



# COVID-19 experiences of Australian adults with complex communication needs living in supported accommodation

**Dr Darryl Sellwood**  
College of Nursing & Health Sciences  
Flinders University  
South Australia, Australia

**Professor Joanne Arciuli, PhD**  
College of Nursing & Health Sciences  
Flinders University  
South Australia, Australia

# Introduction

- Governments worldwide instituted COVID-19 public health measures
  - Containment policies
  - Mitigation policies (Chen et al. 2021)



The United Nations declared COVID-19 a global pandemic in March 2020, prompting governments around the world to institute a range of public health measures. Initial responses varied with governments opting for policies designed to either contain or mitigate the impacts of the virus. Containment policies sought to stop the spread. By contrast, mitigation policies, such as social distancing, sought to control infection rates, and minimise hospital admissions.

# Introduction

- Governments worldwide instituted COVID-19 public health measures
  - Containment policies
  - Mitigation policies (Chen et al. 2021)
- Australian governments
  - Containment in 2020
  - Mitigation from 2021 (Colon-Cabrera et al. 2021; Polonsky and Weber 2022)



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

In Australia both federal and state governments implemented a range of containment measures throughout 2020, including a variety of border enforcement and quarantine measures and stay-at-home orders. These were replaced with mitigation measures, including mandatory mask wearing and physical distancing in public places, as infection rates climbed.

# Introduction

- Australian National Disability Insurance Scheme (NDIS)
  - Introduced in 2013
  - Supports Australians with permanent, significant disabilities
  - Gives people 'choice and control' (Dearn et al. 2022; Kavanagh et al. 2021; NDIS 2020)
  - 554,917 participants (NDIS 2022)
  - Supported independent living



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

The Australian National Disability Insurance Scheme (NDIS), introduced in 2013, is a scheme funded to provide a nationally consistent approach to providing Australians with permanent and significant disabilities, 'choice and control' about where they live and who provides their support services. In September 2022, there were 554,917 participants registered in the NDIS scheme.

Some NDIS participants have severe functional impairments, mostly physical, and require considerable personal support for tasks associated with daily living, referred to as Supported Independent Living. This group are amongst those most at risk of catastrophic outcomes from COVID-19 infection, and disruptions to disability support and health services.

# Introduction



- Public health policies in Australia

- Slow to meet needs of people with disabilities (Dickinson, Llewellyn, and Kavanagh 2022; Kavanagh 2020; Kavanagh et al. 2021)
- No clear guidelines
- People and supporters left to navigate health and safety risks (Kavanagh et al. 2021)
- 25% adults with disabilities had poor access to services (Cicuttini et al. 2022)
- Australians with disabilities lower ratings for physical health (Australian Bureau of Statistics 2022)



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

Public health policies implemented in Australia during the early stages of the pandemic were slow to consider and address the needs of people with disabilities. In the absence of clear guidelines for supporting individuals with disabilities, their families, support workers and disability support agencies were left to navigate the health and safety risks of the pandemic.

The impacts of public policy on support access and wellbeing outcomes for adults with disabilities during the pandemic are beginning to come to light. It is estimated that around a quarter of adults requiring health or disability care, had poor access to such services during the first month of nation-wide restrictions in Australia. During 2021, Australians with disabilities were less likely to rate their physical health as excellent or very good (29%) as compared to those without disability.

# Introduction

- Research on pandemic experiences of Australian adults with disability
  - Focused on people with specific types of disabilities (including spinal cord injuries, brain injury and multiple sclerosis)
  - Identified problems accessing information and support services (Bellon et al. 2022; Lakhani et al. 2022; Lawford et al. 2022)



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

Research on the experiences of Australian adults during the pandemic with specific types of disabilities, including spinal cord injuries, brain injury and multiple sclerosis, has identified themes including problems with accessing information and support services, some noting that telehealth has been useful for promoting access to allied health services.

# Introduction



- This research
  - Investigated experiences of Australian adults with disabilities living with government supports in their homes
  - Focused on changes in life satisfaction before, during and since COVID-19 lockdowns
  - This presentation mainly reports on findings of AAC users within the study



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

This research investigated the experiences of Australian adults with disabilities and living with government supports in the home, with a focus on changes in life satisfaction, before, during and since COVID-19 lockdowns, and the factors underlying these changes. This paper primarily reports findings specifically pertaining to participants in the study who use Augmentative and Alternative Communication (AAC), who will be referred to in this presentation as “AAC users”.

## Method



- Inclusion criteria
  - Living in Australia
  - Self-identify as living independently in accommodation supported by NDIS
  - Able to communicate in English
  - Able to read independently or with assistance
  - Able to respond to questions independently or with assistance



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

In this study, participants were required to:

Be living in Australia.

Self-identify as living independently in accommodation supported by the NDIS.

Able to communicate in English.

