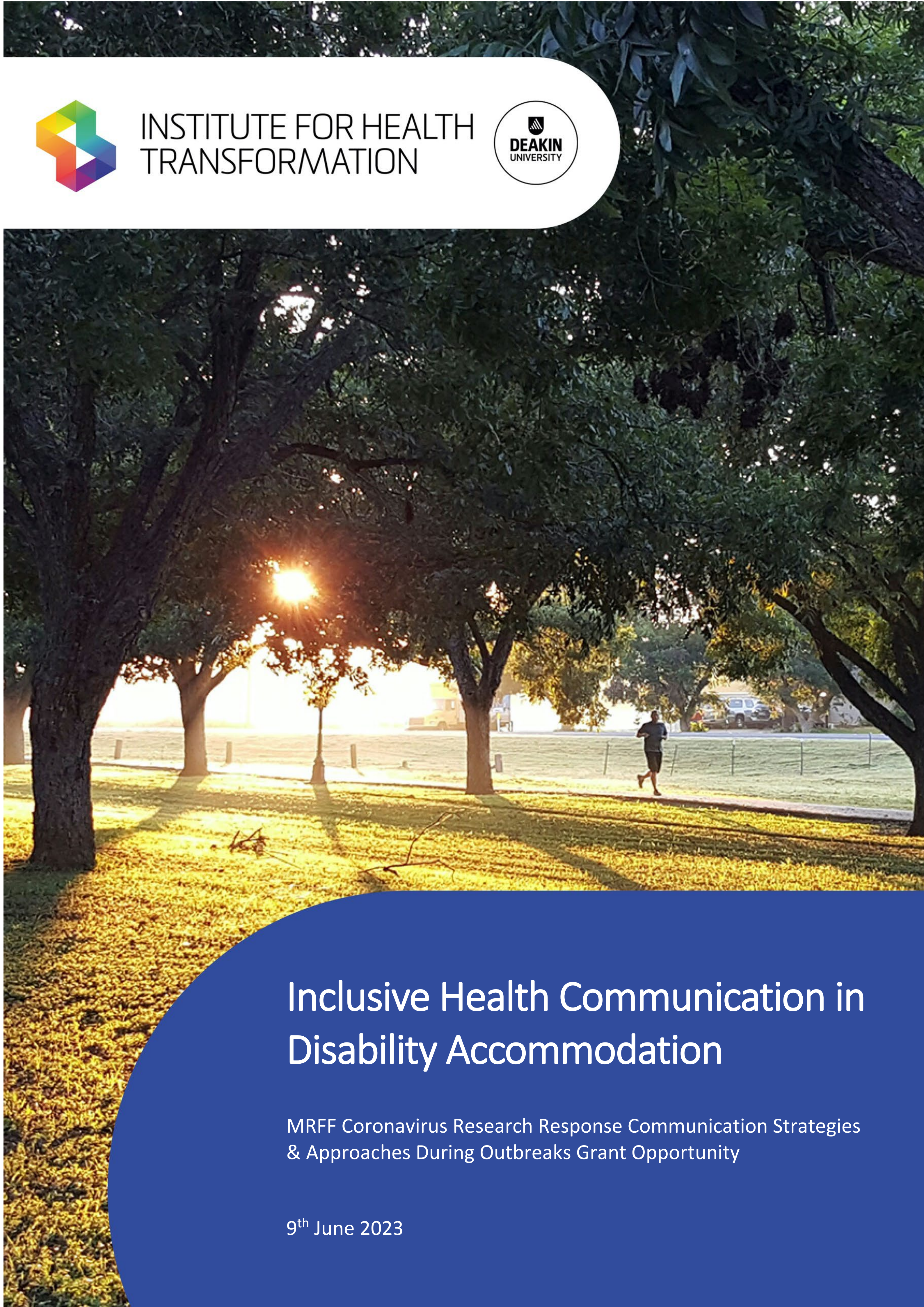

INSTITUTE FOR HEALTH TRANSFORMATION

DEAKIN UNIVERSITY

Inclusive Health Communication in Disability Accommodation

MRFF Coronavirus Research Response Communication Strategies & Approaches During Outbreaks Grant Opportunity

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Inclusive Health Communication in Disability Accommodation

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Project Partners

- Able Australia
- Northcott
- Inclusion Melbourne Inc.
- Agosci Inc.

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Contents

Executive Summary

During the current COVID-19 pandemic, disability group homes have 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.

We applied to the MRFF: Coronavirus Research Response Communication Strategies & Approaches During Outbreaks grant scheme to investigate the health communication needs of disability group home residents, their supporters, and their providers. We wanted to:

- evaluate how well current COVID-19 communication was working for these populations;
- identify what information was important for them to understand and express;
- learn about any communication supports or strategies that were working well; and
- create some guidelines that could inform policies or resources for future outbreaks.

We have worked together as a large research team, including researchers from four universities, advisory partners from Able Australia, Northcott, Inclusion Melbourne, Agosci Inc., and independent consultants from across Australia.

The following report presents the outcomes of our two-year program of research. We expect further work and resources to emerge from this project throughout 2023.

What we did

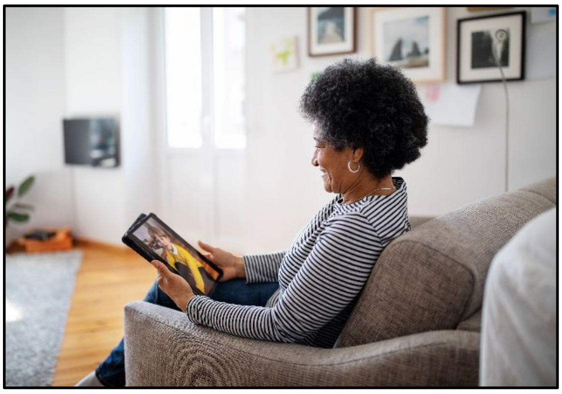
Our research project involved several small studies. Each stage of our research has been guided by advisory partners in industry and advocacy.

Scoping existing knowledge and practice

First, we gathered academic literature, including original research, reviews, and case studies. We also examined policies about COVID-19 in disability services from Australian institutions, State and Federal Governments, and international organisations, including the World Health Organization. This helped us to understand the current practice landscape and identify potential gaps in evidence.

Exploratory Research

Building on what we had learned from the reviews, we interviewed support workers and group home residents with intellectual disability about their experiences of COVID-19 communication and information. We listened to their suggestions for better practice.



To capture what it had been like to live in a COVID-Safe group home, we produced detailed video tours of two group homes, to help us to understand how communication and activities had changed in response to COVID-19 information, risks and policy.

Forming a Consensus

Based on what we learned from our exploratory research, we created some draft practice recommendations. We used a Delphi approach to assess experts' agreement with each recommendation.

> *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.*
>
> *-Support Worker*

What we found

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, and news media. This information has not always been accessible or consistent. Here are four important recommendations for inclusive health communication approaches resulting from this project:

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

Autonomy in information access: In line with the United Nations Convention on the Rights of Persons with Disability[1], 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 this.

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 critical, but they are not always feasible under current group home conditions. Inclusive communication requires time, expertise, staff commitment, tailored information resources and interpersonal rapport.

> *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, I guess.*
>
> *-Support Worker*

Attention to informal knowledge sharing: Some group home communities value and prioritise the informal sharing of information and knowledge, beyond official communication from the organisation or Government. This may include staff sharing personal opinions with residents and each other, and residents sharing their views with staff, other residents, family, and broader community members. Sometimes, this information and advice was different to official health information from the Government. 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.

> *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*

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 changes to staff recruitment or assignment. Co-designing solutions with *all* affected residents and staff is essential. To be effective, change management must account for the intersectional impacts of stigma, cultural diversity, gatekeeping, risk perception and compliance pressures.

Knowledge Translation

Knowledge Translation is the final step of our research and is ongoing. Our team has shared our research findings throughout the project by:

- working in close partnership with disability services and advocacy representatives;
- consulting with Government working parties and COVID-19 task force members;
- convening a free symposium on inclusive health communication; and
- creating and sharing a project website which includes information about inclusive health communication and inclusive research methods.

Working with project advisors from a range of sectors is also helping us to determine:

- the best way of sharing practice recommendations with group home residents and providers;
- how our findings might be used in other healthcare settings, such as hospitals, aged-care facilities and general practice; and
- what format the information should be shared in – for example, text, images, videos, websites, or other types of resources.

We plan to share this work as widely as possible, and we will keep updating our resources as new information becomes available. We will also learn how effective the recommendations and resources are when they are used for future infection outbreaks.

Project Background and Aims

People with intellectual disability make up around 2.9% of Australia's population[2]. Intellectual disability is a developmental condition characterised by significant limitations in both intelligence (general mental capacity) and adaptive behaviour (such as communication, planning, social problem solving, and the management of personal care, personal safety, and occupation)[3]. Intellectual disability is diverse in its expression. With support, some people with intellectual disability can live on their own in the general community. Others with severe or profound disability may be reliant on extensive, around-the-clock care. Many people with intellectual disability have chronic health conditions making them additionally susceptible to infectious disease[4].

Communication access and health equity

Intellectual disability is associated with several risks for health equity[5], and communication access is a major factor. Many people with intellectual disability have difficulty in using and understanding spoken language. Without appropriate communication support, this may leave individuals unable to express health concerns, seek and understand health information, or participate in informed decision-making about their health. Difficulties with reading and writing are also common, causing significant barriers to health literacy when information is in a written form[5]. People with greater degrees of intellectual disability rely on familiar communication partners to interpret their non-verbal communication (e.g., gestures, body language, facial expressions, or sounds), creating additional complexity and power considerations during health interactions[6]. Finally, close physical contact and touch is often critical to communication, particularly for those with profound intellectual disability, deafblindness or other sensory impairment. These complex factors place people with intellectual disability at significant risk of lowered health literacy and poorer health outcomes at any time[5], and at heightened risk during disease outbreaks when access to familiar communication partners may be restricted.

Infection risk in the group home environment

Australian disability accommodation services are rapidly growing and diversifying. As of December 31, 2022, there were over 22,000 NDIS participants with Supported Disability Accommodation (SDA) services included in their support plan, and close to 30,000 receiving some support for independent living.

Disability group homes are a type of accommodation service used by some people with intellectual disability. Group home residents are at higher risk of infection, morbidity, and mortality during disease outbreaks due to their congregate living environment, medical and socio-economic vulnerabilities, increased care needs requiring close personal contact, and large numbers of staff and visitors entering their home[7, 8]. Additionally, the personalisation process supported via NDIS has resulted in a diverse casual workforce that are not unified in the training they are required to undertake, including infection control[9]. Care staff may work across multiple homes, increasing the risk of further transmission of infectious diseases such as COVID-19[10].

Despite their increased risk factors, group home residents with intellectual disability cannot be isolated from their communities indefinitely. The World Health Organization (WHO) recognises that long-term quarantine can induce significant stress, anxiety or agitation, particularly for people with cognitive disability who may not understand infection prevention and control measures[11]. WHO also note that measures such as quarantine should not discriminate on the basis of disability, and "human rights protection mechanisms for people with disability placed in institutional settings should not be reduced as part of emergency measures"[12]. During an infection outbreak, group home residents encounter radical changes to their routines, care and community access. Of particular concern is the United Nations' report that the COVID-19 pandemic is "deepening pre-existing inequalities" for people with disabilities[13]. As for other citizens, people with intellectual disability should be reassured and informed about their rights and responsibilities through equal access to public health information.

Access to information is an internationally recognised right, codified in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)[14]. Article 21 of the Convention unequivocally requires States Parties to provide "information intended for the general public to persons with disabilities in accessible formats and technologies…"[14], while Article 11 similarly establishes that parties take "all possible measures to ensure the protection and safety of persons with disabilities in the national response to situations of risk and humanitarian emergencies"[14]. Over the course of the COVID-19 pandemic, reports of significant human rights violations for people with intellectual disability have amassed, including restricted access to communication systems, familiar communication partners, or equitable healthcare, as a direct result of COVID-19 response policies in hospitals and SDA facilities[13]. For example, in the United States, Luckasson and Schalock observed a trend for disability support organisations to "completely shift their emphasis to safety, security and financial sustainability"[15], neglecting their obligation to provide communication supports to enable residents with intellectual disability to participate in decisions about their own health and well-being in relation to the pandemic. Similar concerns were raised by the NDIS Quality and Safeguards Commission in 2020, regarding some Australian SDA services[16]. Alignment with public health guidelines by group home residents, staff and supporters is imperative in ensuring continued health and successful community inclusion for this population during and following, an infectious disease outbreak.

Rationale for the Proposed Study

It is critical that people with intellectual disability and their supporters (including paid support workers, friends, and family) can engage with public health guidelines in a meaningful and informed way. At the start of this project, our preliminary work with advocacy partners and service providers identified several potential vulnerabilities in the way COVID-19 information was being shared with group home residents. Advocacy partners raised concerns that residents had limited means to provide direct feedback on the Government's pandemic response or the personal impacts they were experiencing. They also noted that the onus of responsibility for accurate interpretation and relay of public health information in group homes seemed to be falling to carers and/or supporters as intermediaries. These concerns were mirrored in other academic commentaries at the time[17].

Communication partners can be valuable in helping people with intellectual disability to engage with health information, but they must be adequately supported in this role. An earlier review conducted by CI Anderson[18] noted that communication access strategies for people with intellectual disability are not always intuitive, with many requiring "...conscious effort and training for partners to master". For example, although easy-read pamphlets, posters and other general resources were rapidly proliferating at this time, evidence indicates that this type of adapted health information "...has a better chance of making an impact when it is tailored to an individual's individual requirements for information and communicative support"[19]. Our team wanted to know what additional insights and practices were being gathered in the provision of communication support to group home residents, amidst the challenging conditions of a global pandemic.

At the start of this project, little was known about the way that disability accommodation residents, providers, and supporters were accessing or sharing information about COVID-19, or what role Government materials had played in this process. Insight from providers and consumers[20] was the key to developing impactful inclusive communication strategies for the current outbreak, and any that follow.

Project Aims

The current project was directed towards three overarching aims:

- **Project Aim 1:** To identify the main communication priorities for disability group home residents with intellectual disability and their supporters during a disease outbreak.
- **Project Aim 2:** To ascertain current engagement with government communication about COVID-19 by key stakeholders within disability group home settings.
- **Project Aim 3:** To develop a comprehensive and scalable strategy for effective communication with disability group home residents with intellectual disability, during pandemics and other major public health and safety events.

Methodology

Our study design drew on a Participatory Action Research (PAR) approach. PAR is defined by its commitment to practical impact (action) and empowerment (participation), and inclusivity of people with lived experience, such as service users and providers, who engage actively at each stage of the research process. PAR is typically categorised by iterative cycles of data collection, reflection, and action[21]. Our project was co-led with researchers from Able Australia. Project advisors (e.g., disability organisation CEOs, managers, support workers and relevant Government agencies and taskforces) were involved in the research planning, data analysis and information sharing throughout the project. Unfortunately, we were unable to recruit any group home residents with intellectual disability to the Advisory Group, but their input during the Phase 2 interviews heavily informed the later project phases.

We used a range of inclusive qualitative, observational and consensus methods to ensure the widest range of perspectives could be represented in the final research. Iterative joint analysis with industry partners and the broader project team ensured that insights from the project could be shared with stakeholders as they emerged.

The project incorporated multiple, concurrent study arms addressing the major aims of the research:

- **Systematic Review:** a review of empirical evidence relating to the engagement of people with intellectual disability in public health and health promotion interventions for infectious disease. This contributed to project Aims 1 and 3.
- **Policy Analysis:** a snapshot review of international, national, local, and organisational policies for COVID-19 management pertaining to people with disability or disability accommodation services. This contributed to project Aim 2.
- **Interviews:** sensitising interviews with residents and SDA support workers to establish current practice concerns. This contributed to project Aims 1 and 2.
- **Observational Case Studies:** observational case studies of SDA facilities, examining resident and support worker engagement with COVID-19 public health information, and the communication strategies used to relay this information to residents. This contributed to project Aim 2.
- **Consensus Forming:** a modified e-Delphi survey to establish a consensus around key communication priorities and recommended practices. This contributed to Aim 3.
- **Knowledge Translation:** discussions with expert consultants to inform an initial implementation strategy for the project recommendations, and to identify future research and practice directions. The multidisciplinary and multi-sector members of this arm also advised on potential scaling-up of project outcomes beyond the disability accommodation sector to adjacent areas (e.g., disability day programs, psychosocial disability services). This phase contributed to project Aim 3.

Figure 1 (below) illustrates the iterative relationship between the research activities. It also demonstrates points of input from our industry partners and project advisors.

