and analyses.



Background

Autistic people have historically had limited representation in autism research, with studies predominantly relying on reports from informants such as parents, teachers, and clinicians (Pellicano et al., 2021). While parental reports can provide valuable insights, they often do not capture the full scope of Autistic individuals' experiences, as there can be significant differences between the perspectives of Autistic people and their parents (Clark et al., 2014). When self-report data from Autistic individuals has been collected, this is primarily via verbal methods such as interviews and focus groups or surveys and questionnaires. This means that research studies that utilise self-report data often do not capture the perspectives of Autistic individuals with co-occurring intellectual disability due to poor accessibility (Nicholas et al., 2019). This underrepresentation is particularly troubling given recent estimates that approximately 31–50% of Autistic people also have an intellectual disability (Maenner et al., 2016).

There has also been an increasing recognition of the value of community involvement in autism research that goes beyond research participation. Community involvement includes engagement with community members (e.g. Autistic people, their parents and family

members, clinicians and other service providers) across all stages of the research process. This can enhance research methods and contextualise findings, aiding in their practical

application for Autistic people and facilitating relevant and meaningful benefits (Long et al., 2017). Although autism research is increasingly incorporating some degree of community involvement, particularly in studies focused on Autistic adults and adolescents, it is not clear whether this trend has filtered into the limited research that focuses on the lived experiences of Autistic individuals with intellectual disability.

Despite recent efforts by researchers to better understand the lived experiences of Autistic adults, a comprehensive analysis of the body of research that includes those with intellectual disability remains absent. Understanding the scope of this research and the methodologies employed is crucial for informing and directing future studies that aim to address the significant gaps in the inclusion of Autistic adults with intellectual disability. A systematic review can also provide researchers with a repository of various methods, enabling them to select and apply appropriate techniques, thereby increasing the usage and recognition of these methods as rigorous and valid approaches.



Study aim

Our systematic review sought to provide a thorough overview of the methods used to collect first-hand information about the experiences and perspectives of this underserved group. Specifically, we wanted to determine the extent of the research focusing on the lived experiences of Autistic adults with intellectual disability using self-report methods, including the topics covered and the nature of the information gathered. We were guided by the following questions:

- 1 What is the nature and extent of the research using self-report methods where the focus is Autistic adults with intellectual disability?
- 2 What self-report measures have been used in this population?
- 3 What proportion of studies reviewed include community involvement? We defined community involvement as the active participation of community members (Autistic adults, their family members or support networks) in the conduct of the research beyond being study participants.

Method

Study design

We systematically searched the following databases from January 2013 to July 2023 for publications:

- PsycINFO (Psychology)
- Scopus (Multidisciplinary Sciences including Social Sciences)
- MEDLINE (Multidisciplinary Medical Sciences)
- ERIC (Education)
- CINAHL (via EBSCOhost)
- Web of Science.

We limited the publication period to studies published in the previous ten years for practical purposes. The search strategy utilised a combination of searches through titles, abstracts, keywords, and full texts related to "autism" and "intellectual disability" or "cognitive impairment" or "developmental delay" or "intellectual impairment". To be included in the review, study samples had to consist of at least 70% Autistic adults with intellectual disability and include at least one self-

report measure. We chose 70% to ensure that the study had a clear focus on this particular cohort as per the aims of the review. Two research team members independently conducted abstract/title screening and full-text reviews.

As shown in Figure 1, after removing duplicates, we screened 4,451 unique articles for eligibility, before conducting a full-text review of 277 full-text articles. We excluded 263 papers for the following reasons:

- <70% of the sample with intellectual disability ($n = 171$)
- no self-report measures ($n = 80$)
- no adult data or the participant mean age <17 years ($n = 6$)
- not peer-reviewed ($n = 4$) or
- the paper was not original research ($n = 2$).

Thus, we identified 14 studies as eligible for inclusion in the systematic review.

