

## Commonwealth Government COVID-19 Response Inquiry

Inclusive Health Communication in Disability Accommodation (Anderson et al.)

### Inclusive Health Communication in Disability Accommodation

The following submission presents the outcomes of research into the way information about COVID-19 and other infectious disease is communicated in disability group homes.

This research was led by [REDACTED]<sup>2</sup> from 2021-2023. The research team included [REDACTED]

[REDACTED] This work was conducted in partnership with Able Australia, Northcott, Inclusion Melbourne, Agosci Inc., and independent consultants from across Australia.

This work was funded with by the MRFF Coronavirus Research Response Communication Strategies & Approaches During Outbreaks Grant Opportunity, and supplemented by the Institute for Health Transformation at Deakin University.

This submission is relevant to the following Terms of Reference for this Inquiry:

1. **Mechanisms to better target future responses to the needs of particular populations.** In this case, the population is people with intellectual disability or complex communication needs, living in disability group home accommodation.
2. **Key health response measures** – in this case, public health messaging.
3. **Governance** including the role of the Commonwealth Government, state and territory governments and other government agencies, is also addressed.

#### Context

When COVID-19 was first detected in Australia, disability group homes worked hard to protect their residents and staff from infection. Having access to health information is an important part of staying safe. We knew that some people living and working in group homes were having difficulty accessing accurate and relevant information, making decisions about their own health, and expressing their concerns. This was especially true for people with complex communication needs, including residents with severe or profound intellectual disability, people who were deafblind, and people who used alternative or augmentative communication modes other than speech. Our research aimed to: 1) evaluate how well current COVID-19 communication was working for these populations; 2) identify what information was important for them to understand and express; 3) learn about any communication supports or strategies that were working well; and 4) create some guidelines that could inform policies or resources for future outbreaks.

Our research project involved several small studies including: a systematic literature review; interviews with group home residents (6), support workers (10) and group home managers (2), guided tours of two group homes, and a Delphi study with experienced group home staff. Each stage of our research was guided by advisory partners in industry and advocacy.

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### Findings and Recommendations

The COVID-19 pandemic has had a significant impact on the wellbeing of people living in disability group homes due to restricted access to work, leisure, family, friends, and communication supports. Residents and staff have navigated complex tensions between personal autonomy, collective responsibility, and duty of care regarding infection control. Our research showed that group home residents have been living in an “information soup” of COVID-19 policy and procedure documents, informal discussion with friends, family and staff, and exposure to news media. This information has not always been accessible or consistent.

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*We got most information through the news and we basically heard it from the media. – Resident*

*We put the poster inside the house everywhere. How to wash your hands properly, how to keep the social distancing ... how to correctly wear masks. This all the information from the organisation. – Support Worker*

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Here are four important recommendations for inclusive health communication approaches resulting from this project:

**Autonomy in information access:** In line with the United Nations Convention on the Rights of Persons with Disability, group home residents should have autonomy in how they access, display, and act on health information relating to infectious disease. Supported decision-making techniques can enable autonomy in health discussions and decisions: for more information see My Rights: Supported Decision Making.

**Accessible and individualised information supports:** Accessible health information formats should be available to group home residents with intellectual disability, including simple and familiar language, videos (which include sign language or key word sign), picture-supported text, repetition, and practical demonstrations of health protection measures. Individualised supports are valuable, but they are not always feasible under current group home conditions. Inclusive communication requires time, expertise, staff commitment, tailored information resources and interpersonal rapport.

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*One of the clients, she's an artist, so she'll say, 'COVID bad.' That sort of thing. And she'll on occasion, she'll paint images of staff wearing masks, that's her way of expressing herself. – Support Worker*

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During the COVID-19 pandemic, staff absence and visitor restrictions reduced access to familiar communication partners for people living in group homes. Proactive strategies such as personal communication dictionaries can be useful in helping new or casual support workers to communicate with residents who have complex communication needs about a range of topics, including health.

**Attention to informal knowledge sharing:** In addition to official information from the organisation or the Government, informal information about COVID-19 was also shared in group homes. Informal ways of sharing health information included: a) staff sharing personal opinions with residents and colleagues, and b) residents sharing their personal opinions with staff, other residents, family, and broader community members. Sometimes, this information and advice was different to official

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health information from the Government. Hearing different information about COVID was confusing for some staff and residents, because they did not know which information to trust.

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*One of the clients doesn't - he doesn't want to have injection. Instead of actually asking us [for information], he is actually telling us why we shouldn't have it – Support Worker*

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Further research is required to understand the drivers of this information sharing, and how informal communication might be leveraged to enhance health literacy in the future.

Comprehensive and collaborative change management

Improved health communication during future outbreaks is likely to require increased resourcing, targeted professional development, mandatory policies and protocols, and the recruitment or assignment of skilled staff. Co-designing solutions in a way that represents *all* affected residents and staff will be essential.

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*People are just given rules, without being included in making those rules – Manager*

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To be effective, change management around health communication in group homes must account for the intersectional impacts of stigma, cultural diversity, gatekeeping, risk perception and compliance pressures. Each disability group home is unique, so policies and protocols must be tailored to the needs of each house and its residents. Managers and leaders in the sector told us that initial policies for COVID-19 management had been a poor fit for the group home context: protocols for nursing homes and hospitals were too clinical and strict, while recommendations for domestic settings did not account for increased medical vulnerability, duty of care, or tensions between collective and individual rights of residents in the home.

### Suggestions for future pandemics

Disability group homes offer potential as important hubs for broader community health promotion. Some residents we spoke to were keen to play an active role in public health, such as helping their housemates, staff, family, friends, community members, or other people with disability to understand or cope with a disease outbreak. Peer-to-peer models of health education have been shown to be effective for people with intellectual and developmental disability; applications of this approach in group home communities during infection outbreaks warrants further support.

Some group home staff and residents told us they felt unheard by decision-makers. Some residents wanted an easier way to tell the Government what needed to change. For guidance on future consultation with people who have intellectual disability, we recommend this resource from Inclusion Australia: [A-Guide-to-Planning-Inclusive-Consultations.pdf \(inclusionaustralia.org.au\)](#). Be aware that it can be difficult to directly access group home staff and residents during an outbreak. Partnering with trusted staff members within disability organisations helped immensely.

For further information about this project please contact project lead Dr Kate Anderson

██████████ A complete report has been submitted as supporting evidence, along with a handout on best practice recommendations for communicating about infectious disease in group homes. A plain language video can also be viewed on our project website: [Inclusive Health Communication for SDA – Inclusive Health Research \(deakin.edu.au\)](#).