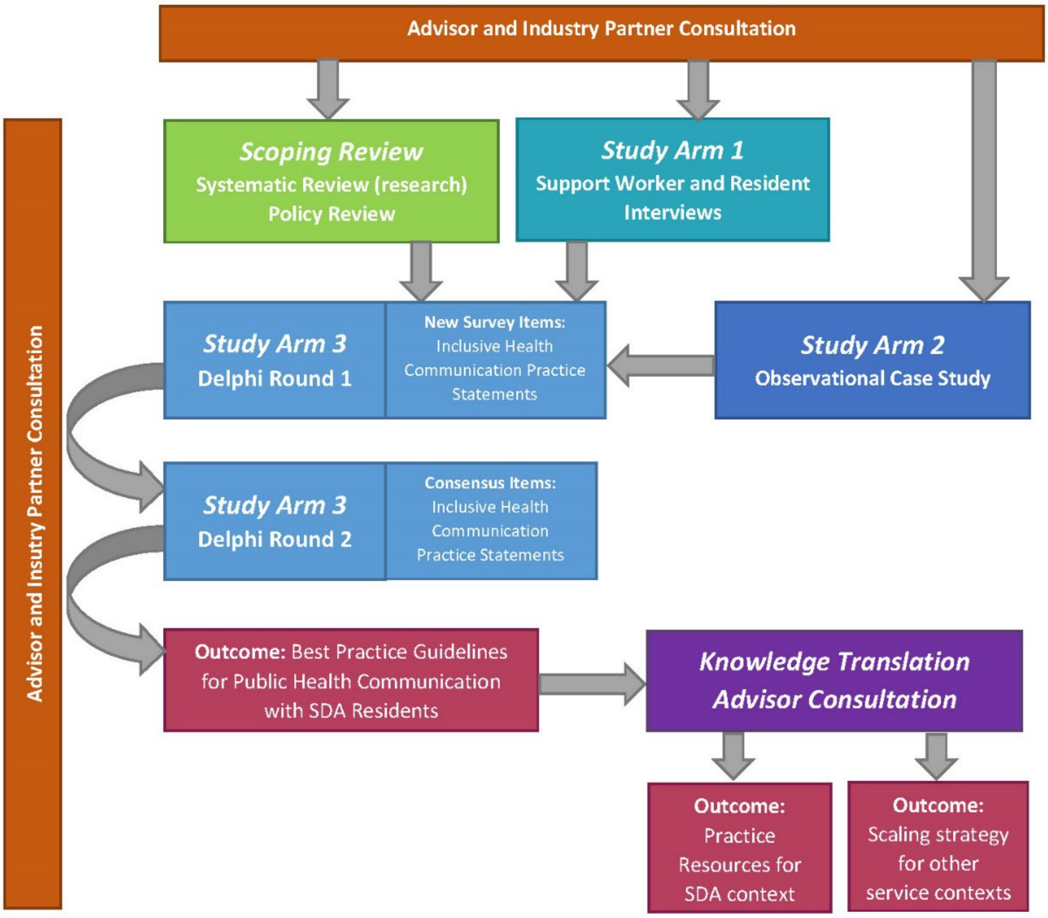


Figure 1: Project structure and relationship between our research components.

Reviewing the Research Literature

The aim of our literature review was to identify and synthesise existing research evidence on the involvement of people with intellectual disability or complex communication needs in public health responses for the prevention and control of disease outbreaks. This review phase established some a-priori themes for our exploratory study arms and contributed to the later development of evidence-based practice principles. To optimise the generalisability of findings to any future outbreaks, we elected to examine historical and contemporary literature on the engagement of people with intellectual disability in public health and health promotion responses to any communicable disease. We adopted a systematic scoping review approach, guided by Arksey and O'Malley's framework[22] and using modifications by Levac et al.[23] to undertake this investigation.

Review Question

The systematic review addressed the following research question: What evidence is available regarding the engagement of people with intellectual disability with infection prevention and control procedures, guidelines, and information?

Inclusion and exclusion criteria

The review included papers of any age, published up to November 2021, that were:

1. reporting primary (original) research data or organisational case studies;
2. published in English;
3. full length articles in peer-reviewed journals or conference proceedings;
4. focused on people with intellectual disability aged 12 years of age or older; and
5. focused on infection prevention and control procedures (e.g., concerning detection, prophylaxis, suppression, transmission), guidelines and/or information, relating to communicable (infectious) disease.

The review excluded papers:

1. with a primary focus on overall health status, individual treatment protocols or efficacy, disease burden or infection prevalence;
2. that did not offer sufficient insight into the involvement of people with intellectual disability in health communication or public health;
3. that only addressed infectious disease as a minor component of a broader treatment or training protocol (e.g., genital hygiene, sexual rights); or
4. where, in studies with mixed populations, where findings relating to people with intellectual disability over 12 years of age could not be separated from other findings.

Search and Selection Processes

Searches of peer-reviewed literature were conducted in the following databases: Medline Complete, Cumulative Index to Nursing and Allied Health Literature (CINAHL) Complete, and Global Health via EBSCO and EMBASE. Keywords relating to intellectual disability, communicable disease, and health communication were searched separately and then combined.

Results from each search were de-duplicated in Endnote[24] (version X9) before being exported to Covidence[25], an online systematic review manager. Double-blind screening of all results (n=1851) was undertaken by two reviewers, and a third reviewer resolved any conflicting decisions. Borderline papers were discussed as a team until consensus was reached. Results were initially screened according to their title and abstract, with potentially relevant papers screened as full texts. The reference lists and citing publications of included papers (n=20) were also screened, identifying a further four eligible publications. Demographic and quantitative data were extracted from each included study by at least two reviewers in Covidence using a custom template. Conflicts were reviewed and resolved by a third reviewer.

Descriptive analysis was used to synthesise and interpret any quantitative data obtained from the included studies[22, 23]. Findings of qualitative studies underwent thematic synthesis[26]. Finally, both sets of results were collated into major themes relating to engagement and inclusive practice. A quality assessment of included papers was also undertaken. The full search and review protocol is available by request, with a review publication pending.

Findings

A total of 24 studies published between 1994 and 2021 were ultimately included in the review, some comprising multiple separate studies in a single paper. Seven articles reported on the outcomes of health promotion or training interventions concerning communicable disease, that involved people with disability as direct participants or learners[27-33]. Four articles evaluated the accessibility or usability of training about infectious disease[28, 29, 34, 35]. A further five articles reported on the process or outcomes of public health responses to communicable disease, that directly targeted or involved people with intellectual disability[33, 36-39]. Finally, 12 articles presented qualitative investigations into the public health or health promotion experiences of people with intellectual disability relating to infectious disease; six presenting the direct perspective of people with intellectual disability[40-45], and six presenting the perspectives of supporting professionals, advocates, or family[34, 46-50]. Most of the included studies were focused on the prevention and management of HIV/AIDS, Hepatitis B, or other sexually transmitted infections[28-32, 34, 35, 39, 41, 44, 45, 47-51], a public health concern that has had significant and sustained attention in the field of intellectual disability research and practice. Other studies addressed COVID-19[27, 36-38, 40, 43, 46], Helicobacter Pylori (H-Pylori)[52], and general hygiene for infection prevention[33].

Impacts of infection outbreaks for people with intellectual disability

The reviewed research indicated that during an infection outbreak, people with intellectual disability can experience significant disadvantages for health and wellbeing[40, 43, 46, 52]. As a result of institutional or local public health restrictions, people with intellectual disability may be unable to access work, recreation, or disability and healthcare services during a health outbreak[40, 43]. They may also be restricted in their access to fellow residents, family, or friends[37, 40, 43]. However, some changes resulting from lockdowns (e.g., increased stability of daily routines when isolating at home) had benefits for some[46].

Studies about COVID-19 suggested that many adults with intellectual disability were aware of and concerned about the risks of infection[40, 43]. Interviewees with intellectual disability reported taking precautionary measures including strict social distancing, which often resulted in significant sacrifice of employment, social and recreational participation[43].

What affects the way that people with intellectual disability understand infectious disease?

In studies about COVID-19, comprehension of risk prevention strategies by people with intellectual disability was variable, with some research participants reporting confusion with fluctuating advice and government directives[43], and others reporting satisfaction with the accessible information that was available[40]. This finding highlights the potential impact of inclusive communication practice in outbreak situations.

In studies relating to sexually transmitted diseases, the knowledge and awareness of people with intellectual disability about risk of infection was also variable, and influenced by:

- their exposure to relevant information at home or school[45, 49, 50];
- the stigma around certain types of infection (e.g., sexually transmitted infection)[41, 45, 49, 50];
- restricted funding for accessible health literacy programs[34]; and
- the views of their family and supporting professionals regarding their personal risk[34, 45, 47, 49, 50]. For example, supporters may overestimate the risk of people with an intellectual disability catching a sexually transmitted infection (due to assumptions around promiscuity or vulnerability), or underestimate it (by assuming that this population have no sexual desire, capability or potential)[49, 50].

In reality, the risks of infection are strongly associated with individual and contextual factors[39, 41, 47, 49]. Misperception of risk, and the presence of stigma, can significantly affect the educational opportunities and subsequent health literacy for people with intellectual disability concerning infection[34, 47-49]. Many of the included studies called for tailored and timely education programs that balanced the need for people with intellectual disability to understand infection risks, with their right to take risks and participate in life[34, 45, 49, 50].

How are infections typically managed in disability accommodation?

The following approaches were commonly reported for infection control in residential or clinical care settings for people with intellectual disability[36-38]:

- environmental measures (e.g., touch-point and deep cleaning and use of personal protective equipment);
- testing of symptomatic clients and staff;
- contact tracing;
- positive case isolation;
- staff training;
- resident training; and
- site visitor management.

One study also reported attempting to implement social distancing between clients, but clients' behaviour, care requirements, and the complexities of a shared living environment had made this measure unfeasible[37]. Treatments were not discussed in relation to COVID-19, but inconsistent efficacy was reported for pharmaceutical treatment of widespread H-Pylori infection[52] in a residential environment.

How do infection control interventions typically engage people with intellectual disability?

Engagement of people with intellectual disability in public health and health promotion interventions was typically one-way, with individuals positioned as the subjects of training, testing and reporting, quarantine and social distancing, or treatment. All but one study[36] described health interventions that were developed and implemented by medical professionals, raising concerns for the health autonomy and informed consent of individuals with intellectual disability. Concerningly, many of the intervention studies did not report any processes for obtaining informed consent from people with intellectual disability as the recipients of intervention or training, and one case study of HIV testing in a man with intellectual disability described significant violations of privacy and informed consent[39].

How do people with intellectual disability learn about infectious disease?

Studies reported that people with disability accessed a range of information sources relating to infectious disease, including school[45, 50], government resources[40, 43], television and radio[44, 45, 50] and social media[36].

We found a lot of studies that had trained people with intellectual disability to avoid getting sick or passing an infection on to others[27-33], by using safe sex practices, hand washing, mask wearing, and good personal hygiene. Overall, people with intellectual disability who did the training programs learned about infection and/or how to stay safe[27-33]. People with intellectual disability found training and information difficult when it included complex words, or things they were not familiar with[40, 41, 43]. We did not, however, find any training studies primarily designed to help people with intellectual disability take charge of their own testing, vaccination, or treatment of infectious disease.

People with severe or profound intellectual disability were not typically included in the training or evaluation studies. The single study that did so[27] chose an individualised behaviour support approach over group training for this population, with 80% of participants reaching target goals for mask wearing by the end of the program.

Most of the training programs were written by health professionals. Occasionally, people with disability or their supporters had been involved in designing or reviewing a training program or information resource[28, 29, 34, 35, 41]. Long resources, and those containing lots of text or complex language, created barriers to understanding[34, 41]. Accordingly, participants recommended the use of clear language (spoken or written), video, simplified, picture supported text and relatable cases or scenarios to demonstrate concepts[28, 29, 34, 35, 41]. These recommendations were mirrored studies that explored participants' own experiences with infectious disease services in the community[44, 45].

How do people with intellectual disability and their supporters experience infectious disease services or communication about this topic?

Some research explored the experiences that people with intellectual disability had had with infection education, prevention, and control in the community[40-45]. Participants shared stories of dissatisfaction with public health services, resulting from a lack of collaboration or crossover in expertise between disability and mainstream health services[34], inaccessible information[34, 41, 43, 44, 49], cost and travel barriers[34], the compounding effect of low health literacy or restricted health education[41], and negative attitudes of service providers[34, 49]. The reviewed research showed that inclusion in the context of infectious disease management involves:

- direct and respectful interactions with the person who has intellectual disability[34, 44];
- support for a person with intellectual disability to give informed consent[39, 44];
- the option to keep health information and interactions private from supporters[41, 44, 45, 49];
- simple and accessible communication and information resources[28, 29, 34, 35, 41, 43, 49] ;
- convenient and accessible healthcare facilities (e.g., for vaccination and testing)[34, 41], such as local outreach and at-home options for testing, vaccination, or consultation;
- culturally sensitive practice[45, 49];
- linking services with culturally familiar or trusted facilities[34, 45]; and/or
- peer mentoring and representative leadership[49].

What role can supporters play?

Although supporters can play an important role in relaying health information to people with intellectual disability and facilitating their access to vital public health interventions[45, 46, 48], they do not always have the capacity to undertake these roles[34, 39, 45, 47, 48]. Strategies to improve this situation included:

- clarifying the role professional disciplines should play in infectious disease health literacy for people with disability[48];
- appointing specialist supporters to champion inclusive health literacy within services[34]; and
- building capability for professionals and supporters to facilitate accessible, culturally sensitive and empowering interactions about this topic[34, 46-48, 50].

Applying this Knowledge

As seen with other areas of preventative medicine[20], direct and collaborative engagement of people with intellectual disability in infection prevention and control contributes to better health outcomes by informing the quality improvement of services, and through increased individual understanding and self-efficacy. This review illuminated many tensions between the rights of people with intellectual disability to inclusive health communication, and the realities of real-world practice in the disability and healthcare sectors. These included:

- complex rights around personal autonomy, collective responsibility, and duty of care, in the case of infection control within disability services;

- the extent to which people with intellectual disability could be reasonably involved in health planning and health communication during infection outbreaks, and how this could be facilitated;
- the value of individualised health communication support versus the demand for feasible and scalable solutions;
- the intersectional impacts of stigma, gatekeeping, and institutional pressures on health communication and equity for people with intellectual disability; and/or
- the need to build capacity of supporters, in the absence of a clear evidence base for approaching this[53].

These identified tensions set the scene for the exploratory phases of our research.

Reviewing Policies and Guidelines

Early discussions with our project advisors alerted us to the important influence of policy and procedure on health communication in group homes. Between 2020 and 2021, policies relating to COVID-19 management were emerging and rapidly changing. Advisors told us that guiding policies had been difficult to source and were not always suitable for group home settings. Local organisations had undertaken significant work to develop and disseminate their own tailored policies during this time. Based on these insights, we undertook a systematic policy mapping exercise, to better understand the policy and procedure landscape and its possible influence on inclusive health communication practice.

Method

We conducted the initial searches via incognito searches in Google, using the following keywords:

1. "disability accommodation" AND "COVID-19"
2. "disability group home" AND "COVID-19"
3. "disability service" AND "COVID-19"

We used a customised date range to search for each keyword combination one month at a time, from Feb-Aug 2020. This entailed a total of 24 separate searches. For each search, a member of the research team screened the first 100 results for any policies/guidelines/position statements with relevance to the Australian SDA sector (i.e., Australia-specific policies/guidelines etc., or international level documents that were likely to be directly influencing Australian practice). We organised all included documents into the following categories:

- international policy (e.g., from influential organisations such as the World Health Organization or US Centers for Disease Control).
- international practice guidelines
- national policy (e.g., from Federal Government departments)
- national practice guidelines (e.g., from national peak bodies)
- state-based policy, practice guidelines or announcements
- local or organisation-level policy and practice guidelines from disability organisations or local health providers.

Additional sources of material included the public record of parliamentary announcements[54], an updated timeline of Australian pandemic-related policies[55], and a large selection of documents sourced and provided by our organisational partners at Able Australia and Northcott. We also conducted a separate Google search using the 'News' filter, collating up to three relevant mainstream news artefacts for each month of the timeline, as indicative examples of how policy and practice in disability accommodation were being reported at the time in mainstream and other media. A member of the research team undertook a content analysis of each document, summarising relevant implications for Australian disability accommodation services and including a hyperlink to the original source material.

Findings

The content analysis helped us to identify gaps in COVID-19 policy and official advice in the first year of the pandemic, specific to disability group homes. Disability accommodation and related concepts were rarely mentioned in Government announcements or policy. We often found references to 'high risk settings', but these were usually accompanied by discussion about aged care or hospitals rather than disability group homes or other congregate living facilities. The quantitative content analysis also provided an effective means to visualise the intensity of Government communication that was generated during the first year of the pandemic.

We found very few COVID-19 policies or guidelines that were a good fit for the unique needs of disability group homes. Group homes are not a clinical environment, so policies made for hospitals and nursing homes were too strict. They assumed that clients would be in separate rooms, and they did not account for the use of shared spaces. On the other hand, group homes sometimes house people with special health requirements, so recommendations for managing COVID-19 at home were also not a perfect fit. Higher-risk procedures such as close personal care, tracheostomy management and suctioning were not addressed in these guidelines. Mental health impacts and their management were also notably absent themes in most of the documents reviewed. Of the limited policies that addressed disability group homes specifically, common types included:

- government advice about lockdowns, outbreak management, infection prevention measures and social distancing rules, as applied to disability group homes and other high risk settings;
- information on support for carers of people with disability;
- submissions to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, relating to COVID-19 management;
- reports about the availability of Personal Protective Equipment (PPE); and
- Easy English or other accessible resources created for people with intellectual disability, e.g., CDC List of Plain English resources.

At the time of review (early 2021), we consulted with several senior managers and CEOs of disability accommodation services who echoed the gaps we had observed. These advisors told us they needed more Government policies that were specific to the group home setting. For example, they needed guidelines on how to manage PPE or high-risk medical procedures in a home environment. They also needed guidelines on keeping all residents and staff in each home safe without restricting the freedom of the individuals who lived there.