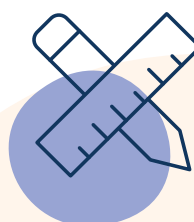
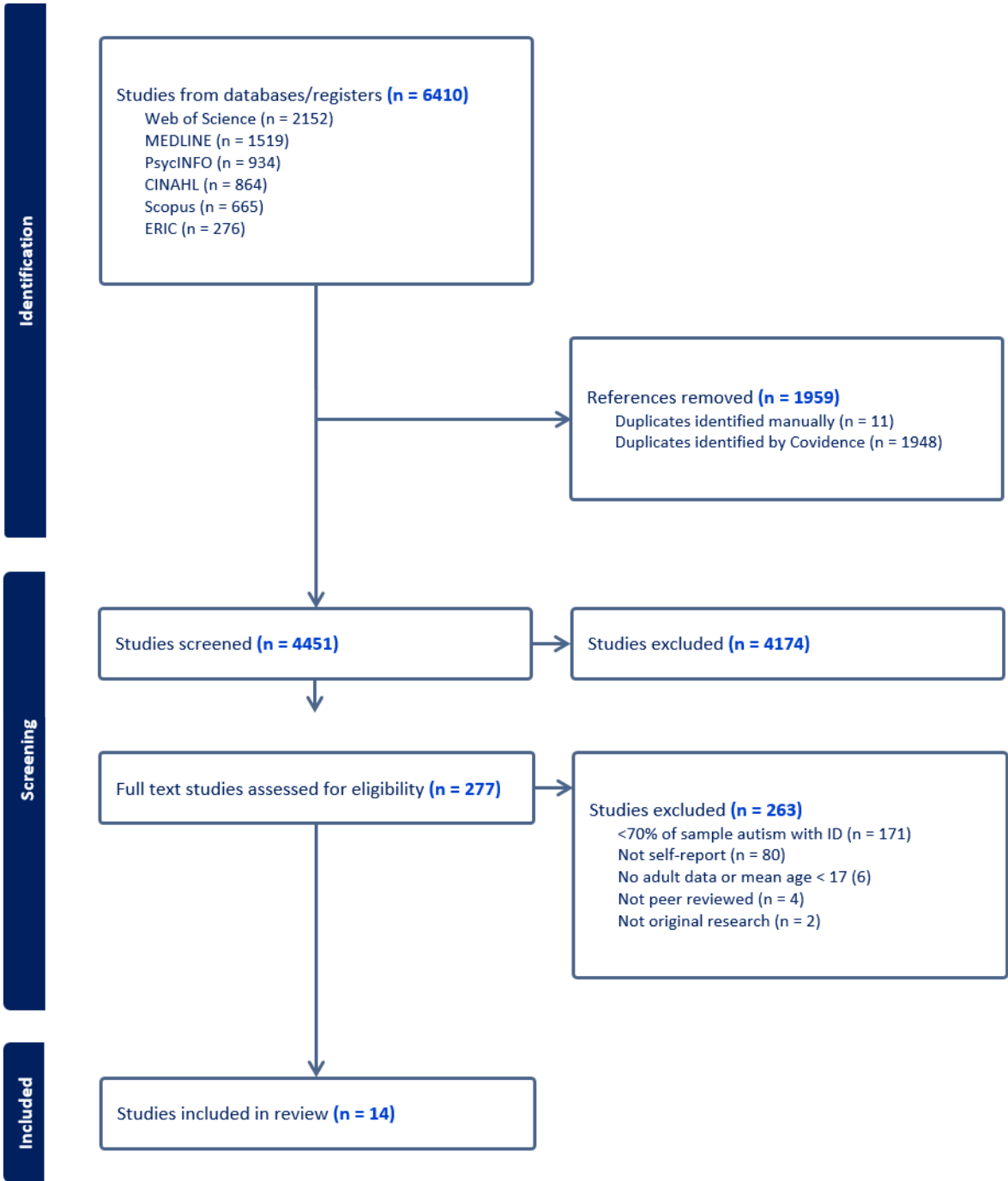


Figure 1
Prisma Flow Diagram Showing Article Selection Process



Summary of results

Only 14 studies were conducted in the 10-year period between 2013 and 2023 where the sample was predominantly Autistic adults with intellectual disability (>70% of the sample) and self-reports were directly collected from participants.

Most studies (11 of the 14) employed self-report measures to evaluate discrete interventions rather than to explore people's lived experiences.

A total of 24 measures were used to gather self-report data from Autistic adults across the included studies. Most of these measures ($n = 14$) were novel questionnaires or interviews designed for each study, with only half of these described as including accommodations such as visual aids, options for items to be read aloud, or the provision of additional explanation of items/questions if required. The remaining ten measures were established questionnaires; however, only two had been validated for use with adults with intellectual disability, and only two of the other studies reported incorporating adaptations, i.e., simplified language or visual supports. Although two studies documented some input in the design stage from siblings and employers of Autistic adults, none reported any co-production elements that included Autistic adults.

Conclusion

Our review underscores the persistent and significant gaps in autism research, particularly the underrepresentation of Autistic adults with intellectual disability. While there is increasing acknowledgment of the importance of amplifying Autistic voices in research, the ongoing exclusion of those with intellectual disability represents a critical shortfall. Future studies should prioritise creating and validating accessible self-report tools while actively involving Autistic adults with intellectual disability in the research process. This approach will help ensure that research captures the full diversity of Autistic experiences and delivers outcomes that are meaningful and impactful for the most marginalised.



References

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aspect.org.au/arcap | research@aspect.org.au