

How is the quality of life and well-being of autistic people measured?

Kate Simpson^{1,2}, Jessica Paynter^{2,3}, Marleen Westerveld^{2,4}, Larah van der Meer⁵, Lee Patrick⁵, Gabrielle Hogg⁶, Helen Heussler⁷, Melanie Heyworth⁸, Alison Gable⁹, Hem Sid Chandran⁶, Rachel Bowen¹⁰, Dawn Adams^{1,2}

¹ Autism Centre of Excellence, Griffith University, ² Griffith Institute of Educational Research, Griffith University, ³ School of Applied Psychology, Griffith University, ⁴ School of Health Sciences and Social Work, Griffith University, ⁵ Autism New Zealand, New Zealand, ⁶ Independent Research (Autistic Expert), ⁷ Children's Health Queensland, ⁸ Reframing Autism, ⁹ The Sycamore School, ¹⁰ Giant Steps,

Autistic people are reported to have poorer quality of life and well-being than their non-autistic peers.

Project aim

To review the research literature on quality of life and/or well-being of autistic people to identify:

- What methods are used?
- Who is reporting?
- Who is being described?

Method

Community involvement

This project was co-produced with autistic and non-autistic researchers, autistic experts, and an advisory group.

Systematic review protocol

Registered with PROSPERO 2022
CRD42022385357

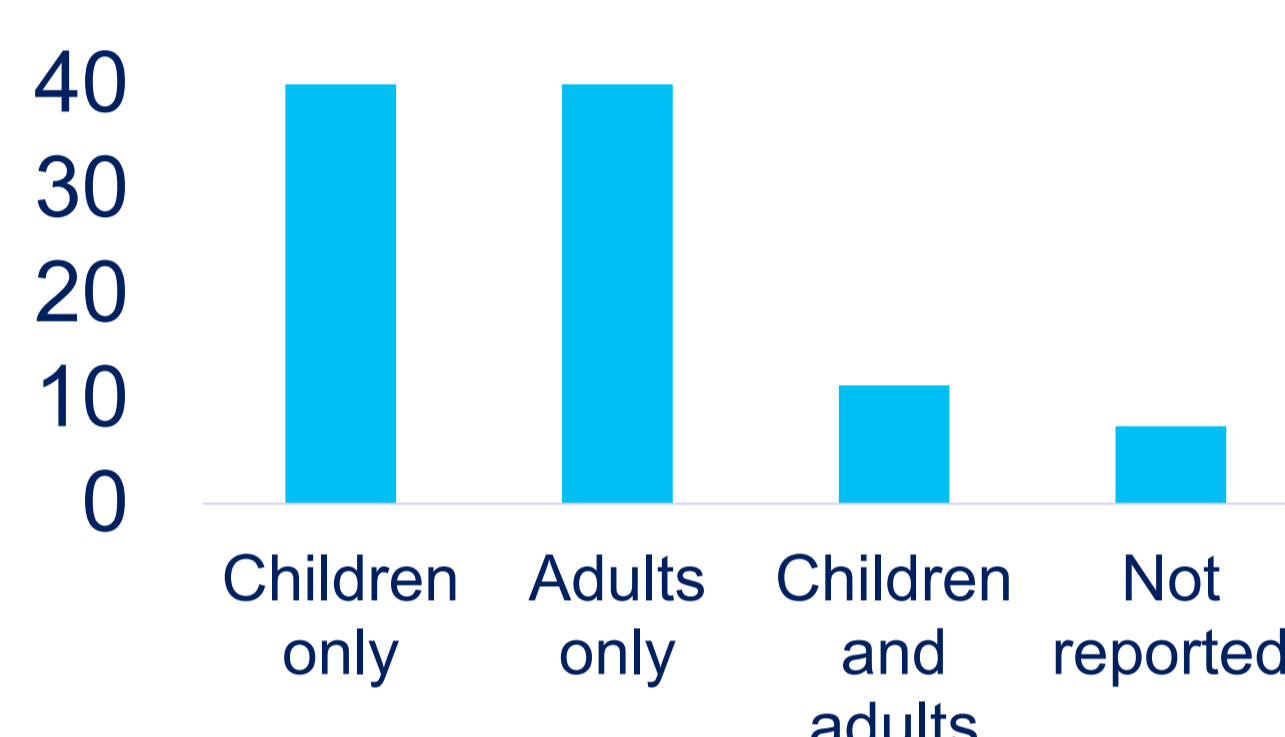


Scan the QR code to get a free copy of the published article.