Month (2020)	National	ACT	NSW	NT	QLD	SA	TAS	VIC	WA
Feb	🟨 Royal Commission		🟩						
	🟨 Annual report								
March	🟧 Biosecurity emergency declared	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
	🟨 COVID-19 Support measures	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
	▨ NDIS Information Links	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
	🟦 DSC		🟩	🟩	🟩	🟩	🟩	🟩	🟩
	🟦 DoH - Disability workers safety measures				🟩	🟩	🟩	🟩	🟩
	🟦 DoH - Disability workers PPE					🟩	🟩	🟩	🟩
						🟩		🟩	🟩
						🟩		🟩	🟩
						🟩		🟩	🟩
									🟩
									🟩
									🟩
April	▨ Disability Royal Commission	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
	▨ Disability Royal Commission	🟩	🟩		🟩	🟩	🟩	🟩	🟩
		🟩	🟩		🟩	🟩	🟩	🟩	🟩
			🟩		🟩	🟩	🟩	🟩	🟩
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					🟩	🟩		🟩	
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						🟩			
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						🟩			
May	🟨 NDIS Guidelines	🟩	🟩	🟩	🟩	🟩	🟩	🟩	🟩
	🟦 Disability management guidelines	🟩	🟩	🟩		🟩	🟩	🟩	🟩
	🟧 Joint Standing Committee	🟩	🟩			🟩	🟩	🟩	🟩
	🟦 DoH - Primary Health Care Services Guidelines	🟩	🟩			🟩	🟩	🟩	🟩
	🟦 DoH - Infection Control training	🟩				🟩	🟩	🟩	🟩
	🟦 DoH - Information for Disability Support Workers						🟩	🟩	🟩
	▨ Disability Royal Commission						🟩		
June	🟨 NDIS - Vaccination Eligibility	🟩	🟩		🟩	🟩	🟩	🟩	🟩
	🟨 NDIS - Vaccination Eligibility				🟩	🟩	🟩	🟩	🟩
	🟨 NDIS - Provider guidelines				🟩	🟩	🟩	🟩	🟩
	🟦 DSS - Guidelines for people with disability						🟩	🟩	🟩
	▨ NDIS - Coronavirus response update								
July	▨ Disability Royal Commission	🟩	🟩	🟩		🟩		🟩	
	▨ DoH Covid Disability Risks Roundtable	🟩						🟩	
	🟨 NDIS - Face Masks for Support Workers								
	🟨 NDIS - Support Worker Information Pack								
August	▨ NDS - Victorian Disability Rapid Response Group		🟩		🟩	🟩		🟩	
	▨ NDS - Victorian Disability Rapid Response Group							🟩	
	▨ DoH - Disability Easy Read							🟩	
	▨ NDIS Commission COVID Factsheet								
	🟦 AHRC - COVID-19 Guidelines								
	▨ Disability Royal Commission								

Key:

🟩 Parliamentary Announcement or Guidelines	🟨 NDS/NDIS Announcement or Guidelines	🟧 Major Policy or Regulation	🟦 Practice Guideline/Position Statement	▨ Information Resource or Repository

Table 1: National and state Government publications identified in scoping search that mentioned disability accommodation and COVID-19 (February-August 2020).

Policy Evolution

Searches repeated in 2021 showed a marked increase in dedicated policies relating to disability group home settings, as well as adapted (e.g., easy read, video) information resources for people with intellectual disability addressing infection prevention and control, vaccinations, and testing. Project advisors told us that disability organisations had formed informal networks during 2020 to find and share relevant materials that had been sourced, to brainstorm common problems (e.g., shortages in staff and PPE availability), and to discuss internal policies or procedures that were being developed.

Policy and procedure were recurrent and complex themes through the exploratory phases of our research. Our interviews and observations indicated that official policy and procedure documents played a dominant role in health communication within group homes during the pandemic. Consultation with project advisors also identified how policy, when effectively designed and implemented, could be a powerful driver of change.

The 2020 policy analysis concluded our scoping phase of the research. Insights from this phase were used to contextualise the qualitative findings of our later research. The following section of this report addresses the exploratory components of the research that occurred between 2021 and 2022.

Exploring Communication During COVID-19

The exploratory components of the research involved interviewing group home staff and residents about their experiences with COVID-19 communication and information access (research arm 1) and visiting group homes to observe the communication environment (research arm 2). The findings from these two study arms have been integrated for the purposes of this report.

Arm 1: Interviews

In this arm of the study, we conducted "sensitising" interviews to gather some initial insights around group home communication priorities and practice concerns during the COVID-19 response, as well as behavioural and attitudinal drivers impacting engagement with COVID-19 information. This arm of the research addressed the following questions:

1. What are the information and communication support needs of people with intellectual disabilities who reside in SDA services during a disease outbreak?
2. What are the information needs of SDA service providers during a disease outbreak?
3. What has helped or hindered access to information by SDA service providers and residents, regarding COVID-19 specifically?
4. Have behaviours, routines and environments within SDA settings changed in response to COVID-19 information? If so, how and why?
5. How has communication changed in SDA settings as a result of the COVID-19 outbreak?

The research opportunity was advertised through primary contacts for disability accommodation providers across Australia.

Who participated?

Participants included 6 residents and 8 support workers from group homes in Victoria and NSW. Inclusion criteria for staff included:

- having worked as a disability support worker, carer or enrolled nurse at the same disability group home since the start of the COVID-19 pandemic (February 2020); and
- being able to understand and speak conversational English (a standard requirement for most support worker roles in Australia).

Inclusion criteria for residents included:

- living in a group home at the time of the interviews;
- being an 'independent communicator' (could converse independently using a range of supports, and understand most of what is said to them[56]. We offered interviews in spoken English, Auslan, tactile sign language or other forms of signed communication if preferred, and range of communication supports (e.g., pictures, drawing, gesture, and Talking Mats™ conversation tool) were available for residents to use if required.

Interview process

Interviews were conducted mid-late 2021. In line with health and safety protocols at Deakin University and the disability organisations, all interviews were conducted via videoconference or telephone. The interviews were recorded and transcribed prior to coding. All interviews were conducted in spoken English as per participant preference. Residents were interviewed by research team members experienced in working with people who have intellectual disability (CIs Watson, O'Shea, and Frawley).

All interviews were analysed thematically using Braun and Clarke's methodology[57]. During the analysis phase we shared preliminary findings with the research team and project advisors. These consisted of initial themes organised into a visual model, accompanied by illustrative quotes and examples. Group discussion of these initial findings helped to refine and contextualise the results and shaped the subsequent research arms (Delphi study consensus statements and knowledge translation questions).

Arm 2: Observational case studies

In this arm of the study, we observed two Victorian group homes where people with intellectual disability had lived during the COVID-19 pandemic. This study addressed the following research questions:

1. What COVID-19 information (if any) has been communicated to group home residents with intellectual disability?
2. What formats of COVID-19 communication (if any) are evident in group home facilities? (including verbal and non-verbal communication between individuals and/or the presence of communication artefacts)
3. Who are the intended recipients for each instance of COVID-19 communication observed in these SDA settings?
4. Have supporters adapted communication about COVID-19 for group home residents with intellectual disability, and if so, how?

These observations helped us to identify how group homes were currently engaging with COVID-19 public health information, and any specific communication strategies that were being used. Critically, these observations allowed us to witness and explore issues relevant to residents with more severe disability who were not independent communicators, whose views were not captured in the Arm 1 interviews. Observational research has been shown to have strong utility where individuals are unable to answer interviews or questionnaires about their experiences[58].

Who participated?

The research opportunity was advertised to group homes run by our two partner organisations across Australia. The inclusion criteria included:

- Residents include adults with intellectual disability.
- The group home does not accommodate any children or young people under the age of 18.

- At least one resident has severe-profound intellectual disability, deafblindness, and/or complex communication (e.g., uses an augmentative communication system such as a communication book, board, or electronic device).

Five group homes expressed an interest in participating in the research. Two Victorian group homes returned consent forms from all five residents, and these two homes were included in the study. The manager/staff of a third home declined to consent. For the two remaining houses, consent was withheld by a single resident (or their proxy supporter), resulting in the group home not being included. Although this resulted in a smaller sample size, we were pleased to see residents and supporters exercising informed and active decision-making about their participation as intended. For further reflection on the role of active and informed consent in this project, see Appendices B and C.

Both participating homes included people with severe-profound intellectual disability and complex communication/care needs (including at least one person with deafblindness). Both homes accommodated five residents of varying ages and disability types. To protect resident and staff privacy, detailed demographic characteristics are not reported.

Observation method

Observational "tours" of the home were conducted by a support worker or group home manager on a mobile device, while a member of the research team (located remotely for health safety), asked questions and prompted for additional information. The observational videos were gathered in accordance with the ethical and methodological guidelines outlined by Mansell[58]. For further information about the complex ethical and practical considerations for this arm of the project, see Appendix C.

Following the tours, we undertook a content analysis on the observational video footage, using a coding schema co-developed by the project team and advisors. The schema focused on the content, format, and intended audience of any COVID-19 communication artefacts that were detected in each home. However, both tours also provoked the generation of rich interview-style data from the staff members leading the tour, relating to resident and staff coping mechanisms, health considerations and incidents, the development of safety protocols, decision-making processes, and the communication environment. On reviewing these data, we decided to undertake a further thematic analysis of the dialogue recorded during the tours[57]. Initial findings from the observations were presented to the broader research team and advisors for collaborative analysis and confirmation.

Initially, we had also intended to undertake an analysis of resident case files and house minutes for each house, to compare patterns in social and health-related communication before and during the COVID-19 pandemic. However, this planned data collection was discontinued due to the following factors:

- The sourcing and de-identification of client data was likely to require significant internal staff resources, during a time period where disability services were already short-staffed and under increased administrative demand.

- Significant insights around organisational communication had already been gathered during the policy review.
- Knowledge translation findings suggested that specific detail about residents' interactions is often shared via informal staff communication and may not be documented.

What we found

We learned a lot from our interviews with group home residents and support workers, and our observations of group homes. Many of our findings to date are consistent with those reported in related international research.

The Context: Communication during COVID-19

One key theme concerned the profound impact of the pandemic on the lives of group home residents and staff. Reported impacts on residents included: a loss of control, routine, and quality of life; reduced social, economic and community participation; a decline in mental and physical health; and reduced access to health and other disability services. Negative impacts on residents' interpersonal relationships with friends, family, other residents, and staff were also reported.

"Most visits have been restricted. There has been very limited family interactions, especially during harder lockdowns. It's common that the clients here don't see their families."
– **Support Worker (interview)**

"We have seen an increase in arguments and sort of friendships that the clients maintained for years breaking down from so much exposure to one another I guess".
– **Support Worker (interview)**

Residents had been frustrated by lockdowns and wanted more information about the public health restrictions in place, particularly when they would be lifted or changed. These restrictions were extremely stressful for staff and residents, and a lack of relevant and accessible information for the group home context was noted. Coping mechanisms included humour, conflict management, anxiety reduction activities such as meditation, maintaining social and family connections using phone and video calls, and building a sense of teamwork and solidarity. Similar concerns and coping strategies have been observed and reported internationally since the start of the pandemic.

"You can't go shopping. ... I had to wait for the shops to open."
– **Resident (interview)**

"They were enjoying themselves before, we used to take them to the park and shopping and things like that. But now with all the restrictions, they are all missing out"
– **Support Worker (interview)**

"Trust me, I hated having to do it for so long but I knew I had to. ...I knew I had no choice".
– **Resident (interview)**

Resident 1: (double interview):
Yeah. [In the lockdown things just] changed because I saved money and stuff.
Resident 2 (double interview):
Yeah. Because we haven't gone out for... over months.

In 'visiting' two group homes via a video link, we were able to directly observe the impacts of COVID-19 on group home environments. As displayed in Figure 2, both households showed significant modification in response to health protection advice, for example:

- separation of living room and dining room furniture to promote social distancing;
- extensive coverage of walls and surfaces with printed health notices and policy documents;
- warning signs on the front door, alerting visitors to restrictions and precautions,
- large tables for visitor/staff sign-in, testing and PPE doffing/donning positioned at the front entrance of the house; and
- sanitising products (e.g., wipes) positioned in multiple locations throughout the house, for example wipes on the kitchen bench, and a hand sanitiser dispenser on the wall by the front door.

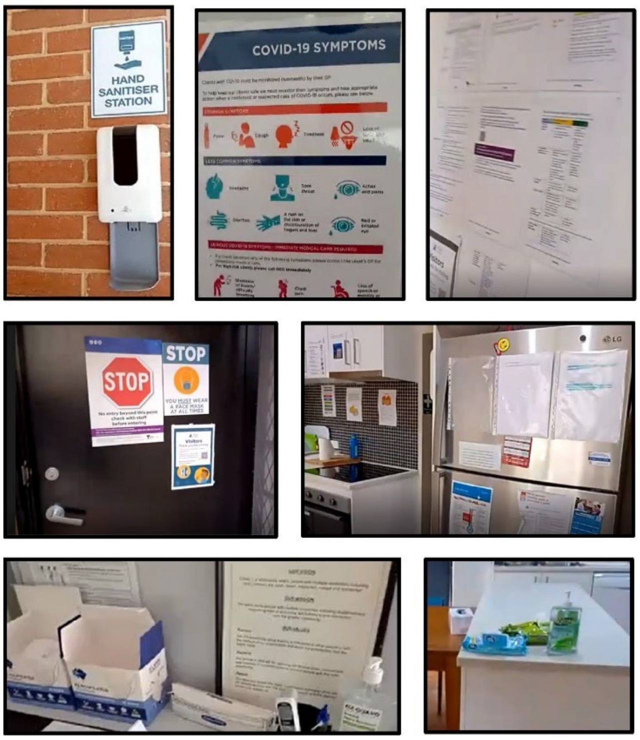


Fig 2: COVID-19 artefacts captured during observations.

During the observations, we were also able to witness the creative and extensive efforts of organisations in implementing 'COVID-Safe' strategies. Both homes had been diligent in displaying Government and organisational materials and in advertising and maintaining COVID-Safe protocols. Customised strategies had often been required to achieve a clinical level of health protection within a home environment. For example, one house had installed a prefabricated garden shed as an outdoor PPE doffing and donning station for use during active outbreaks. Staff noted that these measures had become an 'normal' part of life in the houses.

"It's mostly text instructions here. This area [table in entrance hall] would really be for visitors and staff. That's right. We've got our donning and doffing signage. Site declaration logs which all visitors need to fill in upon arrival. That's our sign-in station at the front of the house."
– Team leader (observational tour)

Interviewer:
"How often do you think people interact with that signage?"
Team leader (observational tour):
"I think, given the point of time that we are now in COVID, it's just become a normality. ... I feel like conversations aren't being held as much, as frequently or regularly, as they would have during the earlier COVID times."

Living in an information soup

We found that residents and staff in group home facilities had been immersed in large quantities of information about COVID-19, including official updates from their organisation, televised news and press conferences, internet media, the visual and environmental artefacts of infection prevention (e.g., the presence of PPE and new cleaning protocols), and the opinions expressed by friends, family, and the broader community. We named this phenomenon the "information soup".

"We have a regular house meeting with the staff, and sometimes with the residents as well. I think the house meeting is one of the good ways to share knowledges. Because what you learn is maybe only very narrow, if there are more people talking about this, so you get more wide knowledges. Everybody share your own knowledge regarding the specific points about the COVID."

– Support Worker (interview)

"It's an open plan space. So I imagine that you know quite a lot of shared conversations [about COVID-19] going on."

– Team Leader (observational tour)

"Most of the time we have time with the client and we always chat, we have a cup of tea together. I like chatting with the clients. ... I think I use my knowledge to influence my clients... I think it [chatting] also shares knowledges."

– Support Worker (interview)

"We used to have the news on every day. Yeah, and saying that, it wasn't really residents putting the hand up to say, 'I want to watch the news'. ...But we would play it during the day."

– Team Leader (observational tour)

"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. So, we got so many posters inside the house."

– Support Worker (interview)

The details that residents were exposed to within this complex soup of information changed rapidly and had at times been contradictory. Despite being pervasive within the group home environment, the content and format of the information soup was not always appropriate for residents' communication support needs. Additionally, residents and their staff had varying degrees of interest in learning about COVID-19, and varying levels of control over the format and content of the information they received. Some residents did not want to know about COVID-19, while others were highly engaged with news about outbreaks, evolving recommendations, and political debates.

> *"It's just both because they're [Government handouts] usually just be on two pages and it's not very information for things. You know?"*
> **– Resident (interview)**

Staff expressed concern about residents' exposure to information about COVID-19, and the potential stress this could cause. In both observed houses, exposure to COVID-19 news was controlled by staff to minimise stress, with staff reporting that other media (e.g., sports matches, music, edutainment videos, etc.) were often screened as an alternative to mainstream news.

