



CLIENT AND FAMILY VOICES ON COVID-19

People with disability share their experiences of
emergency planning and responses.

JULY 2020



genU is pleased to share the experiences of people with disability, their families and significant others during the COVID-19 pandemic. The experiences have been collected in response to the Issues Paper on Emergency Planning and Response published by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability in April 2020.

The experiences collated in this document primarily relate to communication, the provision of essential support and government and community supports during the COVID-19 pandemic.

People with disability, their families and significant others from genU Ability (the disability services division of genU) were invited to share their experiences through multiple channels, including social media posts, website announcements, and 264 direct emails. The gathering of these experiences took place during June 2020.

genU sincerely thanks the people with disability, families and significant others who openly and willingly shared their experiences, which were sometimes distressing, frustrating, exhausting and frightening. We hope these experiences provide a greater understanding of the impact of the COVID-19 pandemic on people with disability, and contribute to improved emergency planning and response.

THE APPROACH

Clients, their families and significant others were invited to share their experiences through the following opportunities that recognised the diverse literacy and communication abilities of the genU community:

The Emergency Planning and Response Online Survey for genU Clients, Families and Carers

- Thirty questions on communication, the provision of essential supports, government and community support, and demographic information.
- Nineteen responses received; 53% from clients and 33% from family members or significant others.
- Fifty per cent of respondents were from genU Individual Support Services.

Focus Groups

- Two Focus Groups scheduled, and two registrations to attend received.
- Only one participant attended; this provided a valuable opportunity for in-depth discussion.
- Facilitated via Zoom web-conferencing due to COVID-19 social distancing and gathering restrictions.

A designated email address (disabilityroyalcommission@genu.org.au)

- Allowed for experiences to be submitted via writing, drawing, video or a voice recording.
- This opportunity was not utilised to share experiences or feedback on emergency planning or response.

Private 1:1 conversations

- The opportunity to speak with a genU Ability Executive General Manager in a safe and confidential telephone or Zoom appointment.
- This opportunity was not utilised to share experiences or feedback on emergency planning or response.

Facilitated Discussion Groups with a Facilitation Guide

- Provided guidance to workers to discuss the COVID-19 pandemic with clients individually or in small groups, and record responses and feedback.
- Twelve genU Shared and Respite Living sites provided responses and feedback gained through the use of this resource.
- Included an Easy Read version that allowed clients to follow the discussion
- The Ability Client Advisory Committee discussed genU's COVID-19 response at their July 2020 meeting, and consented to their feedback being included in this document.

THE EXPERIENCES

Communication from genU

Survey (19 responses)

- Eighty-nine per cent (89%) of survey respondents said genU had provided information during the COVID-19 pandemic, and 79 per cent reported this information had been clear, easy to understand and accessible.
- Seventy-nine per cent (79%) of survey respondents said they felt safe and informed during the COVID-19 pandemic.
- Respondents shared the following experiences of seeking assistance and information during the COVID-19 pandemic:

“genU was very supportive. It was more the assisted accommodation that was not very efficient or organised. It was an all or nothing approach or a knee jerk reaction. It is understandable in a COVID situation but what it did was not allow genU workers in to help and put a blanket ban on everything”.

“As a parent I should not have to advocate for implementation of safety procedures but genU administration [were] slow to respond. There was enough warning for senior management to be decisive and pre-emptive but they were reactive”.

- Seventy-six per cent (76%) of respondents had access to the internet, a mobile phone or smart device during the COVID-19 pandemic and 2019/2020 Australian bushfire crisis. Respondents who did not have access to these technologies, identified their main sources of information to be the television, family or significant others.

All respondents (100%) felt genU understands their circumstances and cares about their wellbeing during emergencies.