256 articles were included

Reporting on 51,576 autistic people

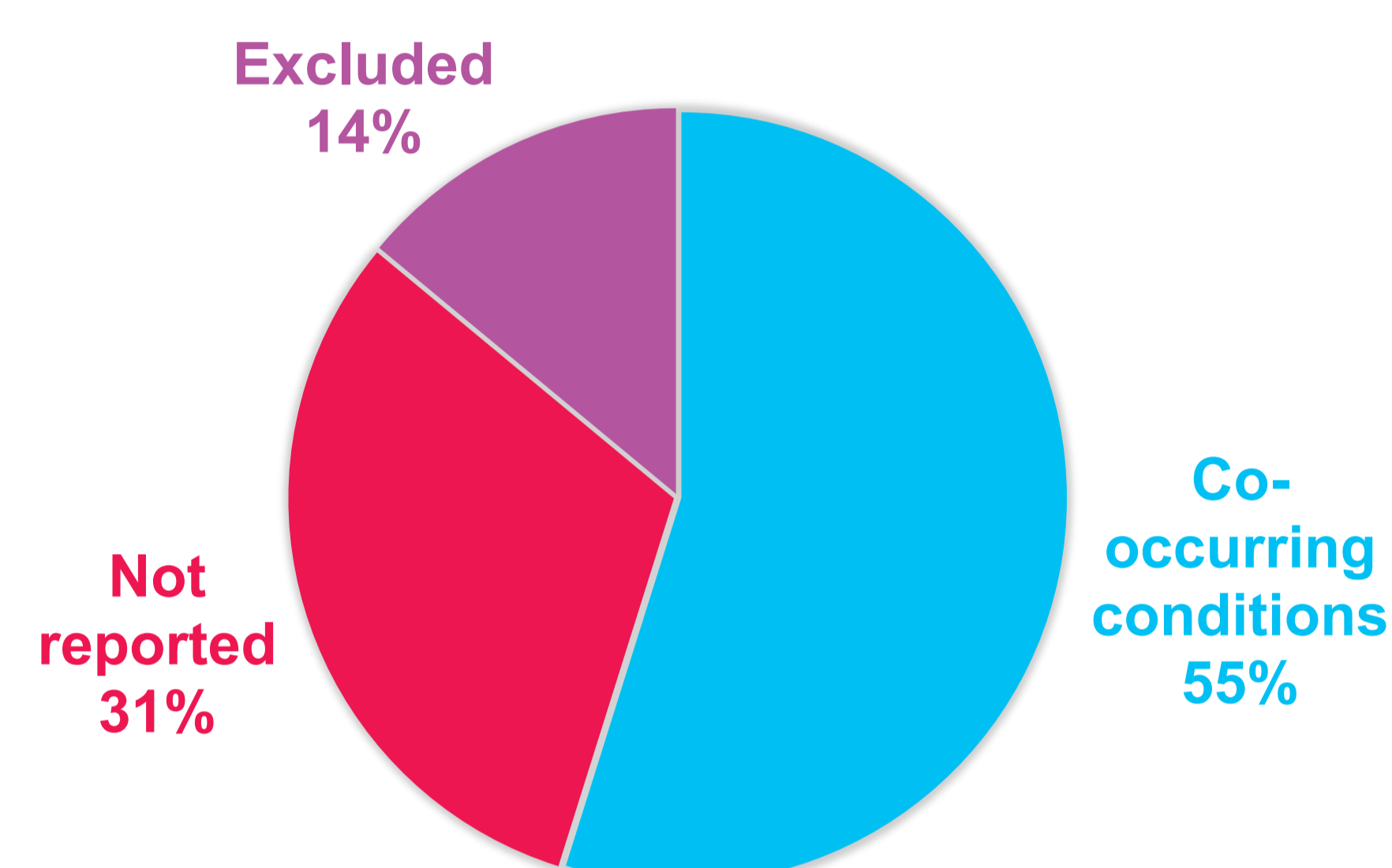
Age group reported (% studies)



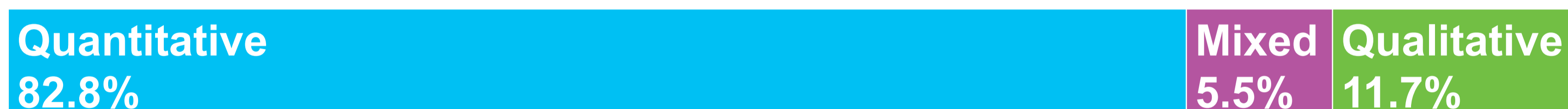
Gender

- 83.2% reported gender data
- 72.7% reported binary data only
- Males to females 2.2:1

Co-occurring conditions



Research design



120 different measures (e.g., surveys, questionnaires)