> *"We're not normally giving that feed, that information to them. They're not interested at all because they're not aware of what's going on outside. ...[We're] not saying COVID, because they might not accept that one."*
> **– Support Worker (observational tour)**
>
> *"We turn on the television just for a bit. ... Yes, she [resident] can hear and see, what we are talking about.... Yeah, that's just a five-minute news and then we don't want the whole day for the news to happen. I don't think it's good. ... Even for us at this time too much news, I think it gives us lots of stress."*
> **– Support Worker (interview)**
>
> *"[Watching the news] was hard me because I suffer from depression, and it was hard for me. I was going crazy about this lockdown"*
> **– Resident (interview)**

Long-term staff of group homes demonstrated a deep familiarity with residents' communication, and described having developed tailored communication strategies to help residents understand information and express themselves. Residents' communication with familiar staff had been largely unaffected by the COVID-19 changes, however, the increased reliance on casual staff in response to worker illness or mandatory quarantine created new communication challenges for group homes to address. For example, as illustrated in Figure 3, both homes we observed had developed supplementary communication materials (e.g., photo-based communication dictionaries, Auslan cheat-sheets, etc.) to support communication between residents and unfamiliar casual staff.

Support Worker (observational tour): *"This resident use a lot of sign language. We came up with a solution for new staff. During COVID time, a lot of staff are sick so new staff are coming all of a sudden. We made a small book like this, with photos of what [the resident] is doing ... and what it means."*
Interviewer: *"So who helped you with that? Did a speech pathologist help you?*
Support worker: *"No no, we did. The staff did this one. Because we know if me or another staff member were not here, it would be difficult for people to communicate with [resident]. ... That's why I like working with this house, because all staff are working together, and any problem we come up with the solution ourselves."*

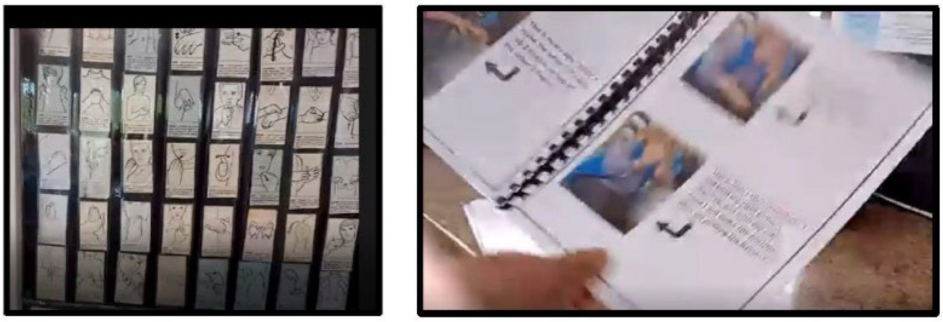


Fig. 3: Communication support artefacts: Sign language poster (L), personal communication dictionary (R).

Residents and staff sought information about COVID-19 from trusted sources

We learned that residents received most of their regular health information from their regular GP. However, during the pandemic, residents were exposed to health information from a range of other sources.

"For the previous vaccine, infection, I think they just follow their GP's instruction, because it is their own GP, they just follow their GP's instruction... But the virus is a little bit different, COVID is a bit different.
– Support Worker (Interview)

"I think because he's mild intellectual disability and his friends have said the vaccine is not good, so it can be harm. I think he was influenced by his friends. I think this is the main reason, because he can't read, but he can talk and he can listen and he can understand from the people around him."
– Support Worker (interview)

Trust appeared to be an important factor for both residents and staff in seeking communication about COVID-19. While official sources of information (Government, GP, and disability organisation) were typically trusted, some residents and staff sought information from other sources that they trusted, including their support staff, friends and family, social media, television, and the Internet. Interestingly, 'trusted' information shared between staff and residents, or accessed from community sources, was not always consistent with Government or organisational messaging.

"We got our most information through the news and we basically heard it from the media…"
– Resident (interview)

"They [residents] heard from like Sky News, they talk about the virus is a bio-weapon, so they say: 'this virus is not a normal virus, I don't want the vaccine, I don't trust the vaccine'.
– Support Worker (interview)

"Sometimes they [residents] ask [staff] question: 'why is always lockdown? where the virus has gone? it comes and it goes'. They ask the question: 'why is the virus different from previous virus?'...".
– Support Worker (Interview)

"I've been talking to [Organisation] staff about it, like getting them to give their opinion on the virus. ... They are [helpful] because it helps me to sort of expand on what I already know."
– Resident (interview)

Although staff executed their professional roles by sharing or displaying official information about COVID-19, they also had their own beliefs, fears, and sources of information. Staff demonstrated a strong kinship with residents and talked about needing to protect residents from misinformation or harm, and a desire to share their own health beliefs and knowledge with the residents they supported. We also saw and heard about similar intentions from some residents, to look after the staff in their homes.

"Usually I've already informed myself with the TV and with the information online from the government et cetera. So I feel like I've got a pretty good idea of information that I'd need to share with the guys."
– Support Worker (Interview)

"I was following one of the COVID programmes, so I know more about the COVID than the average people. ... Sometimes I talk to my client and automatically you know, so I said in my opinion I don't want to have the vaccine. That's why I think part of the reason maybe I influence [resident] as well, I think."
– Support Worker (Interview)

We found that what was being communicated about COVID-19 in the group homes through these relationships was sometimes different from the official information provided by the

Government – for example, that vaccinations were dangerous, or that COVID-19 had been engineered by a foreign government as a form of warfare.

"Some [residents] believe in having vaccine and some don't have vaccine. ...The clients that I'm looking after now... normally they're just going on the internet and finding information for themselves. ...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 (interview)

Residents shared information about COVID-19

Information sharing was not always one-way from the organisation to the residents. Many residents had their own understandings and perspectives on COVID-19, sometimes communicating these with words (e.g., sign language or speech) and sometimes non-verbally (e.g., through behaviours, body language, and creative or artistic expression). Some residents acted as informants for staff, family, and community members about COVID-19. Some expressed frustration at the response of the World Health Organisation and the Federal and State governments, and wanted to play a more active role in advocacy and information sharing within their community.

"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, I guess. The other two women, they often say, 'It's a shame we're in lockdown again. We're not able to go to our programs.' So they're a little bit discontent about that."
– Support Worker (Interview)

"We ask her [resident], 'How you going?' Sometimes we'll have a cry and it's okay"
– Support Worker (Interview)

"[The residents] raise an opinion about why they should take it [vaccination], why they shouldn't take it and maybe argue about it between themselves. But they're not really looking for answer. It's all about giving opinion."
– Support Worker (interview)

Resident 3 (double interview): *"We've both been sick of it because I've been in lockdown the longest."*
Resident 4: *"I'm sick of being... The federal and the state government don't know..."*
Resident 3: *"This is the New South Wales branch. They don't know what they're doing."*
Resident 4: "*They're not doing – the Health Ministers don't know what they're doing."*

Tailored communication support was essential

Our most important finding was that each group home had unique needs relating to health communication. Optimal methods of communicating with residents about COVID-19 changed depending on residents' communication preferences and modes, their level of understanding, and their ability to make independent decisions. Residents and staff shared some practical suggestions for making health information more accessible and inclusive. These included the use of videos, pictures, Auslan/sign language, and alternative communication modes to support written documentation and media reporting. One resident described Government emails with lots of text and no picture supports as "junk mail".

"In many cases, it's probably not easy to understand, but for us it has been."
– Resident (interview)

"Staff have been communicating, either orally or via Auslan, and explained to them what the dangers are, and what they need to do in order to protect themselves. So, everyone in the household practises hygiene and is very cautious and they have a good understanding of what's happening."
– Support Worker (interview)

"[Lockdown] was quite challenging for one resident. ...She needed to get out of the house. So we would have to explain to her. She has her iPad, so she's got an app on there – Proloquo2Go. She had a social story also. That was used to help remind her why she hasn't seen Mum and Dad, and she'll see them soon."

– Team Leader (observational tour)
"She had to take photos like where she [resident] is staying in the house, and the photos get taken and hand washing and all these things.... She understands. ...She has a flip chart. If sometimes when it's hard for us to understand, then we use the flip chart. So then we point to the photos, about feelings and stuff. So then she will say yes or she will say no. So then we know what she wants."
– Support Worker (interview)

"You could have some videos with people getting vaccinated or some graphics with the virus. Yes. So I think a lot of the clients will recognise and embrace that sort of visual concept better, rather than verbal information."
– Support Worker (Interview)

"The clients that we have that have autism struggle to understand. At this point I still don't think that they fully understand what's going on."
– Support Worker (interview)

Fig. 4: A support worker shows us what his PPE looks like from a resident's perspective.

The use of PPE (e.g., masks and face shields) also had an impact on communication, particularly for residents with hearing or vision impairment. Staff were conscious of this and tried to adapt where possible.

Staff played an important role in helping residents to make sense of the many information sources around them, by debriefing with residents in a way that was appropriate to their communication support needs. For example, as depicted in Figure 4, modelling of healthy behaviours by staff and other community members (e.g., mask wearing, hand washing) helped residents with more significant disability to understand what was happening, and what to expect when they were in the community.

"We spoke about germs. More use the term of 'germs'. Probably didn't really use much of vocabulary around Covid, Coronavirus, PPE; more saying, '... you know there's lots of germs out there, and that's why we have to stay home. That's why the [day program] centre is closed, and we're all staying home to spend some time together today.'..."
– Team Leader (observational tour)

"They did [ask questions] towards the beginning of the pandemic and they just relied on the staff to sort of reinforce that they needed to wear masks and stuff to keep themselves safe basically."
– Support Worker (interview)

"It's more visual cues and that sort of thing, but they notice us always dressed in protective equipment and that sort of thing. So those visual cues help them understand that the staff aren't only protecting themselves, but the clients as well."
– Support Worker (interview)

Staff also described their own need for accurate and clear information about COVID-19, to execute their work safely and effectively. While some had found it easy to access information about COVID-19, others had struggled, particularly relating to the changing lockdown rules, or sourcing and using PPE. Staff described diverse information preferences ranging from emails and written communication, to apps, videos, or posters, showing that multimodal communication is required to effectively reach all professionals in the sector.

"I think the most important information, like how to keep social distance here, yeah. How to wear masks and even how to wear the gowns, the goggles, yeah. I think this one very useful for the staff and the residents. Because the staff need to know, have good knowledge how to prevent the virus, try to prevent the virus from the staff to the residents".
– Support Worker (interview)

"What I check the most would be exposure sites. I think that's probably the most useful for me. ... Keep track of your whereabouts and potential exposure so that you're not sharing it with clients."
– Support Worker (interview)

"Well, the pamphlets and the posters and whatnot, the written information is in basic English, there's no jargon that's too complicated. ... So the English is very basic and the team leader is always available to have meetings and discussions to clarify any confusion."
– Support Worker (interview)

"I think it could be increased. I think the government could maybe increase the amount of information that's shared to the sector."
– Support Worker (interview)

Ultimately there was no single communication or coping strategy that was perfect for all group home communities. Inclusive practice required the co-design of strategies in partnership with residents, staff, managers, and supporting professionals, to ensure everyone's unique needs were met. Staff demonstrated creativity, resourcefulness, and professionalism with respect to this process.

"One of the staff – because we couldn't get resources, she made this beautiful big plant for [resident] out of cardboard, just a birthday thing. And made leaves, they painted them. ... They all got involved to do that for her birthday. Couldn't get her a gift this year, but that's what they did, they made that."
– Support Worker (interview)

"The manager always said ... 'let's not panic. Let's work it through together as a team ... for the people we care for. Because if we're feeling panic they will panic.'..."
– Support Worker (interview)

"It's a privilege to be with them in their lives."
– Support Worker (interview)

Forming a Consensus

A Delphi study is a method of research, where a panel of experts (people who possess lived experience or professional experience about a topic) come to a decision about good practice. *Study Arm 3* used a modified e-Delphi study approach[59, 60] to establish a consensus around key communication priorities and recommended practices. Traditional Delphi methods involve experts participating in a series of consensus surveys that are interlaced with in-person interviews/group discussions to explore topics in more detail. We used a modified approach by drawing on our Arm 1 and 2 exploratory data to help develop the consensus statements, and by consulting with our Knowledge Translation participants and project advisors to contextualise and refine the Delphi findings. The surveys were delivered online (e-Delphi), which further reduced the time commitment required by experts in an over-stretched sector.

The Arm 3 Delphi study sought consensus around practice findings identified in the earlier study arms, primarily concerning:

1. the information content shared with group home residents about infectious disease;
2. the format of information shared with group home residents about infectious disease; and
3. how disability accommodation services should support residents to seek, understand, share, and co-design information about infectious disease.

Who participated?

We assembled a heterogeneous expert panel of seven experts: three support workers with a minimum of three years of experience supporting residents with intellectual disability in a group home (range 11-20), and four disability accommodation service managers with a minimum of three years' experience (range 3-20 years) in their current role or a similar role. Five experts identified as female and three as male. All were between 31-60 years of age. For this study we asked about experts' linguistic backgrounds, given the relevance of communication diversity for this topic. Participants spoke between 1-3 languages (including English). 4/7 experts (57%) spoke English as their first language, and all spoke English at home.

We surveyed the support that experts had provided across eight common disability categories (intellectual or cognitive disability, psychosocial disability or mental health support needs, autism or neurodiversity, physical disability or chronic health conditions, d/Deaf or Hard of Hearing, vision impairment, and people who were mostly unconscious or comatose). Experts had provided support to individuals across 3-6 categories. All seven experts had supported people with intellectual/cognitive disability, Autism/neurodiversity, and physical disability or chronic health conditions, and none had experience with people who were unconscious or comatose. Collectively, experts had experience supporting residents who used a range of communication modes, including speaking, reading, writing, Auslan/Key Word Sign/other signed languages (expressive or receptive), Augmentative and Alternative Communication (e.g. communication books, boards, pictures, or speech generating devices), and people who only use their body languages, sounds or behaviours to communicate). A breakdown of experience by disability and communication categories is provided in figures 5 and 6, below.

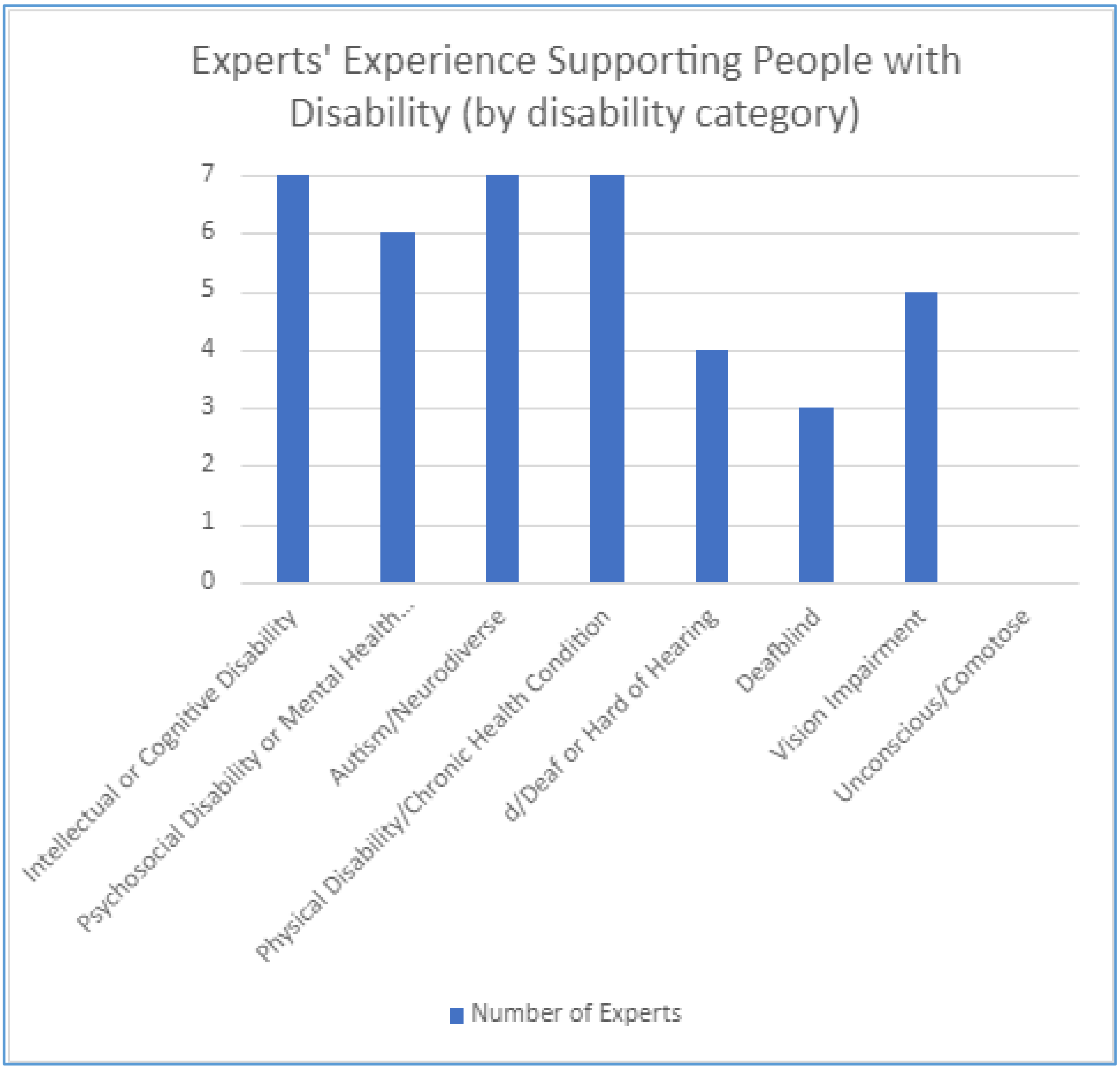


Fig. 5: Support experience (by disability category).