Facilitated discussions with Shared and Respite Living clients, their families and significant others (12 discussion forums)

- Overall, the communication that genU is providing on COVID-19 is providing families and significant others with reassurance, confidence and satisfaction that the safety and wellbeing of clients is being prioritised.
- Clients report information is easiest to understand when it is in Easy Read, and identified the need for greater amounts of information to be available in Easy Read.
- Illustrations, graphics and symbols in Easy Read documents are not always understood or recognised. Clients would like to see a greater use of photographs in Easy Read documents produced by genU.
- A COVID-19 Social Story and workers providing regular explanations of changes assisted with feelings of safety for one client.
- Clients identified that they would like to receive more information via videos or Zoom. Families and significant others supported the delivery of information to clients in this format.
- Families and significant others expressed the need for important or urgent information from genU to be sent via SMS.
- Information on COVID-19 had been a little overwhelming for one house, and had caused some stress and confusion amongst clients.
- It was expressed that it seemed the disability sector may have been “forgotten” during the early stages of the pandemic as the focus of information seemed to be on Aged Care.
- Clients from one house said they have access to an ipad with internet connection anytime they wish. However, they said they would struggle to use the ipad to find important information without support from workers.
- Some clients felt information was targeted towards workers rather than the people with disability.
- Families and significant others would like a clear contact point for COVID-19 related inquiries and more information on client safeguards.

“As the person with the disability, we are not all the same and we all communicate differently so we need different ways to understand”.

- Shared and Respite Living client

Other Facilitated Discussions

- Communications on genU's COVID-19 response were seen as "inconsistent", "disjointed" and "infrequent", and did not instil a lot of confidence that anyone was managing a COVID-response
- "Not knowing who's leading genU through the pandemic is disconcerting"; families were not aware genU CEO had resigned
- Barwon Health CEO is providing weekly video updates about how the pandemic is being managed; families would like similar from genU
- Shared and Respite Living and day services "didn't know what the other was doing"; Shared and Respite Living were seeking information from families on the changes in day services
- Families reported they needed to approach genU for information on the organisation's response to COVID-19.

Focus Group (feedback from one participant)

- There is a lack of communication from genU on COVID-19 and the safety protocols being implemented at day services. In the initial phases of the pandemic, information was inconsistent and unclear.
- Family initiated contact with genU on how the organisation was responding to COVID-19.
- Early in the pandemic, "great risks" were seen in allowing some day services to continue. The School Leavers Employment Supports (SLES) was identified as one of these services. Risks in this service were primarily related to the inability to maintain social distancing during travel.
- Identified the need for:
 - a "Key Contact Person" at genU for COVID-19 related inquiries
 - the centralised distribution of information to help ensure consistent information and messaging
 - increases in regular communication (i.e. weekly) about how genU is keeping clients and workers safe such as the availability of hand sanitiser and provisions for staff (i.e. PPE, training).
- It was reported that other service providers had provided more updates on COVID-19 safety protocols than genU.



- The relocation of day services to Zoom presented significant challenges for a client with Autism which included:
 - requiring the support of a family member for all sessions
 - finding it difficult and confronting to have to engage in a back and forth conversation without time to think about responses which caused distress*
 - having difficulty with staying focused for the one hour session.

***It needs to be noted the family member tried to resolve this issue by turning to mute while other clients responded. This provided the opportunity for a response to be discussed before it had to be provided. However, a genU worker advised that turning to mute during the session was not allowed. This allowed other clients to witness the distress of this particular client, and ask about the behaviours that were being exhibited. The family member then felt compelled to provide an explanation of the behaviours in front of the whole group.**
- Zoom had been adopted for day and therapy services, and the following benefits had been observed:
 - Therapy could continue
 - Provided access to some genU programs that could not operate face-to-face
 - Saved funds as eliminated travel costs for therapists.
- The potential was seen for appointments to continue via Zoom post COVID-19, particularly for running through reports with therapists that did not require a face-to-face visit.

Essential Supports during COVID-19

Survey

- Eighty-seven per cent (87%) of respondents stated they were continuing to receive essential support services from genU during the COVID-19 pandemic.
- When asked to rate their wellbeing on a scale of 0 ("Not well") to 10 ("Very well"), respondents on average rated themselves to be a "7".

