

Safe Homes: Co-designing evidence for inclusive, individualised support for people with intellectual disability

Project Executive Summary

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April 2026



National Disability
Research Partnership

Lead Organisation: University of Melbourne

Partner Organisation: Inclusion Australia

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Period of project activity: July 2025-April 2026

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Contributors and acknowledgements

We would like to acknowledge Inclusion Australia's Complex Needs Reference Group for sharing their insights into the project design and conduct. We would also like to thank research participants for sharing their stories and for their generosity with their time.



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We hope that this evidence will help government make decisions about how to spend their money.

How to cite this summary

Bright T, White B, Nelson L, Canham B, McLean D, Conley Wright A, Mason K, Aitken Z, Dimov S, Dickinson H, Kavanagh A. (2026) *Safe Homes: Co-designing evidence for inclusive, individualised support for people with intellectual disability in Australia. NDRP Final Project Executive Summary*. University of Melbourne, Inclusion Australia. Published by the National Disability Research Partnership (NDRP).

Acknowledgement to Country

We acknowledge the traditional owners of the lands and nations on which this project was implemented and pay our respects to the Elders past and present.

Content notes

This report discusses topics including disability support systems, unsafe housing environments, abuse, neglect, restrictive practices, hospitalisation, and interactions with emergency services. Some readers may find this content distressing. Please engage with the report in a way that supports your wellbeing. If reading this material raises concerns or distress, you may wish to seek support from a trusted person or relevant support service. In Australia, support is available through Lifeline Australia (13 11 14) or Beyond Blue (1300 22 4636).

The issue we explored

This research project was a partnership between researchers from the University of Melbourne, University of New South Wales Canberra, and Inclusion Australia, the national voice for people with intellectual disability and their families.

The focus of this project was on people with intellectual disability and high support needs who live in a home in the community using something called a “service-for-one”. This is a model where National Disability Insurance Scheme (NDIS) participants and their families directly employ their own support workers using their funding. We were particularly interested in whether this model was safe, compared to other housing options such as group homes. Group homes are places where people live together with other people with disability with support.

Why this issue matters

The Disability Royal Commission heard many stories of people experiencing abuse, neglect, and restrictive practices, particularly in group homes, and said that Australia is failing to do what it agreed to do when it signed the United Nations Convention on the Rights of Persons with Disabilities. We think service-for-one may offer greater safety, choice, and wellbeing, but there is not enough evidence to show this. This important research is needed to ensure policy decisions support genuine choice, inclusion, and safety for people with disability and high support needs. Inclusion Australia think this is an important area for research because of what families have told them in their Complex Needs Family Reference Group. They have long advocated for this model.

What was co-designed

The aim of this project was to develop a proposal for research funding as a group through co-design. We created this proposal together to find out more about service-for-one in terms of how safe people feel, how much it costs, and what helps or does not help people set up or choose a service-for-one. This report is about the co-design process.

What were our key lessons from the co-design process

- A project “governance group” is an important part of research that involves people with lived experience and their families. A governance group is a group of people who help guide the project. They make sure the work is being done in a good, fair, and inclusive way.
- Including lived experience researchers in the project team strengthened the quality of the research project and improved the research process.
- Working together like this needs more time, planning, and funding, but it leads to better research.
- It is important to include people with intellectual disability and high needs in research, in ways that work for them.

What the future research could achieve

The future research proposal we have designed together will create evidence about service-for-one in terms of how safe people feel, how much it costs, and what helps or does not help people set up or choose a service-for-one. This evidence will be valuable for advocacy by Inclusion Australia, self-advocates, families and disability organisations, and for government decision making to guide changes to the NDIS. It will also mean there is information available about how service-for-one works for people with disability and high support needs.

What people with disability, policymakers, advocates, services and others need to know about this project

- Co-design is essential to disability research. This project was created together with people with disability, families and advocates to make sure the research focuses on what matters most and produces findings that are meaningful, relevant and usable in practice and policy.
- We need better evidence. The NDIS rules mean that group-based models are still common, even though they might not be safe or promote choice and inclusion. This project looked at personalised approaches, specifically the service-for-one model, and how a person experiences safety, choice, community participation, and quality of life. We hope that this evidence will help government make decisions about how to spend their money.

Authorisation and endorsement

This Project Executive Summary has been reviewed and authorised by: Dr Tess Bright, Chief Investigator; Dariane McLean, Partner Organisation Lead; Bella White, Co-researcher representative; Luke Nelson, Co-researcher, Partner Organisation; Brooke Canham, Co-researcher, Partner Organisation.

Disclaimer

This Project Executive Summary represents the views of the project team and does not necessarily reflect the views of the National Disability Research Partnership (NDRP) or the Australian Government.

Acknowledgement of funding

This activity received grant funding from the Australian Government as an initiative under Australia's Disability Strategy 2021–2031, delivered through the National Disability Research Partnership (NDRP).



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