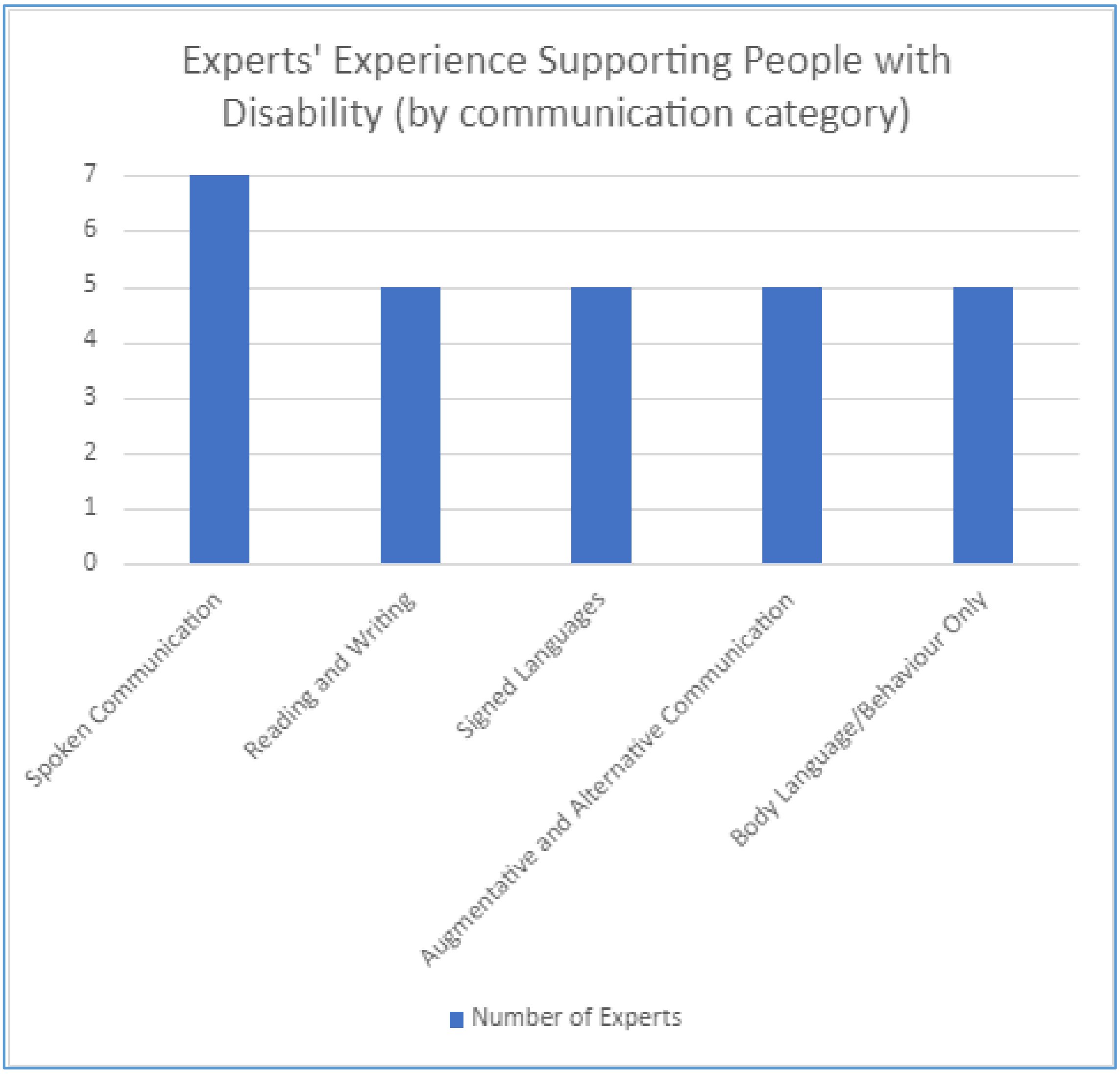


Fig. 6: Support experience (by communication category).

There is no established consensus around the ideal cohort size for e-Delphi methods, although some studies suggest that a panel size of 12 participants, sharing similar practice/training backgrounds, can achieve good reliability[61]. Despite holding the survey open for a longer period than originally planned, we were only able to recruit seven participants in total, possibly due to the resourcing pressures affecting the disability sector at the time. Further research may be required to validate these statements with a larger expert cohort.

Delphi Method

Based on the findings from the first four research phases, we drafted a set of recommendations for group homes, regarding inclusive communication about infectious disease. Experts rated each statement on a scale from 1-5, where 5 = strongly agree, 4 = somewhat agree, 3 = neither agree nor disagree, 2 = somewhat disagree, and 1 = strongly disagree.

The e-Delphi consisted of two survey rounds. On the initial round, our criterion for outright acceptance of a statement was that 100% of experts indicated agreement (i.e., ratings of 4 or 5). If any expert gave a statement a rating of 3 or less, we revised the wording of the statement based on any qualitative feedback/advisor input and returned it to experts for a second round of consensus rating. Eighteen statements were accepted during this initial round, but one was later revised by the research team members based on Advisor feedback and was included in the final Delphi round for review. No recommendations received a unanimous rating of 3 or less in the first round, so none were excluded outright. The remaining statements were revised and consolidated, and 10 were presented back to the expert panel for re-rating in the final round, along with detailed quantitative and qualitative feedback on the initial rating results.

Our original criteria for acceptance on the final round was that at least 80% of experts rated the statement as 5. However, due to the small number of responses in the final round (n=4), this criteria meant that individual participants would have unilateral influence over the decisions, even if their rating was an outlier. Consequently, we reduced this requirement to 75%, with no individual ratings of 1 (strongly disagree) or 2 (disagree).

The final outcome of the e-Delphi was an agreed set of 20 best-practice guidelines for public health communication with group home residents who have intellectual disability. Below we present the statements, contextualised with additional input from Delphi experts and Knowledge Translation advisors. These are also provided as a list in Appendix A.

Consensus Findings

Statements were grouped under the following themes (see figure 7): 1) access to information, 2) topics of information, 3) sources of information, 4) understanding information, 5) sharing information, and 6) consent and decision-making.

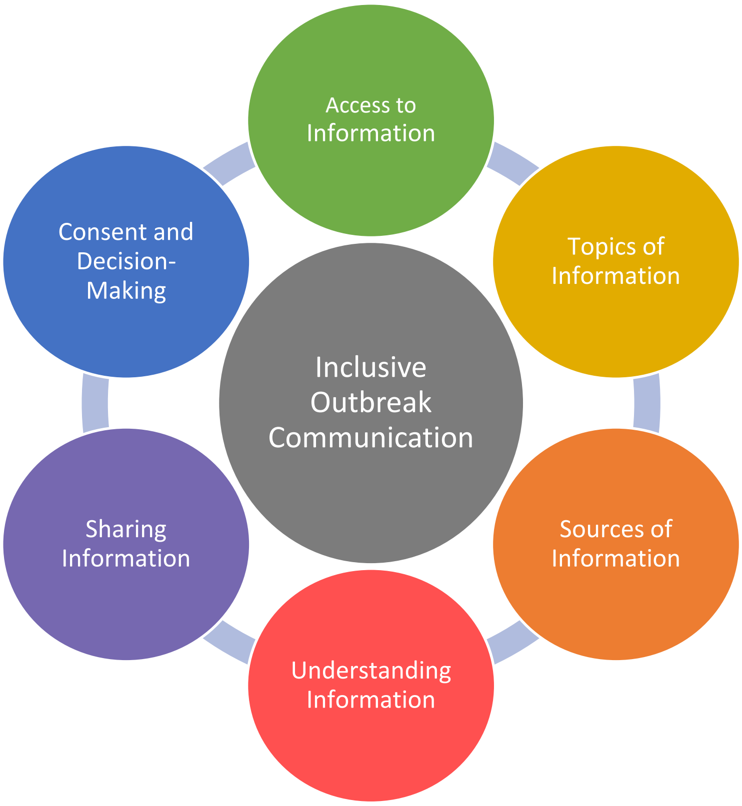


Figure 7: Pillars of Inclusive Outbreak Communication.

Access to information

The following approved recommendations address the way that information about disease outbreaks is presented to group home residents.

1. If residents want information about a disease outbreak, this should be provided in a format that meets their individual communication needs, such as plain language, visual aids, sign language, or tactile (touch-based) communication.
2. Group home residents should have access to video, audio, and pictures as part of any information provided about a disease outbreak.
3. Posters and visual displays can be helpful in communicating information about infectious disease. Residents should be involved in deciding if, and how, posters or visuals are displayed in their group home.
4. Modelling or demonstrating health protection behaviours (e.g., hand hygiene, mask wearing, social distancing) is an important way to inform group home residents during disease outbreaks.
5. Group home residents should have the opportunity to design or contribute to information resources about outbreaks, that will be used by them and their staff.

Development Notes

While experts and project advisors agreed that information should be made accessible, they also emphasised the importance of resident choice around information access, display and exposure. This is illustrated in the following comments regarding visual materials.

"... [Saying to residents] 'We've got these posters. Do you want this?' That would probably be a good start in a lot of the places."
– Manager (Project Advisor)

"The question around Posters on walls, this can be done but taking into consideration that this is people's home and not a medical institution. This should also be done with consent and involvement of the residents."
– Manager (Delphi expert)

Topics of information

The following approved recommendations address the breadth and depth of topics about infectious disease that should be made available to residents. The specific topics will depend on the type of infectious disease being managed.

1. Group home residents should have access to the same topics of information about a disease outbreak as everyone in the general community. Information about each topic may need to be simplified for some residents to support their understanding.
2. Group home residents should be involved in deciding what topics of information they have access to regarding disease outbreaks.
3. Supporters (e.g., family or friends), professionals (e.g., disability or healthcare workers) and government bodies should be involved in deciding what topics of information people with disability have access to regarding disease outbreaks.

Development Notes

An additional statement from this section (*"Group home residents should have access to the same topics of information about a disease outbreak as group home staff and managers"*) was rejected in round one, based on feedback that managers are given high-level information about infectious disease management that would be unnecessary for residents to know.

Some experts felt that residents should have access to the same topics of information about infectious diseases as staff, managers, and other community members. Others disagreed, noting the risk of information overload for residents, and suggesting that simplified or reduced content was more appropriate. This difference in opinion is likely to reflect differences in the cognitive capability or psychological wellbeing of residents that each expert supported.

"We, the providers, got a duty of care, and obviously don't want to give a person anxiety. That's why it's really important to have a discussion about the information. We don't need to dump all together, or we don't necessarily need the whole lot."
– Support Worker (Project Advisor)

"With the clientele I support, they have expressed it is not their job to communicate about COVID and have expressed anxiety and/or disinterest when asked to do so. I will clarify that them being the driver for the format they receive information could be important to people."
– Manager (Delphi expert)

While access to information was generally viewed as important, experts and advisors noted that not all residents want to be exposed to information about infectious disease. In addition to accessibility considerations, the provision of information should be consensual.

"Again, it comes down to the individual person. We can always ask them, or try to communicate with them, whether they understand. So we could say, 'We've got this piece of information that's from government. Some people find it's quite full on, the information. It can be a bit too much. Some people find it's okay.' So up to them to decide. 'Would you like to try and go through the whole information?'..."
– Support Worker (Project Advisor)

However, advisors cautioned against short-cutting this process without ensuring adequate support for decision-making by residents.

"Some [staff] might ask with this: 'Would you like to read it?'. If participants say, 'No, I don't want it', and [staff] just say, 'okay, don't worry about it.' - It could be a really important information!"
– Support Worker (Project Advisor)

For health information presented in shared environments (e.g., posters, television), advisors noted that decision-making also needed to include all residents in the home.

"Especially in group settings - all the residents, I think needs to be part of it. So not just one or two."
– Support Worker (Project Advisor)

Sources of Information

These recommendations are about the role of group home providers in ensuring that residents can access information about disease outbreaks from a range of sources.

1. Group home services should support residents in accessing information about disease outbreaks from the following sources:
    a. television or radio (mainstream media)

    b. government or health agencies (e.g., press conferences, Government websites, Government apps)
    c. disability agencies (e.g., group home meetings, case conferences, emails from service provider)
    d. familiar health professionals (e.g., GP).

2. Group home services should support residents who want to access information on social media (e.g., TikTok, Facebook, Twitter, YouTube, online discussion groups and forums), or via the Internet (e.g., Google searches, general websites). This may include support to understand the risks or limitations of these information sources.

Development Notes

Although our research showed that many residents and staff were accessing information through other sources such as the Internet, social media (e.g., Facebook, YouTube) and friends or family members, experts did not all agree that group home services had a responsibility to support residents in accessing these forms of information.

"Yes, we did talk about Covid [to residents], obviously because it's just happening. But I was always mindful trying not to say my opinions. I'm basically trying to ask the person: 'Oh, okay, how did you feel about that? ... Would you like to find the information about this? Where would you prefer to find that, or what did you think of that? So I actually ask them more questions instead of telling them what I think, what I know. I felt that was my duty, for them to figure out what's important. I was a part of the support network. I'm not a medical professional. I'm not trained in that area. So my opinion probably shouldn't be there."

– Support Worker (Project Advisor)

Some experts expressed concern that social media was not a reliable source of accurate information and noted that they would respect residents' rights to access this information and would support them to access it if desired, but would also provide some education around the risks of social media disinformation as part of this support.

"Social media platforms are not fact checked/regulated particularly mentioned platforms like TIK TOK. I would not encourage this for the source of information. I would respect people's choice if they wished to access this and support them to do so, but also let them know the above."

– Manager (Delphi expert)

"The web or internet is the future and as long as people are taught or trained to use the internet responsibly, and awareness of short comings and exposure to other vulnerabilities such as fraud."

– Manager (Delphi expert)

An additional statement was rejected in round two, after one expert awarded a rating of "strongly disagree". This statement, which had been revised following consultation in round one, was: "*Group home services should assist residents who want to access information from their supporters (e.g., a resident's family members or friends). This may include support to arrange a visit or make a phone call.*" We did not receive any additional feedback on this item. Although this statement could not be included in the final recommendations, we strongly recommend that organisations consider the way that residents access information from family and friends, given the significance of this communication channel in our broader project findings.

Supporting residents to understand information

These recommendations address the role of group home staff in supporting residents to seek and understand information about disease outbreaks.

1. When a group home resident is exposed to information about a disease outbreak, group home staff should help the resident to understand the information, for example by using simpler language, sign language, pictures, or gestures.
2. Group home staff should be trained and supported in how to help group home residents understand information about a disease outbreak.

Development Notes:

Project advisors and Delphi experts stressed the important role that group home staff play in this process. They also noted that good practice in this space can take time.

> *"To give them [residents] clarity to understand the piece of information sometimes takes months, for them understand one single information. But that's fine, as long as they get it eventually. But it takes time."*
> **- Support Worker (Project Advisor)**

Although we know that many staff have strong opinions or extensive knowledge about topics such as vaccination, risk of infection, or virus origins, there was no consensus on whether staff had scope to share these with residents in their professional role. Two statements in this pillar were rejected in round 2, despite significant redevelopment. These were: *"Group home staff should support and encourage residents to ask questions about a disease outbreak. For example, helping them to identify what information they want to know, and who they could ask"*, and *"Organisations should develop clear guidelines for group home staff, concerning what information they can share with residents about infectious disease, and how that information should be shared."* While some experts emphasised the value of staff knowledge and perspectives on this topic, others strongly disagreed that staff should be involved in directly sharing their opinions with residents. As one expert explained:

"Staff should always be objective when it comes to provision of information, especially maintaining professional boundaries and keeping opinions and beliefs to self."
– Manager (Delphi expert)

"I wouldn't share a very personal information about my health [with residents] for instance, or like whether you were going to get a vaccination or not... Because all this little information, especially if you have a really good relationship, it does influence on them. So, imagine if someone's got a very radical idea..."
– Support Worker (Project Advisor)

A diversity in practice values around staff sharing informal knowledge/personal opinions with residents was also reflected in our interview and observational data. Although we could not establish best practice guidelines around this within the scope of the 2-round Delphi, we recommend that services examine the role their staff play in both formal and informal information sharing across their organisation and consider developing supportive policies and guidelines for this critical channel of communication.

Residents sharing information

The following statements address the roles and capabilities of group home residents in communicating and sharing information about disease outbreaks.

1. Group home residents should be encouraged to express their thoughts and feelings about a disease outbreak.
2. Monitoring behaviours of concern is an important way to understand how a group home resident may be responding to a disease outbreak.
3. Some residents may want to play an active role in health communication, such as helping their housemates, staff, family, friends, community members, or other people with disability to understand or cope with a disease outbreak. Group home providers should support interested residents to meaningfully participate in these roles.

Development Notes

Experts also agreed that some residents could play a role in sharing information about an outbreak, but this will ultimately depend on their individual interests and capabilities.

"In my experience the residents/participants did not have capacity to support each other to understand the information provided. If group home residents do have capacity to support staff, other residents and the broader community, I believe they be able to relate to [them]."
– Manager (Delphi expert)

"We listen more and understand things better when it is from our peers, peer support is very effective"
– Manager (Delphi expert)

By contrast, in our interview study, some staff said that discussing and comparing information with residents had been useful to their own knowledge about COVID-19, and some residents described adopting an advocacy role in educating their family and friends about vaccinations or social distancing. Two residents also expressed interest in political lobbying about COVID-19 issues.

Consent and Decision-Making

These recommendations are about informed decision-making and consent for residents, relating to health information.