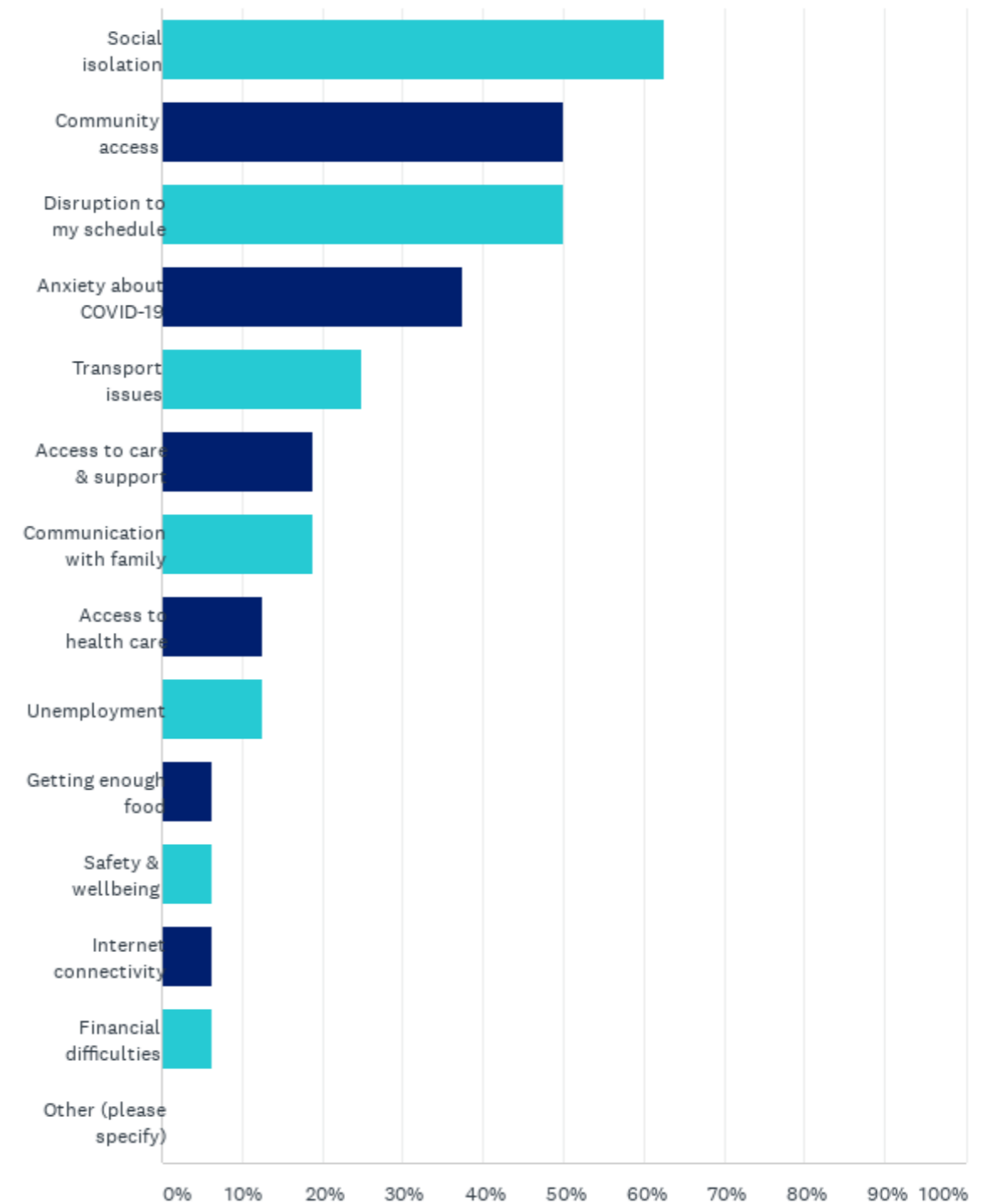
"genU have done everything right by liaising officially with all and have the safety and wellbeing of their clients and staff at the forefront"
- Shared and Respite Living family member

- The giving of flu shots so late into the pandemic was considered "unacceptable" given the COVID-19 pandemic and vulnerabilities of many genU clients.
- When asked whether there was anything further genU could assist with during the pandemic, respondents said:
 - more support with shopping and groceries
 - the provision of timely and reliable information, and
 - providing the support workers that clients request.