- only **4** measures specific to autism

Accommodations identified in **17%** of these studies

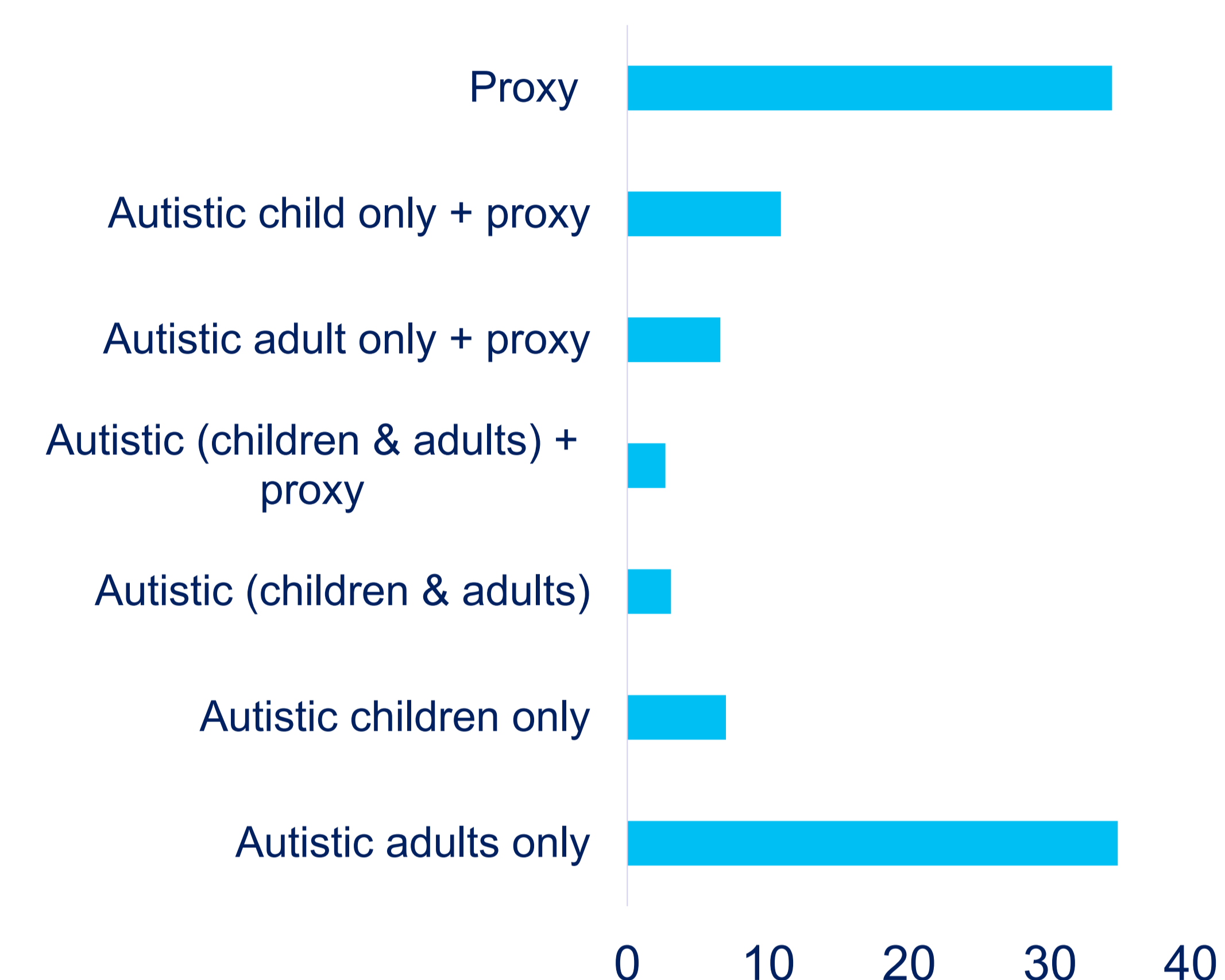
- e.g., support person, additional examples, verbal or visual prompts, easy read format

- Semi-structured interviews, focus groups, photo-elicitation, open-ended questions.

Accommodations identified in **52%** of studies

- e.g., accessible venue, visual prompts including pictures, photos, drawings, and artifacts, and optional modes of responding

Reported by (% studies)



Community involvement

Only **10%** of studies provided evidence of autistic input informing the research

Conclusion

Future research needs to:

- use measurement scales that reflect the values of autistic people
- use co-design methods with autistic people to enhance their participation
- report participant details to identify impact of co-occurring conditions on quality of life and well-being.

For more information

Kate Simpson | Phone: +61 (0) 7 3382 1513 | Email: k.simson@griffith.edu.au

The authors acknowledge the financial support of Autism CRC, which was established under the Australian Government's Cooperative Research Centres Program.

[autismcrc.com.au](https://www.autismcrc.com.au)
[@autismcrc](https://www.instagram.com/autismcrc)