4. Group home residents should be supported to make their own decisions about health risks during disease outbreaks.
5. Group home residents should be supported to make their own decisions about following public health rules.
6. Group home residents should be supported to make their own decisions about following public health guidelines and recommendations (e.g., getting vaccinated, practicing hand hygiene, or avoiding high-risk activities).
7. Group home residents should be supported to make their own decisions about who has access to their health information (e.g., knowing a positive test result or vaccination status) during an outbreak.
8. The personal opinions and beliefs of group home residents about a disease outbreak should be respected.

Development Notes

Experts unanimously agreed with all statements in this category in the first round. One expert qualified that supports for informed consent and decision-making should be in line with legislation (e.g., UNCRPD) and appropriate for the individual’s capacity.

Our project advisors also agreed with the importance of co-design but noted that a participatory paradigm was not yet widely understood or adopted across the sector.

> *“A lot of the places I've worked, they don't really do co-designing as such. It's more support work, or it's just probably the management to decide what's going to happen, instead of actually going back to the residents that actually live there.”*
> **– Support Worker (Project Advisor)**

In the final section of this report, we present novel practice guidelines and future research directions arising from this report.

Translating our Findings

Over two years of research we have learned a lot about inclusive health communication in group homes. Knowledge translation is the final step of our research and is an ongoing process. It includes the "synthesis, dissemination, exchange and ethically sound application of knowledge to improve health, provide more effective health services and products, and strengthen the health care system."[62] This approach is often referred to as Knowledge-to-Action.

Knowledge translation processes helped us to refine our research findings and start developing an inclusive communication strategy for future disease outbreaks. This aspect of the research has addressed the following specific questions:

- What is the best way of sharing our recommendations with group home residents, staff, managers, and advocates?
- What format should our findings be shared in? For example, text, images, videos, websites, or other types of resources?
- How could our findings be used in other healthcare settings, such as hospitals, aged-care facilities and general practice?

What we did

Consistent with our Participatory Action Research approach, we embedded knowledge translation activities from the start to the end of the funding period. These included:

Synthesis

Our early literature review and policy view allowed us to synthesise a large body of existing research and practice evidence into a format that could be easily shared and used by service providers and policy makers.

Dissemination

Emerging insights and methods from our research have been continuously shared with the public via our project's website. We have created knowledge materials in a range of formats (e.g., text, audio, visual diagrams, captioned and signed videos) to accommodate diverse accessibility needs of knowledge users. In December 2022 we also hosted a free research symposium on Inclusive Health Communication, where all three teams funded by the same grant scheme (MRFF: Coronavirus Research Response Communication Strategies & Approaches During Outbreaks grant opportunity) shared and compared their research findings with interested researchers, industry representatives, students, and diverse community representatives.

Exchange

During the research we created many opportunities to exchange knowledge with industry and community stakeholders. Early in the research process, consulting with policy managers and CEOs from disability organisations yielded mutual benefit. For our team, it enabled the inclusion of organisation-level policies and insights into our review work. For organisations, it offered a consolidated, bigger-picture view of relevant policy, and gave voice to their local concerns through our project dissemination work. Similar benefits were gained from monthly consultation with our industry advisors throughout the project timeline.

Multisector collaboration was undertaken during the Inclusive Health Communication symposium, with representatives from aged care, the Aboriginal and Torres Strait Islander community, the Victorian Deaf community, refugee and asylum seekers services, and the street-based sex worker sector. The event provided a forum for sector representatives to brainstorm how community members, researchers and health organisations could form effective partnerships for inclusive research, policy development, and service design, and to share their own insights and resources for potential use in other sectors.

Knowledge Application

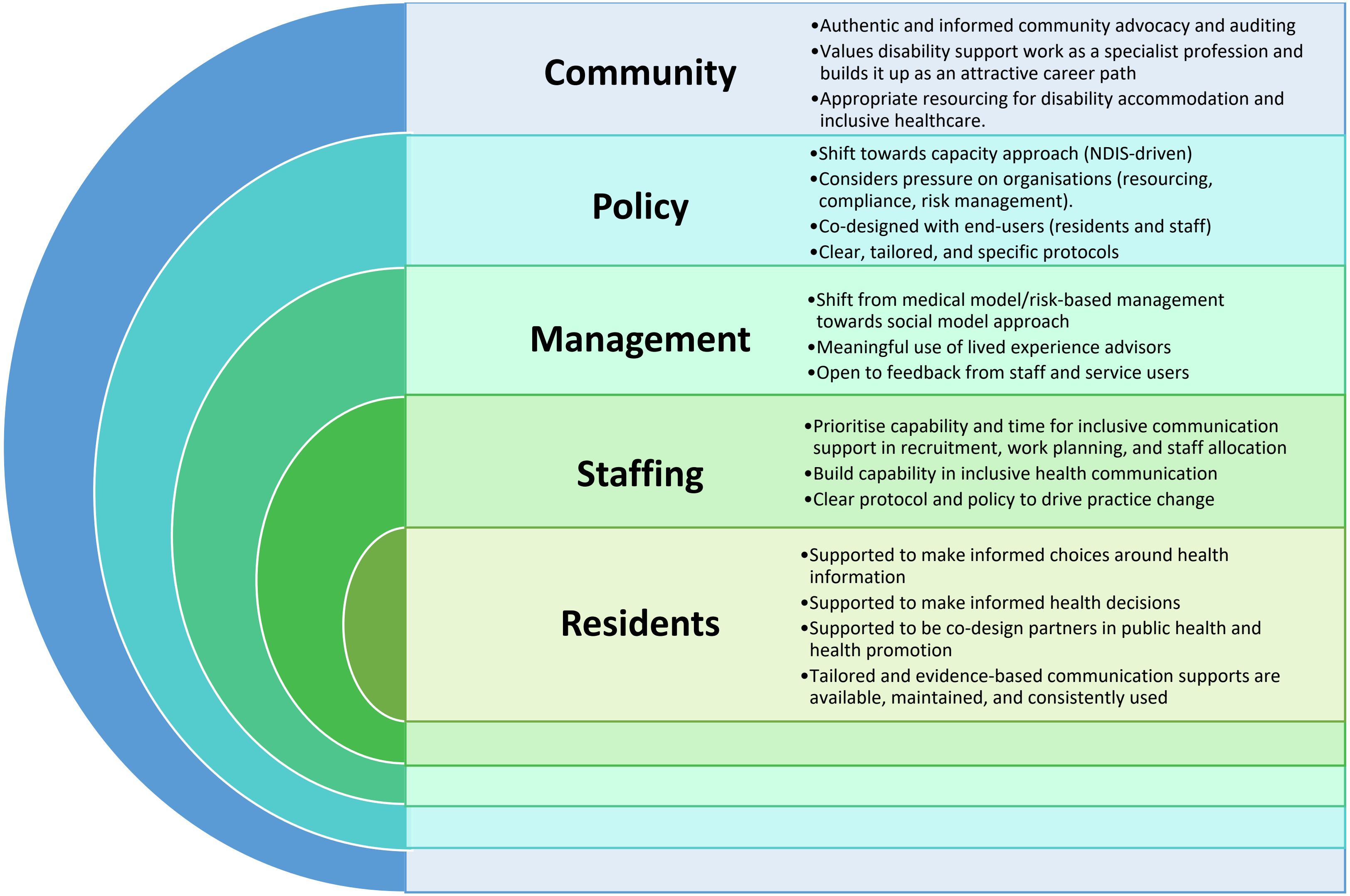
During the final stages of the project, we consulted industry and community advisors about the practical implications of our findings. Advisors had worked in many areas across the disability sector, including group home and individual accommodation support, supported employment services, day or leisure programs, psychosocial disability support, advocacy, and service management. Guided by the CORRECT[63] attributes, work with advisors was aimed at selecting which inclusive health communication strategies would be most amenable to scaling-up or translating to other settings, as well as identifying potential barriers and facilitators to their application. Insights from this phase of the research have been integrated into earlier sections of the report to contextualise our findings.

Throughout the project, team members also had significant opportunity to share and apply our research findings within the disability and healthcare sector. For example, team-member Prof. Catherine Bennett used interim findings from the project to inform the Australian Government Department of Social Services COVID-19 Task Force ‘Red Team’ scenario testing (July 2022) and AstraZeneca Australian Covid Vaccine Advisory group, around issues impacting disability service users and providers. Additionally, insights gained about the feasibility of inclusive research and health communication strategies have been applied in other projects that our researchers from Deakin University and Able Australia are involved with.

Considerations for Knowledge Translation

Consulting with different stakeholder groups produced a range of recommendations. Stakeholders in one area of the sector, however, were not always aware of pressures or responsibilities at other levels. An example of this is seen in recommendations around training: while some project advisors in academia or advocacy recommended increased training of support workers, advisors who were working in these roles identified significant limitations in staff capacity and time. These are likely to impact the efficacy of any training programs delivered in isolation. Similarly, while some advisors working in direct care or management roles called for increased standards in the recruitment of personnel to support worker positions, consultation with sector leaders revealed significant resourcing and workforce barriers to this strategy.

To account for these complex pathways of influence, we have collated the practice factors and recommendations gathered across the study arms and presented these in an ecological framework (see Figure 8). This model represents concentric domains of influence, with the resident at the centre and the domains of staffing, management, policy, and community surrounding them. Each level addresses factors arising from that domain that could directly impact the success of inclusive health communication efforts. Factors likely to influence change management within one domain can often be seen in the level above.



Community

- Authentic and informed community advocacy and auditing
- Values disability support work as a specialist profession and builds it up as an attractive career path
- Appropriate resourcing for disability accommodation and inclusive healthcare.

Policy

- Shift towards capacity approach (NDIS-driven)
- Considers pressure on organisations (resourcing, compliance, risk management).
- Co-designed with end-users (residents and staff)
- Clear, tailored, and specific protocols

Management

- Shift from medical model/risk-based management towards social model approach
- Meaningful use of lived experience advisors
- Open to feedback from staff and service users

Staffing

- Prioritise capability and time for inclusive communication support in recruitment, work planning, and staff allocation
- Build capability in inclusive health communication
- Clear protocol and policy to drive practice change

Residents

- Supported to make informed choices around health information
- Supported to make informed health decisions
- Supported to be co-design partners in public health and health promotion
- Tailored and evidence-based communication supports are available, maintained, and consistently used

Fig. 8: Proposed ecological model for drivers of success: Inclusive communication about infectious disease in disability group homes.

Drivers of Success: Residents

Four core themes came from the Knowledge Translation phase, relating to residents:

- **Residents should be supported to make informed choices around health information.**
- **Residents should be supported to make informed health decisions.**
- **Tailored and evidence-based communication supports should be available, maintained and consistently used.**
- **Residents should be supported to be co-design partners in public health and health promotion.**

Communication access is core to residents' self-determination and confidence, with respect to their health. This project identified that residents have a right to accessible information about infectious disease and a right to control the quantity and mode of information that they receive. Residents have a right to make informed and consensual decisions about the way infectious diseases are managed and communicated about in their homes.

While supporters play an important role in facilitating health decisions, it is critical that individual decisions are not outsourced to family, staff, or managers without the person's involvement. Additionally, while it was clear that residents, staff, friends, and family frequently exchanged informal information about infectious disease with each other, disability organisations must be vigilant to the risks of misinformation spreading via these mechanisms and clarify the role of support workers in the information sharing space.

"The truth is, people want information when it comes to anything that puts them in danger. ...But then we've got the risk of overload of information for people with disabilities. So this is where it comes to: 'Do you want to receive this information?'. 'How much of this information do you want to receive?'..."
– Manager (Project Advisor)

"I feel like it's... more professional... it's not so much what about what I think, or what I do, it's about them having access to the variety of information that they understand, and they can make a decision not based on your personal opinions. So I think it's a really important to be able to distinguish that difference as a paid worker."
– Support Worker (Project Advisor)

Supported decision-making is a process where a person with intellectual disability or cognitive impairment is supported to participate in (or make) a decision about their lives[64]. This process is different from substitute models of decision-making, including proxy consent and guardianship models, because it requires the direct involvement of the person with disability, at whatever level they are comfortable and able to participate[65]. In supported decision-making, individuals with disability share information about their will and preference (for instance, their current or historical reactions to/feelings about an activity, environment, interaction, etc.) through their own established modes of communication (e.g., behaviours, vocalizations, posture or body language, facial expressions and eye movements, physiological reflexes, etc.). Supporters who know the person well recognise and interpret these signals, and use them to inform the next step of a decision[65]. The process involves four iterative and repeated steps: a) identifying decision options together, b) listening together, c) exploring options together and building evidence, and d) making a decision and acting on it together[65]. Documenting the supported decision-making process is essential for transparency and learning.

Supported decision-making approaches are aligned with Article 12 of the United Nations Convention on the Rights of Persons with Disabilities, which states that ”*persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life*”, and that that signatory nations (including Australia): ”*shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity*.”[1]

Staff are likely to require specific training and exemplars to help them undertake successful supported decision-making with residents.

> *“If the support worker been asked: ‘Oh, you need to do support supported decision making. Can you help them to make decisions?’, they [staff] have no idea what they look like. It's really important to show them what they [co-design and supported decision-making] look like. Supported decision-making could mean so many different ways to some people. ...Having that expert to create the process... a bit of a guideline. ...Maybe provide them a little bit of training. So they get a bit of understanding what their role in those process, instead of giving [residents] your opinion, or telling them what to do. So they understand the difference in being supported, versus being in the ‘old school’.”*
>
> **– Support Worker (Project Advisor)**

Augmentative and Alternative Communication (AAC) encompasses a wide range of communication supports that may be used by residents with intellectual disability and their supporters, to enhance infectious disease information sharing. Successful examples seen in this study included mainstream and adapted sign languages, electronic speech-generating communication devices, picture books, boards and flip-charts, drawing or artistic expression, and the use of real objects and physical demonstration. The efficacy and suitability of these techniques are dependent on many individual factors including residents’ cognition and understanding, sensory capability, language and cultural background, vocabulary needs, and personal preferences.

In most cases, tailored communication approaches and resources will be more effective than generic ones, in supporting people with intellectual disability to understand and communicate about infectious disease. A speech pathologist can be consulted to develop optimal resources and strategies for individual use.

> *"I've managed a service where I had 18 [group] homes that I looked after. ...They are 18 totally different homes, and in each home, we are talking probably five totally different lives."*
> **– Manager (Project Advisor)**

For broader practice guidelines on supported decision-making and individual communication supports in healthcare contexts, we recommend:

- Watson, J., Wilson, E., & Hagiliassis, N. (2017). Supporting end of life decision making: Case studies of relational closeness in supported decision making for people with severe or profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, *30*(6), 1022–1034. Link to Journal
- Dahm, M. R., Georgiou, A., Balandin, S., Hill, S., & Hemsley, B. (2019). Health information infrastructure for people with intellectual and developmental disabilities (I/DD) living in supported accommodation: communication, co-ordination and integration of health information. *Health Communication*, *34*(1), 91-99. Link to Journal
- Shogren, K. A., Wehmeyer, M. L., Lassmann, H., & Forber-Pratt, A. J. (2017). Supported decision making: A synthesis of the literature across intellectual disability, mental health, and aging. *Education and Training in Autism and Developmental Disabilities*, *52*(2), 144-157. Link to Journal
- Blackstone, S. W., & Pressman, H. (2016) Patient Communication in Health Care Settings: new Opportunities for Augmentative and Alternative Communication, *Augmentative and Alternative Communication, 32*(1), 69-79. Link to Journal

Although many practical challenges were raised around the involvement of people with intellectual disability in health information sharing and service design, we have identified and reported on several successful examples of this. Inclusive design was a strong consensus point in the Delphi study and a clear recommendation from several advisors. For case studies and practice guidelines on inclusive design in partnership with people who have intellectual disability, we recommend the following resources:

- Evidence Brief: https://www.disabilityevidence.org/questions-evidence/how-can-we-promote-inclusion-people-disabilities-programme-design
- Connect with Me toolkit: https://www.pwdwa.org/documents/connect_with_me/co-design-toolkit/index.htm
- National Safety and Quality Health Service (NSQHS) Standards (https://www.safetyandquality.gov.au/standards/nsqhs-standards/): Specifically the Partnering with Consumers standard.

Most importantly, disability group home residents need to feel welcomed, supported, and safe in the co-design and consultation process.

"I believe in Access to All information that affects your living for all people, regardless of where they live. All stakeholders need to be involved in development of rules - at least consulted."

– Manager (Delphi expert)

"It was really nice to see that the idea of co-design was supported [in the Delphi]. It's slowly coming in. People actually understand those phrase now – some, not everyone. I still get the funny look. 'What are you talking about?' It's maybe 5% of people that I come across, maybe they get a bit of idea."

– Manager (Project Advisor)

"It's really important that when people are willing to share those information. Especially people experiencing a psychosocial disability, a lot of them are already traumatized by the community. So it's really important that we create a safe environment for them when they share the information.

Ask them what's comfortable for them to share... whether it's anonymously, one-to-one ...or are they more comfortable in the group settings? Again, it all comes down to individual preference, but it's really important that it's a safe place for them to express their ideas, to be part of that process.

I did have a few people, really hesitant to share information because they were so afraid to be judged, even just from me. So imagine for them to need to share their very personal opinion about something in the meeting or conference. It can be confronting."