"Communication is a huge problem with genU staff as they don't seem to keep up to date with up to date with news or they don't think they need to communication and pass on any information particularly when another support worker has to cover the usual worker. It is vital we know when a change is to occur as our son can have a fatal seizure. On call in particular do not understand the need or understand that there is a red flag that will pop up when they open our sons file to this effect".

- Survey respondent

The three biggest challenges identified during the COVID-19 pandemic



Facilitated discussions with Shared and Respite Living clients, their families and significant others

- Essential supports continued for all clients in genU Shared and Respite Living.
- Clients were very happy that day service practitioners and Individual Support Services workers had been able to do activities with them in their own homes. This also provided a change of people to talk to and interact with in the house
- A perception existed amongst some clients that they were not able to go shopping or to their day services because they had done something wrong.
- The most significant challenges for clients in Shared and Respite Living were:
 - not seeing family and friends
 - not having community access, and
 - disruptions to their schedules, particularly not being able to go to day services or work.

“Overall, GenU have been very accommodating and have had to adapt to a changing environment that initially was very challenging. They have managed to help him adjust and settle into the changing routines”.

- Shared and Respite Living family member

“Happy that program staff are providing interesting things for us to do and house staff care for us”.

- Shared and Respite Living clients

Focus Group

- Appreciation was expressed towards the flexibility of services; individual support was delivered at home while day services were suspended or conducted online.
- Considerations needed to be made around support workers and which ones would continue to work within the home. Considerations included whether support workers used public transport to commute to and from shifts, and how many other clients they were working with.
- The most significant challenges for a client with Autism included:
 - the uncertainty of when some normality would return; needed a time and a date
 - skills that had been learnt had to stop (i.e. travel training)
 - being an active and energetic person cooped up inside and
 - the unavailability of items that would have assisted (i.e. basketball hoops that were sold out).



Government and Community Support

Survey

- Seventy-nine per cent (79%) of respondents thought that an emergency hotline would help people with disability stay safe and informed. Their reasons included:
 - the need to have “a reliable information centre; there was too much hysteria and paranoia around information that did not deal with the facts”
 - the ease and convenience of just having a single contact, and;
 - the availability of advice or assistance quickly.
- Respondents identified governments could implement the following strategies to increase the safety and wellbeing of people with disability during emergencies:
 - increased funding for emergency supports
 - increased advice on services available to assist people with disability
 - laws and policies on the acceptable treatment of people with disability in emergency events
 - guidelines for Supported Residential Services to abide by and implement.
- Preventative measures to protect people with disability from violence, abuse, neglect and exploitation during emergencies consisted of:
 - the availability of constant support
 - having external people continually checking in; “another set of eyes so to speak”
 - hotline for people to report violence, abuse, neglect or exploitation
 - regular “RUOK calls”
 - support to maintain social contact.
- In identifying preventative measures, respondents also expressed their concern about whether people with disability are actually able to access protective services and whether they fear reprisal for seeking help.

“Our son, had his parents who are trained in the disability sector, to inform ignorant people. Our son cannot help coughing due to weak throat muscle causing dysarthria, dyspraxia and dysphagia. Our son also has excellent carers, however I do fear if his father and I were not around how exploited would he be. We do not trust anyone”.

- Survey respondent

- Seventy-one per cent (71%) of respondents thought the initiatives implemented by businesses to support people with disabilities during the COVID-19 pandemic, such as designated shopping times at supermarkets had been effective.
- Ideas for other initiatives that could support people with disability included:
 - “drop-ins” on families who may be at increased risk during isolation.
 - designated shopping hours extended to include primary carers and held later in the day, and;
 - letterbox drops to neighbourhoods asking for neighbours to look out for each other.
- People with disability could be included in emergency planning to ensure the right strategies are implemented to support people and reduce the risk of violence, abuse, neglect and exploitation by:
 - “asking them”
 - arranging meetings during genU programs to “actually involve these adults and get feedback or their ideas. But it would need to be done as soon as possible so the effects are still current and in their minds”
 - Round table discussions with representatives from aged care and disability providers, and
 - greater education.

