

# Unheard Voices: A Systematic Literature Review of Studies Using Self-Report Methods to Gather the Perspectives of Autistic Adults with Intellectual Disability

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## Background

- Autism research has often relied on informant reports which may not fully capture Autistic perspectives.
- Although there have been recent improvements in using self-report methods, these studies often exclude individuals with intellectual disability (ID) due to accessibility barriers.
- There is increasing recognition of importance of community involvement in autism research, however the extent of community involvement in studies on Autistic individuals with ID remains unclear.

## Study Aims

The aim of this study is to conduct a systematic review to answer the following research questions?

- What is the nature and extent of the research using self-report methods where the focus is Autistic adults with ID?
- What self-report measures have been used in this population?

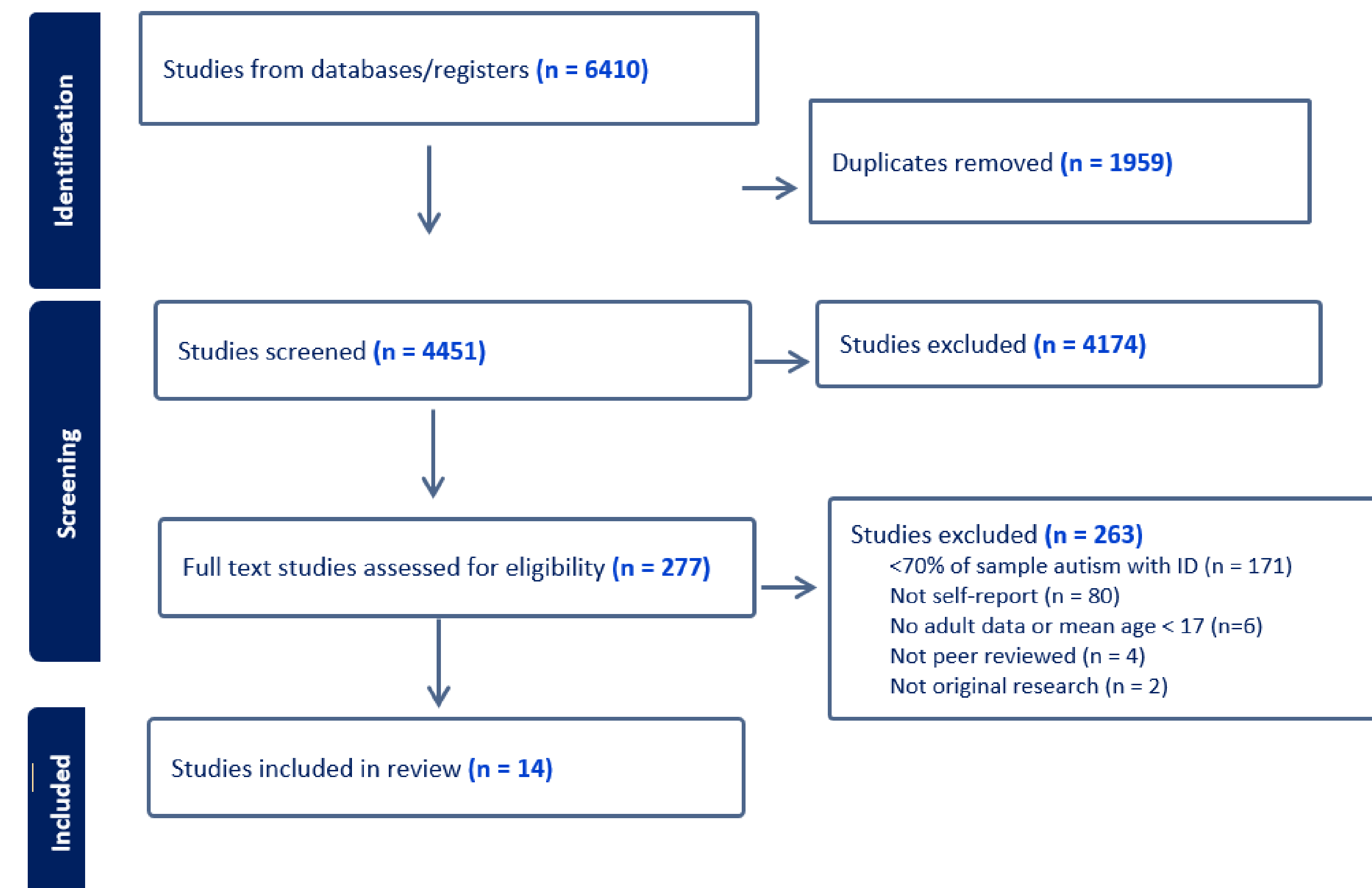
## Search Strategy

- Search terms included "autis\*" "intellectual disab\* or ID" "cognitive impairment" and "adult"
- Limited to English peer-reviewed, 2013-2023
- At least 70% Autistic adults with ID AND collection of self-report