– Support Worker (Project Advisor)

Drivers of Success: Staff

Three core themes came from the Knowledge Translation phase, relating to staffing:

- **Roles around inclusive health communication support needed to be clarified and prioritised, particularly in relation to job advertisement, staff recruitment, workload planning, and the allocation of staff to specific homes.**
- **Staff require support and incentives to build their skills and knowledge around inclusive health communication.**
- **Staff are more likely to implement inclusive health communication practices if they are embodied in clear practice protocols, tailored to each house or resident.**

Participants and advisors noted that support for information access or health decision-making was not a clear or consistent aspect of the support worker role.

> *"People didn't bother talking to anything to the participants, because they basically said, 'Oh, they don't understand. Who cares!'. Happens all the time – again, doesn't necessarily the COVID case. I would really like to have that education about how communication can be achieved through a different venue. ..."*
> **– Support Worker (Project Advisor)**

Time was a limiting factor raised by many participants and advisors to the project. Many of the communication support strategies identified as best practice necessitate time and attention to individual residents, which were not always feasible in the group home environment.

> *"People normally say 'we don't have that kind of time'. That's why I think it's practical for them to basically cherry pick the information that they think is necessary for [residents]."*
> **– Support Worker (Project Advisor)**
>
> *"If the funding allows, I think people can start having those conversations [about health information and decisions]. It comes down to the time and money under the current system. It's very difficult because people are normally on the go. Yeah. Very time-poor."*
> **– Support Worker (Project Advisor)**

Time was particularly stretched during the pandemic as staff had new and increased responsibilities. Shifts were also operating with reduced staffing loads to minimise the risk of cross-infection, and less familiar casual staff were increasingly present.

> *"...Honestly, I think I just talked them [staff] down last week. ...We had to consider these two staff on shift, trying to balance engagement time, mealtimes, cleaning, administering, medication, completing case notes, handing over to evening staff, topping up donning stations, making sure doffing stations were cleared away of used PPE. So that there was a significant amount of work that the staff were having to manage, and having those new [casual] staff in the house was very, very, very difficult."*
> **– Team Leader (observations)**

In addition to workload pressures, participants noted that many staff had limited proficiency in the specialist skills required to support health information access and decision-making for residents. Targeted capacity building for staff is essential, particularly regarding the provision of mental health support, the appropriate adaptation and sharing of health information, and the use of supported decision-making approaches relating to health or information access.

> *"The people I support will often request information from their staff, so training staff to effectively communicate messages is VERY important. This was particularly relevant with the COVID outbreaks and changing mandates, at a time when mental health and anxiety was impacted."*
> **– Manager (Delphi expert)**

All phases of our research highlighted a need for improved training of disability and other healthcare professionals around inclusive healthcare and communication practice. In their meta-analysis of training for staff working with people with intellectual disability, Van Oorsouw and colleagues[53] provide valuable insights and key considerations for running effective training. These include: a) in-service training in combination with on-the-job coaching is more effective than either one in isolation; b) in-service training should vary in technique, for example providing literature, instruction, video demonstration and modelling; and c) verbal feedback is important for better outcomes of both in service training and on-the-job coaching. However, the most effective methods for changing staff behaviour, particularly amidst an active health crisis, remains unclear.

Participants and advisors also noted that staff and managerial attitudes could present a resistance to change, even when training was provided. However, they also acknowledged that services were affected by high staff burnout, turn-over, and a lack of trained support workers entering the job market.

> *"Our company used to have those training [on supported decision-making]. Then, it basically wasting the money and time really, because not everyone interested in."*
> **– Support Worker (Project Advisor)**
>
> *"These [staff] ended up just to sit in the desk and then in the office for 4 hours, and then their phone, and they go home. So that's the reality of the quality of people we're getting at the moment."*
> **– Support Worker (Project Advisor)**
>
> *"Companies are just desperate to get the people, so they would just hire anyone. ... If the company knows the participants actually need that depth of support, then, to start with, I think the company actually needs to start looking for the people who understand those [support] processes."*
> **– Support Worker (Project Advisor)**

Hall and Hall[66] point out inconsistencies in the way organisations define desirable characteristics in direct support staff and call for better evaluation of staff attitudes prior to hiring them. However, low wages and a demanding role make support positions difficult to fill[67], limiting the degree to which recruitment decisions can align with organisational values.

There is, then, the need to develop resilient cultures of inclusive communication practice within organisations, into which new staff can be indoctrinated.

Several of our advisors pointed to the value of having clear, detailed, and mandatory policies to institute practice change. For example, with respect to shared decision-making between staff and residents in the group home, one advisor said: *"It will happen as long as there is a protocol."* It is important to note, however, that policy and paperwork fatigue can present additional barriers to inclusive communication practice in group homes[6], so resulting policies must be tailored and relevant to each setting.

"Like, the NDIA has a change. There was no options, people have to change, so they're doing it. Doesn't necessarily they might want to do it. But at the time it goes, hopefully, people actually understand what accessibility means, what inclusion means, what community engagement means. ... Legislation that would give a kick-start, and then hopefully, that [inclusive practice] will to follow through"

– Support Worker (Project Advisor)

"People are just given rules, without being included in making those rules. ...When we are changing the [health protection] rules, do we also involve the consumers of these rules? We don't. We usually get an email out there: 'Things have changed'. But now the people without access to go out are frustrated, and the people that stay in are also frustrated, because now they follow all these rules that are not relevant [to them]."

- Manager (Project Advisor)

"I didn't really think much about the posters back then. I think it was more - we were getting flooded with paperwork that we had to have up for [organisational] policy. So it was kind of like, 'okay, put that up'.

– Team Leader (observational tour)

"I think the front-line workers, they are supposed to be included in the developmental stages of policy. Because we are out of touch as managers and leaders. So sometimes, some of the things we implement, they [front-line workers] say: 'oh, this doesn't work. But anyway, that's the rules'."

– Manager (Project Advisor)

Drivers of Success: Management

We identified three primary themes during the knowledge translation phase, relating to organisational ethos and management.

- **Many decisions by management are still indicative of medical model or risk-averse position. Inclusive communication requires a shift towards a social model or capability-based approach.**

- **Increased accountability and transparency are needed, with services being open to feedback from staff and service users.**
- **Meaningful use of advisors with professional experience and lived experience of disability should inform inclusive service planning.**

Although participants consistently identified self-determination and co-design as essential drivers for inclusive health communication, advisors also noted the challenge with client-led practice change when participants had significant communication or cognitive disability. Participants described a common approach by services and managers that was consistent with the outdated 'medical model' of disability care. This was in contrast to what some advisors recommended as more appropriate, progressive models of disability service, such as the social model of disability (which places stronger emphasis on self-determination and the righting of inequity).

"I know that we have come through the social movement [of disability]. ...But there are a lot of other people ... including leadership, who are still in that medical model of disability, where they think they have a responsibility to look after people with disabilities, despite the issue of capacity. So this is the kind of mentality that is guiding our policy and practice."
– Manager (Project Advisor)

"A lot of people in this sector – it's a sector that is left with the legacy of the medical model. Also, most of the leadership in the disability sector are from the medical field. So if a person like that leads an organisation, how will the medical model decline? So, I think there is a big deficit within the sector, if they can act from the top to drive policy, to drive practice, this needs people who have contemporary ideas of disability."
– Manager (Project Advisor)

"In the advent of the NDIS now, we are saying there is an issue of capacity. There is an issue of supported decision-making. There is an issue of being able to be the authors of your own life. I don't think that question is being posed enough."
– Manager (Project Advisor)

Advisors raised concerns about accountability and transparency in organisations, noting that concerns around inclusive practice and communication often fell under the radar of quality assurance checks. Surface-level policy compliance was also identified as a common way to mask underlying issues in under-resourced or pressured service systems.

"It all really depends on how much participants, are they going to make a noise based on [negative experiences]. ... These are people, generally speaking, just a bit left behind because they're quiet. They're not the problem.
I always find those safety [assurance] things that Government or the NDIS trying to place ...It's almost like a defeat. The purpose is meant to be supporting the people that need

support to voice themselves, but it's actually not getting to them, because of the way the method works.”

- Support Worker (Project Advisor)

“What's happening is ... ‘Yes, we've got this protocol here. We've got this, this, this in the group home.’ No one's actually checking. Ideally, yes, coordinators, house managers, they should be really keeping an eye on - but the reality, the most of them, they’re too busy on their plates, so as long as nothing happening, as long as it looks good on paper... So, a lot of underlying issues is still hidden.”

– Support Worker (Project Advisor)

Project advisors described a lack of receptiveness in some disability service management teams, to concerns or ideas raised by residents or staff. Our project advisors called for increased use of advisory boards, feedback mechanisms and auditing to support this process.

“I’m always trying to be the voice of people who can't talk. Then what? What do I get in feedback? Unfortunately, I got bullied by the management, because they didn't want to hear from me.”

– Support Worker (Project Advisor)

“A lot of [senior leadership] don’t want to be questioned. Or if there is a question, they look at it as defiance.
They think ‘we [leadership’] are there to inspire’. When in fact, they are not there to inspire, but to create an environment that allows people to be inspired. So, still we are in the doldrums when it comes to that”.

– Support Worker (Project Advisor)

“A lot of organisations have got systems in place so that we keep things inside. Take for example the complaints policy. You [staff] have to complain within, before you go out. ...People with disability... have the right to go to the commissioner if they want to. But ... how we write our policies, we give them their freedom, but we write it in so little font that you never read it. So this is what happens – they are not told that they can go to the Commissioner before they go to the CEO. They are encouraged to keep it inside.”

– Manager (Project *Advisor)*

“Internal reporting, sometimes it's not practical or even reliable. It depends on who's the boss. I’ve had some company really responded to [feedback] well, with genuine concern ...they really took it seriously. Then some places, it's just point blank: ‘We don't want that. We don't want to listen’.”

– Support Worker (Project Advisor)

"The organisation is the voice of people with disabilities. Just be sure that the voice is present and is heard in policies. How do we do that? We create [advisory] groups within the community, the organisation, of people with disabilities. ...They can discuss amongst themselves, what do they think about things, without influence of people without disabilities."

– Support Worker (Project Advisor)

Drivers of Success: Policy, Procedure, and Protocol

From the project, we identified four core knowledge translation themes relating to policy.

- **There has been a slow but noticeable shift towards more progressive models of service in the disability accommodation sector, accelerated by the advent of the NDIS.**
- **New and revised policy must account for pressure on organisations (resourcing, compliance, risk management).**
- **Policy and procedure must be co-designed with end-users (residents and staff).**
- **Clear, tailored, and specific protocols form an important translation of policy into practice.**

During the consultations, many participants across our stakeholder domains expressed gratitude to the NDIA and Government departments for the provision of general information during the pandemic. Dedicated policies and procedures were called for, with two caveats: 1) that any new or revised communication policies released during a pandemic were useful and relevant (to avoid unnecessary burden) and 2) that policies and procedures could accommodate the diverse communication needs of different residents, staff, and group home environments.

"It's a matter of looking at looking at the NDIS and the governance of the Health Department. I think that they were wonderful with the dissemination of information, and the directives that were given to disability organisations were straight forward. But then you see that there was a clause at the bottom to say: 'Each organisation can be able to tailor make this to fit the dynamic in their organisation'. ...So, we are able to go into our teams and see what is relevant, what is happening in our teams, and see what applies to them."

– Manager (Project Advisor)

Advisors saw co-design and consultative practice as essential elements of successful policy development, to ensure they are fit for purpose, and to embody values of self-determination and inclusion. We heard many reflections indicating that this had not always been the case during the pandemic.

> *"There is a lot of policies that would have been done without even going back to them [residents] and saying: 'what do you think about this'. Take, for example, putting posters in a home. ...If I come to a person's home right now, do I see a poster? To put pictures of yourself on your own wall, that's your own decision. Imagine if it's a picture or a portrait that tells you to do something every day. ...I saw a blip of institutionalisation there. In an institution, we all look to the wall, we all go to the noticeboard. ...But this is not the group that is deciding that. It is the people who live outside the group."*
> **– Manager (Project Advisor)**

Drivers of success: Community

Finally, three core themes relating to the role of the broader community and sector arose from the Knowledge Translation phase:

- **Appropriate resourcing for disability accommodation and inclusive healthcare.**
- **Authentic and informed community advocacy and auditing.**
- **Valuing disability support work as a specialist profession and building it up as an attractive career path.**

Lack of resourcing (funding, staff, and time) to support inclusive communication practice was a core finding of this project, affecting every aspect of practice. Any future quality improvement interventions must consider the backdrop of a poorly resourced sector governed by policies that are not always relevant or feasible for end-users (staff and residents). However, some advisors noted that the representation of people with disability in senior leadership and governance roles was helping to combat these issues.

> *"I think we can see this difference in the NDIA. [The people running NDIA] bring lived experience that we don't have when we put policy. ...Because they've used these systems, they are users, they are consumers, and they are now making these decisions. ... It's the same as saying, he who puts food on the table should also be eating. ...In a restaurant... if we were including a chef at our table and saying, 'we are dining with you today', I'm telling you, that meal would be totally different. ... This is the kind of information we get from people with disability when they are at the policy vetting or development stage."*
>
> **- Manager (Project Advisor)**

Community members can also be powerful agents of change. Noting previously described challenges in accountability and pressures from compliance and risk-aversion within the sector, some project advisors called for increased external/third-party scrutiny of inclusive health communication and supported decision-making in group homes. However, they also recommended that auditing and compliance teams needed to gain more "insider knowledge" within group homes in order to ensure an accurate assessment was made.

> *"The company gonna be in trouble if they don't listen to all the family members. ... If come from the family, it's a little easier. They have to deal with it."*
> **– Support Worker (Project Advisor)**
>
> *"They [auditors] don't really spend enough [time] to understand, because people can put the best of behaviour on when these people around. So it's almost like it you need someone going to the workplaces employed as a support worker. Spend a few weeks. Then you actually get to see the real things that are actually happening. Otherwise, if you just to go there as someone from external, you will never find out the issues. You're only gonna see the good part, or you might find little issues that they don't mind sharing, because that's not going to be issue for the company."*
> **– Support Worker (Project Advisor)**

Finally, participants raised concerns that communication practice within group homes was unlikely to change until the culture and capabilities of support workers had been grown. Advisors called for an elevation of Disability Support Work in the sector and the broader community in order to attract and retain high-quality and committed workers to the sector.

> *"Disability Support Worker – I think as a sector we undermine that role a lot. It is the most important role of all. There's a lot of information that the Disability Support Worker understands about the [NDIS] participants that we [managers] don't."*
> **– Manager (Project Advisor)**
>
> *"It's a stepping-stone [job] for most people. And that really breaks my heart, because you have these people who would have done so well [as a support worker], but they are studying something else. And after probably two years of doing so well, they say: 'Oh, I'm an accountant now'. So it's about making sure that we make the Disability Support Worker role a better role, a career. So that people say: "I want to be a disability support worker' – full stop."*
> **– Manager (Project Advisor)**

Future Research Directions and Next Steps

Participatory action research has been challenging to undertake in an overstretched sector amidst the backdrop of a global pandemic. Nevertheless, we cannot overstate the value of working inclusively with industry partners and service users to address the complex practice issues this project has unearthed. We hope that future researchers can learn from our experiences when undertaking similar work. To this end, we have prepared two appendices (B and C) as research guides, and we encourage readers to visit our Doing Inclusive Research portal on the project website.

> *“I think we have a role to play, as people in practice, to fit into the production of knowledge.”*
> **– Manager (Project Advisor)**

We plan to share this work as widely as possible, and we will keep updating our project resources as new information becomes available. The team will continue collaborating with our partners and project advisors, using techniques such as brainstorming and rapid prototyping to develop specific resources for use in each sector. Panel members will be encouraged to use the resources within their organisations and provide feedback on their utility and uptake.

All information resources produced within this study will be available to Australian service providers free of charge via our project website. Usability testing and revision of these ‘living resources’ is likely to continue beyond the formal study period, and we encourage anyone using our resources to provide us with ongoing feedback. We will also learn how effective the practice guidelines and resources are in the event of future infection outbreaks.

Further research is needed to guide the application of these results for future pandemics across sectors that support people with intellectual disability. Questions for future research include:

- Who should be responsible for sharing these findings, and why? What would be the best way of sharing the findings with relevant sectors such as disability services, age care, acute care, and general practice?
- What changes, practical resources, or funding would be needed to implement and evaluate the relevant recommendations from this project in each sector?
- Given the heterogeneity in settings, experiences, and support requirements, how could benchmarks for inclusive health communication about infectious disease be defined and assessed?
- How could group home residents be involved in sharing and implementing these recommendations, and what conditions and/or resources would enable this?
- How could policy changes or new policy assist in putting these recommendations into action?
- How could the Government or health agencies help in putting these recommendations into action?

Conclusion

Communication breakdown is a significant contributor to adverse healthcare outcomes for people with disability; this includes both interagency communication as well as interactions between staff and service users[68]. People with intellectual disability are frequent users of mainstream healthcare, and frequently report negative experiences and poor outcomes from these encounters[69]. While general guidelines have already been developed for communicating with people who have intellectual disability in a range of healthcare settings[68, 69], the validity and usability of these practises during pandemics or other public health emergency responses had not been established prior to this project.