Able to read independently or with assistance.

And able to respond to questions independently or with assistance.



# Method

- Survey responses
  - 34 valid responses (“participants”) after screening out ‘bots’ (Storozuk et al. 2020)
  - 5 self-reported as using AAC for communication (“AAC users”)



Survey responses were screened for potential, ‘bot’ responses, in line with the recommendations of Storozuk et al. (2020). This included checking IP addresses, postcodes, demographic information and determining genuine responses to open-ended questions. Thirty-four responses were identified as valid. Five of these self-reported as using AAC for communication.

## Method

- Online survey
- Explored three periods
  - Before COVID
  - During lockdowns
  - After lockdowns
- Multiple choice questions and five open-ended questions



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

The survey explored three periods: before lockdowns in 2020, during the most restrictive periods, and after most public health measures were scaled back (late 2021 onward). The majority of the survey questions were multiple choice, with five open-ended free, text questions. The survey was open from September 2022 to March 2023.

# Method

- Recruitment

- Open between September 2022 and March 2023

- Research flyer distribution
  - email
  - social media
  - posted on websites and noticeboards



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

We used convenience sampling in this study. An ethics approved research flyer, with a QR code, advertising the aims and requirements of the study, was distributed widely, via email and social media, and posted on websites and noticeboards.

# Method

- Data analysis

- Descriptive quantitative analysis
- Qualitative analysis of responses to open-ended questions
- Manually compared data from AAC users with whole dataset



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

The research team used descriptive quantitative analysis to review the overall survey data, and qualitative analysis of the responses to open-ended questions. I then took a descriptive approach to compare the data from the AAC users against the whole dataset.

# Results

## Demographics (AAC users)

Participant	Age range	Self-reported disability	Living arrangements	Communication methods (self-reported)	% of questions completed
P1 (Female)*	41-50 years	Autism, ADHD, Ehlers-Danlos Syndrome	Live alone	Speech, AAC ("Otter transcription for meetings etc."), writing, other ("Wild gesticulation")	84
P2 (Male)*	51-65 years		Share with other NDIS participants	AAC ("Ipad Communication App, verbal gestures")	94
P3 (Male)*	51-65 years	Cerebral palsy	Live alone	Speech, AAC ("touch screen sgd")	94
P4 (Female)*	26-30 years		Live with family	Speech, AAC ("Touchchat HWP")	85
P5 (Male)	51-65 years		Live alone	AAC ("Sign language")	50

\*Responded to at least one of the open-ended questions (other than demographic questions).



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

As you can see from the slide, of the five AAC users, two were female and three male. The males were in the 51–65 years age range. One of the females was 26–30 and the other was 41–50 years. Three of the participants lived alone, one with family and one in shared accommodation. The types of communication methods reported included AAC, speech and writing. It was difficult to break the data down more specifically, as the participants were invited to elaborate on the type of AAC or other communication modes that they use in free text fields. Four of the AAC users completed at least 80% of the survey questions. The fifth person only completed 50% of the questions. Of the AAC users, Participant 4 responded to four of the open-ended questions. Most AAC users only provided responses to one or two. Only one of the AAC users reported having had Covid-19, indicating they experienced moderate symptoms and moderate impact on the disability and medical supports they received.

## Results



- Life satisfaction
  - Four AAC users reported decrease in overall wellbeing and mental health
  - These improved but have not returned to pre-COVID levels
  - Considerably lower than other participants across all categories/periods

While one of the AAC users reported being strongly satisfied with all aspects of life during all three periods (which were, before, during and after lockdowns), the other four AAC users reported a decrease in overall wellbeing ratings, from before, to during lockdowns, which, while improving, have not returned to baseline levels since the lifting of COVID-19 restrictions. These levels were all considerably lower, across all the categories and periods, than the rest of the participants.

# Results

- Daily activities

- Decrease in most daily activities
- Most have returned to pre-COVID levels
- One AAC user indicated voluntary work has not resumed
- Frequency of study less affected by lockdowns



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

Participants generally reported a decrease in most daily activities, from before to during lockdowns. The frequency of most daily activities has returned to near-normal (pre-lockdown) levels since the ceasing of lockdowns, though some activities appear to be lagging (e.g., participation in voluntary work and community groups). Findings among AAC users were similar. For example, the one AAC user who indicated doing voluntary work before Covid reported that this had not resumed since restrictions were lifted. Frequency of study was less affected by lockdowns, possibly due to these activities moving online. In fact, one AAC user apparently started studying during lockdowns and this continued after restrictions were lifted.

# Results

- Self-care supports

- Participant 4 reported

“immediate family helped on daily basis.”

“I rely on my mother and stepfather to assist with all my personal [support]”

“I have been unable to resume my regular community participation, groups or 1.1 supports due to lack of [...] support worker pool with relevant qualifications for personal [support].”