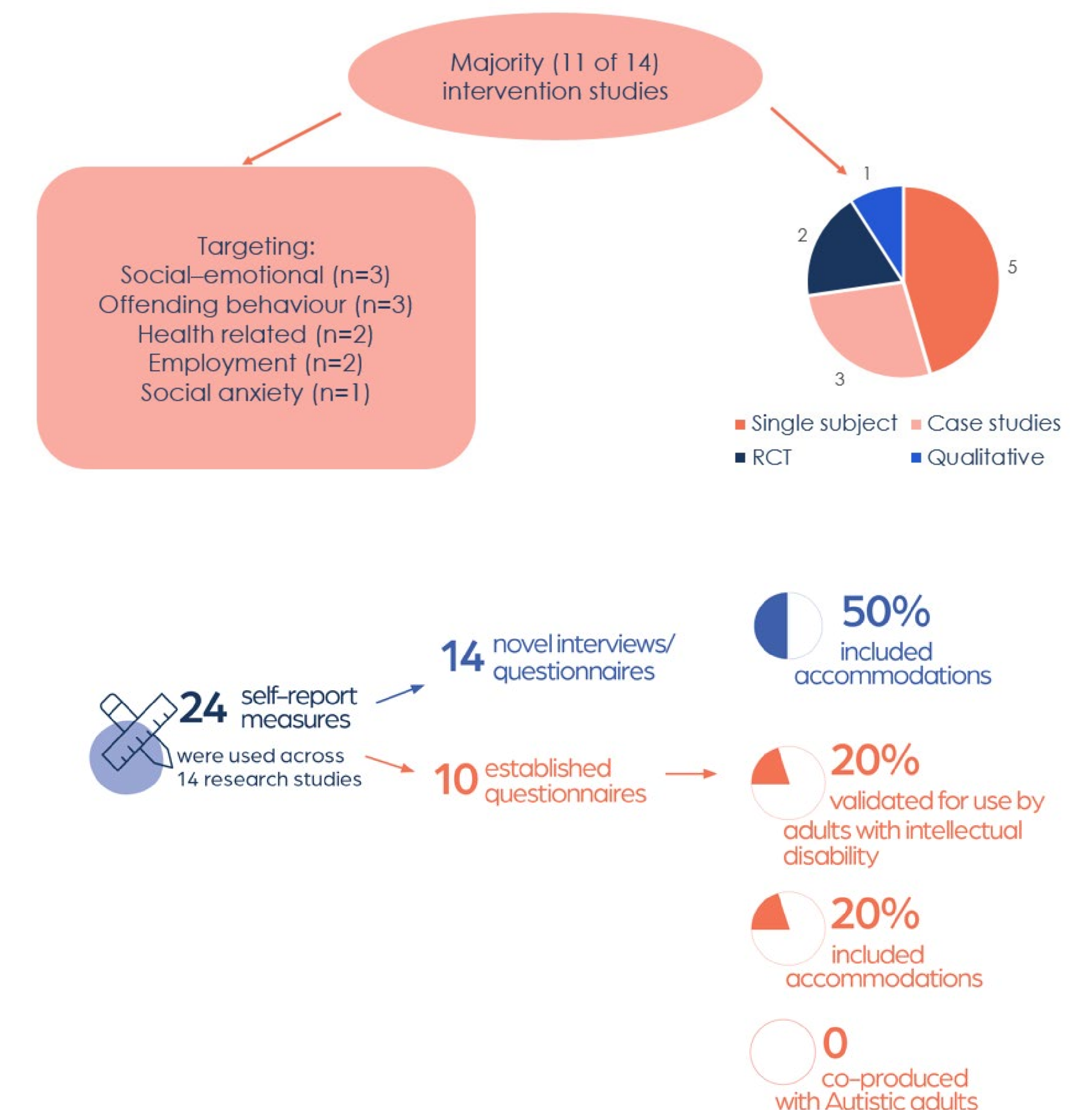
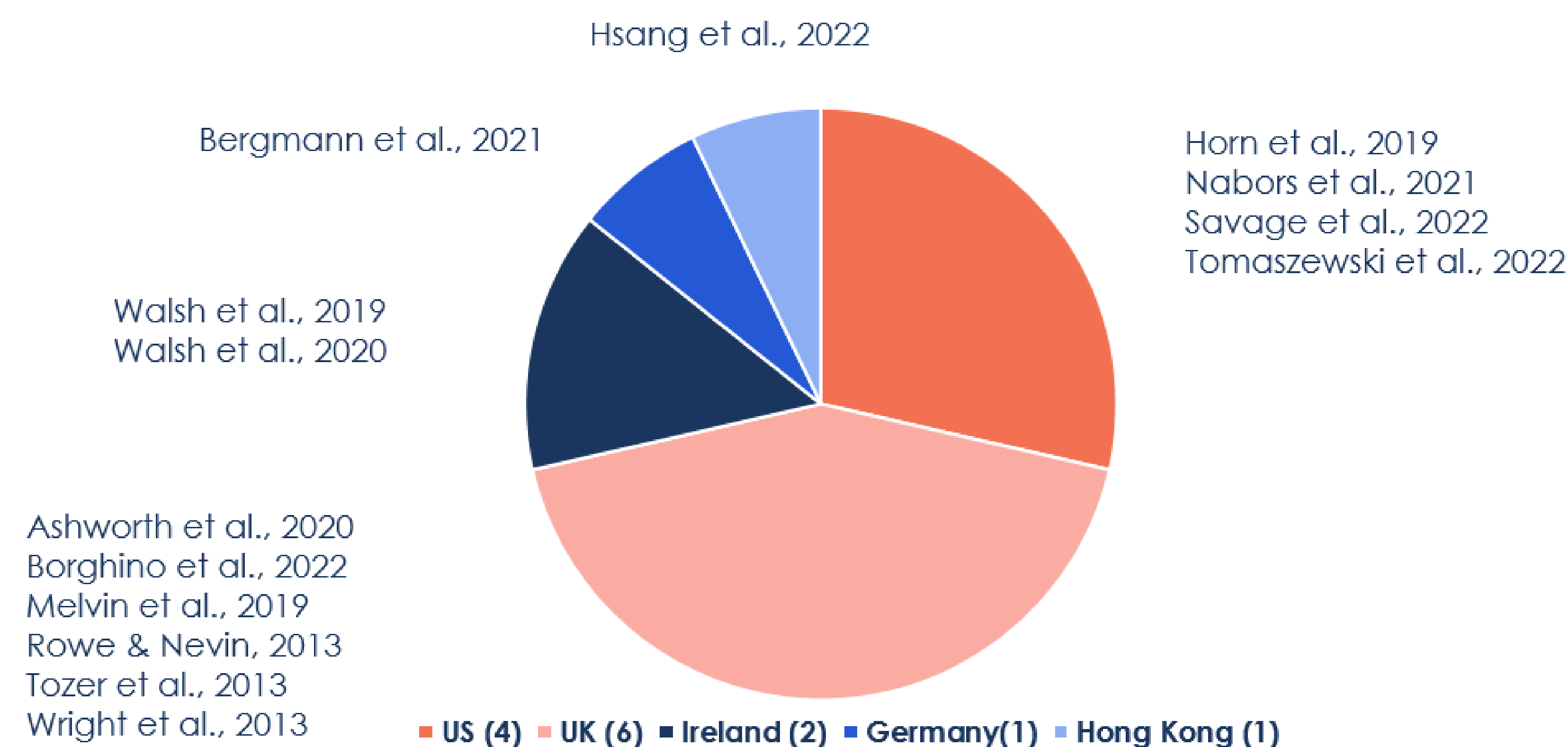
Paper



Poster



## Results



## Conclusion

- Only 14 studies in 10 years; most looked at interventions
- 24 self-report tools, but only 2 validated for ID, less than half used supports or accommodations
- No co-production

### We need:

- Greater focus on lived experience of Autistic adults with ID
- Encourage innovation in autism research methods – look to ID research
- Go beyond intervention outcomes
- More inclusion of adults with ID in the research process