Our research addressed this knowledge gap by exploring how the disability group home sector has approached communication support for residents during COVID-19 and identifying key practice implications for future pandemics. This project has generated several novel insights into the way that information about infectious disease is communicated to, and within, group home settings. Most prior research about public health interventions for people with intellectual disability have described a one-way flow of information from experts (e.g., Governments, health professionals and service providers) to individuals or their supporters. Hygiene training programs and accessible information materials are two common examples of this model. However, our research suggests that group home staff and residents do not rely solely on these lines of communication to make informed decisions about their health. Instead, we have learned that understandings about infectious disease are formed through complex, multi-way dialogue between residents, staff, and people outside the home. Time, trust, and tailored and accessible communication strategies are an essential part of this process.

This project has delivered a suite of practice guidelines for inclusive health communication in group home facilities. We have also developed a framework to guide knowledge translation, addressing all practice domains in the disability accommodation sector. Although this project was instigated in response to the current COVID-19 pandemic, we expect the resulting communication guidelines to be applicable in future disease outbreaks that potentially impact group home residents, such as measles, norovirus, rotavirus, influenza and SARS. The inclusion of multidisciplinary and multi-sector representatives throughout the proposed project is also enabling us to evaluate the applicability of the core guidelines and resources beyond the disability accommodation context.

For further information about this project, or to collaborate on future research and knowledge translation activities, please contact our lead researchers:

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Glossary of Terms

Augmentative and Alternative Communication (AAC): Methods of communication used by people with communication disability, that supplement or replace spoken communication. AAC includes both ‘aided’ strategies (e.g., pointing to words or picture symbols in a communication board or book, using an electronic speech generating device) and ‘unaided’ strategies (e.g., gestures, facial expressions, vocalisations).

Complex Communication Needs (CCN): People with CCN have significant difficulty with understanding or producing spoken language. They may use limited speech or no speech to communicate, and they may use forms of AAC (see above) to supplement their comprehension or expression. Also known as Complex Communication Access Needs, Complex Communication Support Needs, and Severe Communication Impairment.

COVID-19: The name of the infectious disease that’s caused by the SARS-CoV-2 novel coronavirus. This research was conducted during the global COVID-19 global pandemic period and is a significant theme in our findings.

COVID-Safe: A term commonly adopted by Australian businesses and in Australian Government documentation to refer to a range of public health measures for preventing the spread of COVID-19, including contact tracing measures (e.g., visitor registers, Government check-in apps), the use of personal protective equipment (PPE, e.g., masks, gloves, and gowns if appropriate), and the maintenance of social distancing.

Deafblindness: A combination of hearing and vision impairment, also described as “dual sensory impairment”. People with Deafblindness may communicate in a range of ways, including the use of speaking and listening, print, braille, sign languages (including tactile sign language), and AAC (see above).

Delphi study: A Delphi study is a method of research, where a panel of experts (people who possess lived experience or professional experience about a topic) come to a decision about good practice. The experts rate practice statements in a survey, and they explain why they did or did not agree. The statements are revised based on feedback, and the surveys are repeated until a consensus is reached.

(Disability) group home: A supported home environment where multiple people with disability are accommodated together and receive support from carers (typically paid staff).

Infectious disease: Any disease that you can catch from other people, such as COVID-19, influenza, HIV, gastroenteritis, or the common cold. Infectious diseases can be caused by bacteria, parasites, fungi, or viruses.

Intellectual disability: Intellectual disability is a developmental condition characterised by significant limitations in both intelligence (general mental capacity) and adaptive behaviour (such as communication, planning, social problem solving, and the management of personal care, personal safety, and occupation).

Specialist Disability Accommodation (SDA): Purpose-build housing facilities for people with extreme functional impairment or very high support needs. People may be supported to live in SDA independently, with family, or with other people (e.g., disability group home).

Outbreak: A sudden rise in cases of a disease, above the rates that are normally expected for the affected community/communities. An outbreak is called an epidemic when is spreads rapidly to many people.

Pandemic: A global outbreak of an infectious disease, affecting many countries (often worldwide).

Communicating about Infectious Disease in Disability Group Homes: Best Practice Recommendation

These best-practice statements were informed by interviews with group home residents and staff, group home observations, and existing research and policies. They were revised by our industry advisors, and were approved by seven experts (experienced group home managers and support workers) as part of a Delphi study. We welcome further feedback and adaptation.

Access to Information	Topics of Information	Sources of Information
These recommendations address the way that information about disease outbreaks is presented to group home residents.	*These recommendations address the breadth and depth of topics about infectious disease that should be made available to residents. Topics will depend on the infectious disease being managed.*	*These recommendations are about the role of group home providers in ensuring that residents can access information about disease outbreaks from a range of sources.*
If residents want information about a disease outbreak, this should be provided in a format that meets their individual communication needs, such as plain language, visual aids, sign language, or tactile (touch-based) communication. Group home residents should have access to video, audio, and pictures as part of any information provided about a disease outbreak. Posters and visual displays can be helpful in communicating information about infectious disease. Residents should be involved in deciding if, and how, posters or visuals are displayed in their group home. Modelling or demonstrating health protection behaviours (e.g., hand hygiene, mask wearing, social distancing) is an important way to inform group home residents during disease outbreaks. Group home residents should have the opportunity to design or contribute to information resources about outbreaks, that will be used by them and their staff.	Group home residents should have access to the same topics of information about a disease outbreak as everyone in the general community. Information about each topic may need to be simplified for some residents to support their understanding. Group home residents should be involved in deciding what topics of information they have access to regarding disease outbreaks. Supporters (e.g., family or friends), professionals (e.g., disability or healthcare workers) and government bodies should be involved in deciding what topics of information people with disability have access to regarding disease outbreaks.	Group home services should support residents in accessing information about disease outbreaks from the following sources: • television or radio (mainstream media) • government or health agencies (e.g., press conferences, Government websites, Government apps) • disability agencies (e.g., group home meetings, case conferences, emails from service provider) • familiar health professionals (e.g., GP). Group home services should also support residents who want to access information on social media (e.g., TikTok, Facebook, Twitter, YouTube, online discussion groups and forums), or via the Internet (e.g., Google searches, general websites). This may include support to understand the risks or limitations of these information sources.

Understanding Information	Residents Sharing Information	Consent and Decision-Making
These recommendations address the role of group home staff in supporting residents to seek and understand information about disease outbreaks.	*The following statements address the roles and capabilities of group home residents in communicating and sharing information about disease outbreaks.*	*These recommendations are about informed decision-making and consent for residents, relating to health information.*
When a group home resident is exposed to information about a disease outbreak, group home staff should help the resident to understand the information, for example by using simpler language, sign language, pictures, or gestures. Group home staff should be trained and supported in how to help group home residents understand information about a disease outbreak.	Group home residents should be encouraged to express their thoughts and feelings about a disease outbreak. Monitoring behaviours of concern is an important way to understand how a group home resident may be responding to a disease outbreak. Some residents may want to play an active role in health communication, such as helping their housemates, staff, family, friends, community members, or other people with disability to understand or cope with a disease outbreak. Group home providers should support interested residents to meaningfully participate in these roles.	Group home residents should be supported to make their own decisions about health risks during disease outbreaks. Group home residents should be supported to make their own decisions about following public health rules. Group home residents should be supported to make their own decisions about following public health guidelines and recommendations (e.g., getting vaccinated, practicing hand hygiene, or avoiding high-risk activities). Group home residents should be supported to make their own decisions about who has access to their health information (e.g., knowing a positive test result or vaccination status) during an outbreak. The personal opinions and beliefs of group home residents about a disease outbreak should be respected.

Appendix B: Inclusive Consent Protocol

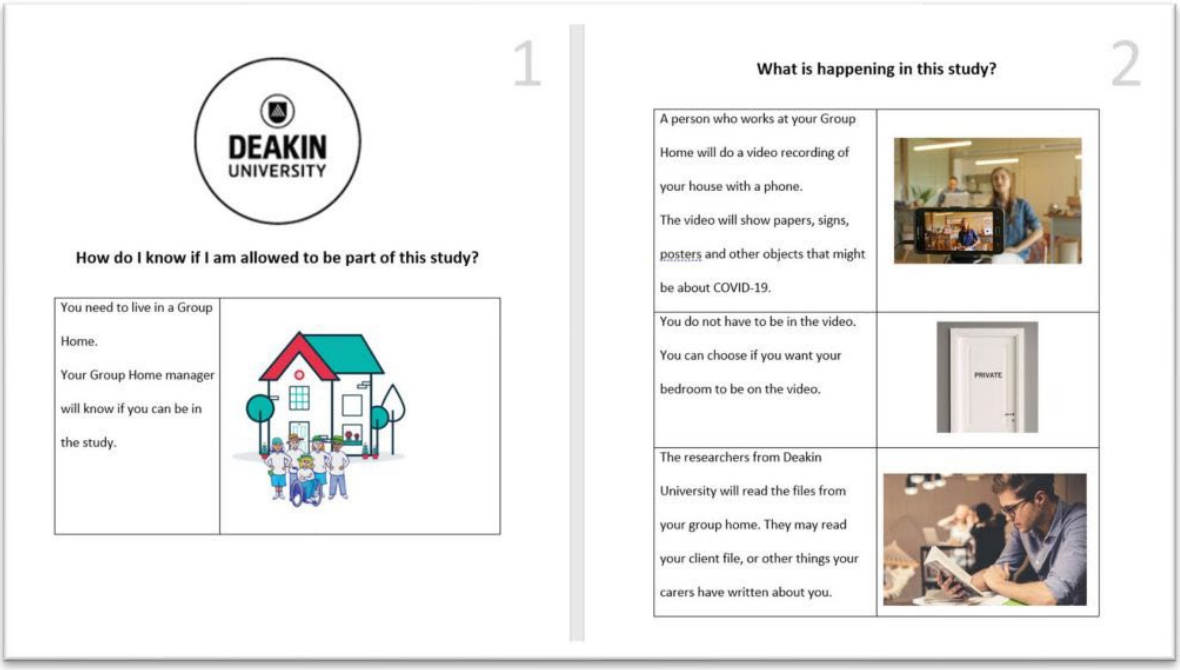
Information about the study was written in Plain English, as per standard research protocol. However, our project was inclusive of many participant groups who required additional access or information support due to communication diversity. This included:

- Staff, residents, and family members with limited English fluency or literacy,
- Staff, residents, and family members who had limited experience or confidence with research activities, or were anxious about the research process,
- Participants with vision impairment,
- Participants who were Deaf, Hard of Hearing or Deafblind, and
- Residents with intellectual disability who required help to give informed consent.

This project employed several strategies to maximise all participants' ability to receive and comprehend research information and make an informed choice to participate. These strategies were co-designed by expert advisors and members of the research team who shared significant expertise and experience supporting people with diverse communication needs to understand information and make informed choices. The strategies and materials were also piloted with organisational partners, and adjustments were made based on their feedback.

Picture-supported and video-based information statements

There are several ways that we have adapted our consent process for participants. One strategy is to use very simple language combined with meaningful pictures, as shown in the screenshot below. This format is easier for people with lower literacy or language skills to understand. It can also be useful when a participant and a researcher/supporter are having a less formal conversation about the study.



How do I know if I am allowed to be part of this study?

You need to live in a Group Home. Your Group Home manager will know if you can be in the study.	

What is happening in this study?

A person who works at your Group Home will do a video recording of your house with a phone. The video will show papers, signs, posters and other objects that might be about COVID-19.	
You do not have to be in the video. You can choose if you want your bedroom to be on the video.	
The researchers from Deakin University will read the files from your group home. They may read your client file, or other things your carers have written about you.	

Another strategy we developed with the support from our Advisors is **video information statements.** These were first suggested to us by our industry co-researchers at Northcott and Able Australia. You can see lots of examples on our project site, e.g., for support worker interviews and group home case studies. We usually record our videos using Microsoft PowerPoint. They are a combination of simple spoken language, simple text, and pictures. We sometimes add captions or sign language, depending on the audience. Our video process was first designed for participants with intellectual disability who were unable to read, and for disability support workers who were very busy or did not have strong English language skills. However, we have since found the videos to be very helpful for research with other participant groups. They are easy to access on a mobile device, quick to watch, easier to understand, and they can also be very reassuring. We strongly recommend the approach!

Individually tailored information

A modified participant information process was further tailored to each participant's communication needs, where this was deemed appropriate and potentially useful. In these cases, a familiar staff member or internal research at each participating organisation assisted staff, residents, and their family members to understand the study through a range of strategies, including one-on-one spoken or signed conversations, and the use of pictures or real objects to help demonstrate research concepts.

Supported decision-making

For people with severe or profound intellectual disability such as the participants in Arm 2 of this study (group home observations), gaining informed consent can be challenging. In cases where a resident could not provide independent informed consent, a person who knows the potential participant well (a proxy) will use a supported decision-making process to represent their will and preference regarding their participation in the study. **Supported decision-making** is a process where a person with a cognitive disability, such as intellectual disability, is given the necessary support to participate in decisions about their life.

When participants required support from a proxy decision-maker, we applied a set of criteria to determine whether a supporter was able to represent the person's will and preference, in relation to their participation in the research. These criteria were based on a growing body of research on supported decision-making for people with severe intellectual disability[64] , and included:

1. having a positive and stable relationship with the participant, or being willing/able to develop such a relationship;
2. knowing the focus person's history or are willing to learn about it;
3. having a commitment to the focus person's duty of care;
4. being familiar with the focus person's communication and therefore their expressions of preference;
5. being committed to prioritising the perspective of the focus person;
6. being committed to the principle of Assent. This meant that any consent obtained by proxy was required to be accompanied by nonverbal indications that the person is comfortable participating in the study. If at any time a person's non-verbal behaviour

indicated a discomfort with participation, supporters had a responsibility to communicate this to the research team.

These criteria were communicated to decision-making proxies via the proxy consent form and were also discussed during a phone interaction with a member of the organisation's own research team. Proxy decision-makers were required to acknowledge their capacity to act in this role before signing the consent form.

A dynamic approach to consent

We were mindful that COVID-19 could be a sensitive topic. For some participants, particularly those with intellectual disability, distress or fatigue can be communicated through subtle non-verbal indicators or behaviours of concern. The research team carefully monitored participants for signs of fatigue or distress during data collection and were prepared to offer participants a break or the option to end their participation if these issues were suspected. To increase the sensitivity of this protocol, only interviewers who were very experienced in working with people who have complex communication support needs undertook interviews with group home residents. Researchers also spoke with group home staff to better understand a resident's communication support needs before an interview.

Appendix C: Ethical and practical considerations for video observation

In designing the observational arm of the research, we had to consider several practical and ethical challenges, including health safety, privacy, usability, connectivity and consent.

Remote Observations for Health and Safety

COVID-19 outbreaks were active in the community for most of the research period, so we opted to use remote video-based observation as the safest data collection method. To make this feasible, we purchased a water-resistant mobile phone that could be sanitised for use between group homes, and pre-loaded it with internet data to remove the need for staff to use an internet connection at the house. We associated the phone with a project-specific gmail account, which we then used to create video appointments with a research team member in Zoom. At the time of the interview, a research assistant from the organisation delivered the phone to staff at the home and assisted the staff member in joining the observation session via the dedicated appointment link. The observation session was then moderated and recorded by the researcher directly via Zoom, avoiding the need to transfer any confidential video data via a digital device.

Informed Consent for Remote Observation

Being the subject of video observation is an abstract concept, and this brought additional considerations for ethics and consent. Some residents with intellectual disability were unlikely to realise that they were being observed in their home without a stranger being physically present. Without this awareness, they would be less likely to control their own privacy by removing themselves from the observation field, or keeping private spaces and belongings hidden. To manage these risks, the research team implemented the following additional procedures:

- Residents were not recorded as part of the video tours.
- Observations were scheduled for times when most residents were not at home, and staff were instructed to pause the recording or avoid certain spaces if residents were present to prevent them from being captured on film.
- A consent question was added concerning the inclusion of residents’ bedrooms in the video data collection. Given that the majority of participants/supporters answered “no” to this question, we decided to avoid all bedroom spaces during the video tour.
- Group homes were encouraged to post notices before the tour, to notify alert any potential visitors that a recording was in progress. However, due to COVID-19 restrictions the likelihood of visitors entering during this time was very low, and none appeared during the actual filming.

Unanimous and independent consent

Group homes are shared spaces, so we needed to ensure that all residents in the home provided independent consent to participate. To achieve this, a research assistant from the partner organisation spoke to members of the group home community or their family members privately, to explain the nature of the study, answer any questions, and seek consent. Group home staff and managers were also engaged in separate discussions about the research. We kept residents' individual decisions private from other residents and staff. Finally, in the consent process we reassured residents about their right to decline or withdraw their consent, with the following wording:

'Please remember, even if your provider, house manager or housemates want to be part of this study it does not mean you have to say "yes". If you're worried about what other people might think, you can call us or talk to us in private. We won't tell your staff or housemates if you say "no" or change your mind.'

Communication and Rapport

Accessible research tools and forms played an important role in our study's informed consent process. Ultimately, however, the most effective strategy was offering clear and open discussion about the research with a trusted professional. Some residents, staff and supporters were uncertain about the research at first. They were worried about whether videos or individual details about residents would be shared or published. Residents, family, and staff had experienced an increase in consent requests for research and medical procedures during COVID-19, and we detected some fatigue or frustration around this additional workload. Having access to a familiar research assistant within the partner organisation helped to provide clarity and reassurance around the research process. The research assistant also provided staff, residents, and proxies with practical assistance in completing and returning research paperwork. This interpersonal role ended up being critical to the success of the project.

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