Participants reported reductions in support they received for self-care, from before to during lockdowns. Self-care supports have returned to near baseline levels since lifting of lockdowns. Participant 4 stated, immediate family helped on daily basis. She also commented, I rely on my mother and stepfather to assist with all my personal support, and later reported, I have been unable to resume my regular community participation groups, or 1.1 supports, due to lack of support worker pool with relevant qualifications for personal support.



# Results

- How supported did you feel by various groups?
  - immediate family
  - extended family
  - neighbours
  - close friends
  - extended social network
  - work colleagues
  - social groups (e.g. Rotary, church)



Participants were asked to rate how supported they felt with regards to various groups of people. Support declined, from before to during lockdowns, most strongly in relation to support received from extended social networks and groups. There were relatively small reductions in the level of support received from immediate and extended family, neighbours, close friends and work colleagues. Levels of support across most of the explored groups have returned to near-baseline levels since lifting of lockdowns. Interestingly, although almost half of the survey participants reported feeling supported by neighbours, AAC users indicated they felt little support from neighbours across the three periods. All four AAC users who responded to the question, were concerned about the number of different support workers coming into their homes. This is almost one third of the survey participants who expressed the same concern.

# Results

- How connected did you feel to various groups?
  - immediate family
  - extended family
  - neighbours
  - close friends
  - extended social network
  - work colleagues
  - social groups (e.g. Rotary, church)



Participants reported decreasing connectedness with almost all the explored groups. Participant 3 indicated it was helpful when neighbours were, 'bringing over a beer to share.' Levels of connectedness have returned to near pre-lockdown levels for most groups since the lifting of restrictions, though the proportion of participants connected and strongly connected with their extended social networks, work colleagues and social groups has remained relatively low. However, Participant 4 reflected that after lockdowns, 'many neighbourhoods have changed with new people and old people have moved, Social groups have shut down, Friends have moved states, family are older and suffering from limited finances or supports to travel.'

## Results

- Experiences with mask wearing and social distancing
  - Difficult or not possible to wear a mask
  - Difficult or not possible to socially distance
  - More difficult for AAC users than other participants
  - No AAC users felt comfortable going out in public
  - All AAC users had bad experiences in public



One AAC user did not answer the questions relating to experiences with mask wearing and social distancing. Three indicated it was difficult or not possible to wear a mask or socially distance from others because of their disability. This is almost half of the participants in the study who indicated difficulty with these things. Mask wearing and social distancing seemed to be more difficult for AAC users than for other participants.

None of the AAC users indicated feeling comfortable going out in public and all reported having negative experiences in public places because of not being able to practice social distancing and/or wear a mask.

## Discussion

- Research in UK and Canada found negative impacts of public health policies (Derakhshan et al. 2022; Emerson et al. 2022; Shakespeare et al. 2022)
- Mental health and happiness not rated highly at any point (Dew et al. 2018)
- AAC users life satisfaction noticeably lower across all categories/periods



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

Research conducted in the United Kingdom and Canada has shed light on some of the negative impacts of COVID-19 public policies on the mental health and life satisfaction of adults with disabilities. Australian adults with disabilities in the current study reported similar experiences. Our data indicates that Australian participants' life satisfaction returned to near pre-lockdown levels following the lifting of restrictions.

While encouraging, it is important to acknowledge that mental health and happiness were not rated highly at any point by this group (e.g., only 50% of participants were satisfied or highly satisfied with their mental health before lockdowns). This is consistent with studies conducted before the pandemic showing lower levels of mental health among people with disabilities, highlighting a need for better mental health support for people with disabilities beyond the pandemic. Although one AAC user responded 'Strongly Satisfied' to all the life satisfaction questions, the remaining four AAC users demonstrated a similar pattern to the broader group. Levels of satisfaction dropped during lockdowns and raised to near baseline levels afterwards. Nevertheless, it is striking to note that all these four AAC users' responses to the life satisfaction questions were noticeably lower across all the categories and periods than the rest of the participants.

## Discussion

- NDIS provides support for people with ‘demonstrated’ psychosocial mental health conditions (NDIS 2020)
- Other NDIS participants cannot gain support for mental health issues
- “Mainstream” mental health services can be problematic for people with disabilities (Adshead, Collier, and Kennedy 2015; Eres, Reddihough, and Coghill 2022)
- AAC users face additional challenges with accessing mental health support (Eres, Reddihough, and Coghill 2022)



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

While the Australian NDIS does provide support for people with disabilities that are due to ‘demonstrated’ psychosocial mental health conditions, people who are eligible for the NDIS due to other types of disability cannot gain funding to access supports for mental health issues on the basis that these services are provided by health services. Relying on so-called mainstream mental health services can be problematic for people with disabilities as personnel working for these services may not be trained or adequately resourced to deal with the additional complexities associated with severe and permanent disabilities and communication difficulties.

Eres et al (2022) report that AAC users, in particular people with CP, face challenges in being diagnosed with mental health problems and accessing mental health services in Australia. The authors highlight many families, support workers and practitioners, not having the skills required to recognise differences between the symptoms of mental illness and the person’s disability. They also observed that many AAC systems are lacking appropriate vocabulary, to adequately express emotions during therapy sessions.

# Discussion

- Factors supporting life satisfaction and daily activities
  - Many had to rely on informal supports as formal support unavailable (Courtenay and Perera 2020; Rose et al. 2022; Shakespeare et al. 2022)
  - Critical personal assistance can be contingent on ongoing goodwill of family and friends (Foster et al. 2016)
  - Power imbalance is different to that with paid supporters (Phillips et al. 2020; Pino-Morán, Rodríguez-Garrido, and Burrone 2023; Sharma, Whiting, and Dutta 2022)
  - Can lead to strained relationships (Whitley, Reeve, and Benzeval 2023)



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

Immediate and extended family, neighbours, close friends, and work colleagues were all rated as providing a relatively consistent level of support. While this is heartening, it is concerning that, consistent with research conducted overseas, many had to rely on these informal supports during the pandemic due to the unavailability of paid support services. Reliance on informal supports also places adults with disability in a position where critical personal assistance is contingent on the ongoing goodwill of family and friends. The resulting power imbalance between people with disabilities and their supporters is quite different from that of people with disabilities and their paid supporters, and can potentially lead to strained relationships and discontinuity of care. It is essential that systems are put in place to ensure the continuation of formal, paid, supports throughout future health crises.

## Discussion

- Factors hindering life satisfaction and daily activities
  - Communication with NDIS and support services slow
  - Difficult to negotiate with service providers to ensure continuity of support (Kavanagh et al. 2021; Winkler et al. 2022)
  - Almost half the participants felt uncomfortable going out in public during the pandemic
  - AAC users need to be able to communicate during a crisis (Boesch et al. 2022)



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

Consistent with previous studies participants reported that communication with the NDIS, support and accommodation services was slow throughout the pandemic and that it was difficult to negotiate with these services to ensure continuation of care. This applied to support workers, accommodation and essential resources, including personal protective equipment, potentially impacting on the safety and participation of Australian adults with NDIS support during the pandemic.

Almost half of Australian adults with disabilities in the current study, including all four of the AAC users who responded to those questions, felt uncomfortable going out in public during the pandemic. It is critical that public messaging in future health crises includes information on the limitations of social distancing and personal protective equipment for people with disabilities so that these people avoid unnecessary negative interactions in public during future health crises. It is important to be able to communicate in every phase of a crisis.

AAC users face additional challenges during man-made, and natural disasters which require extra preparedness which often is not happening.

# Strengths and Limitations

- Strengths
  - Timing of the survey
  - Rich insights into experiences of dealing with the pandemic



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

The data collection timing is a strength as it occurred soon after restrictions lifted, providing rich insights on disability experiences during the pandemic.



# Strengths and Limitations

- Strengths

- Timing of the survey
- Rich insights into experiences of dealing with the pandemic

- Limitations

- Sample size was small, including of AAC users
- Lack of clarity of disabilities and AAC systems used by participants



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

However, participant recruitment was limited to online platforms, potentially underrecruiting those with limited Internet access. As a result, the sample size, particularly for AAC users, was small, limiting the paper's ability to draw conclusive inferences. Therefore, caution is needed when interpreting the findings. Future research should include improved questions about participants' disabilities and the AAC systems they use.

## Conclusion

- COVID-19 public health measures had significant impact on life satisfaction, mental health, and daily living activities
- Formal (paid) and informal (unpaid) supporters played a valuable role
- Need more specialised mental health services for people with disability, particularly for AAC users
- Need more research into additional support for AAC users during disasters



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.

This study explored the lived experiences of Australian adults living independently with support from the Australian government during the COVID-19 pandemic. Results show that COVID-19 public health measures had a significant impact on the life satisfaction, mental health, and daily living activities of these adults, including the AAC users in this study. Formal (paid) and informal (unpaid) supporters played a valuable role in supporting adults with disabilities throughout the pandemic, however, there were often gaps in their availability and this placed at least some participants in potentially dangerous situations.

There is a need for more specialised mental health services for people with disability, particularly for AAC users, beyond what is available in mainstream services. Furthermore there needs to be more research into the additional support needed by AAC users in both man-made and natural disasters.

# References

A list of references is available at <https://tinyurl.com/mrxkzy5p>



This material has been reproduced and communicated to you by or on behalf of Flinders University in accordance with section 113P of the Copyright Act 1968 (the Act). The material in this communication may be subject to copyright under the Act. Any further reproduction or communication of this material by you may be the subject of copyright protection under the Act.