Facilitated discussions with Shared and Respite Living clients, their families and significant others

- In the initial stages of the COVID-19 pandemic, families and significant others said they felt people with disability and the disability sector had been “forgotten” and “overlooked”.
- While clients believed an emergency hotline service would help people with disability stay safe and informed and provide them with another source of information other than genU, families and significant others responded with more caution, expressing that not all people have the cognitive or physical ability to use a hotline.
- The designated shopping hours implemented by supermarkets such as Coles and Woolworths were thought to be a good concept. However, it was widely stated that the times of these shopping hours were too early for people with disability who require personal support of a morning.
- Restrictions on the purchases of certain food and household items made it difficult to maintain the larger Shared and Respite Living houses. Limitations on home deliveries also impacted upon the running of houses.
- Clients, families and significant others were united in their stance that emergency planning needs to involve people with a diverse range of abilities because “not all people with a disability are the same”.

- Measures to protect people with disability from violence, abuse, neglect and exploitation during emergency events included:
 - The provision of Easy Read resources to enable people to “self-recognise” violence and abuse.
 - Hotline for people with disability
 - Whistle blowing

“Continue to utilise people from all backgrounds in decision making and idea generation so that every demographic has their voice”.
- Shared and Respite Living family member

Focus Group

- Government support for people with a disability feels like an “afterthought”. The following examples were used to substantiate this claim:
 - no increased financial support for people with disability; people with disability are not immune to price rises or delivery expenses
 - COVID-19 social distancing or gathering restrictions did not consider people with disability who required two support workers to exercise or access the outdoors; a limitation of two people together did not allow for the required support to be given. No one was able to clarify what was allowed, and the family feared they would be fined for breaching social distancing or gathering rules.
- The designated shopping hours implemented by supermarkets such as Coles and Woolworths were not accessed successfully; the family member was initially denied access due to having no evidence of being a carer, and the challenges involved with taking the person with disability to the supermarket meant this service was abandoned after one attempt.
- The family member felt “unsupported” by their local community, “on their own” and expressed fears about:
 - medication being bought out and becoming unavailable
 - who would care/support persons with disability if other family members contracted COVID-19 and support workers could not enter house.

SUGGESTED IMPROVEMENTS

For genU

Communication:

- Prepare and distribute all communications from a centralised point at frequent intervals during emergencies
- Provide a clear and centralised contact point or person for COVID-19 related inquiries (or future emergency related inquiries)
- Provide greater information on client safeguards to families and significant others
- Produce greater amounts of emergency related information in Easy Read
- Use more photographs in Easy Read documents to support image recognition and familiarity amongst clients
- Deliver emergency information or updates via “video bulletins” that can be screened across multiple platforms (i.e. website, intranet, social media), including Shared and Respite Living houses
- Facilitate Zoom meetings across Shared and Respite Living to advise clients of emergency responses or preparedness with the opportunity to ask questions of genU leadership teams and management
- Distribute important or urgent information via SMS.

Essential Support:

- Increase support with shopping, groceries and errands
- Ensure that support workers who cover or fill in shifts are aware of a client’s support needs, especially when health complexities are involved.

For Government and Community

- Increase funding for emergency supports
- Increase advice and communication on services available to assist people with disability during emergencies
- Develop and implement laws and policies on the acceptable treatment of people with disability in emergency events
- Develop and implement guidelines for Supported Residential Services to abide by and implement during emergencies
- Fund and implement “drop-ins” on families who may be at increased risk during isolation
- Schedule designated shopping hours for people with disability and carers later in the day
- Establish letterbox drops to neighbourhoods asking for neighbours to look out for each other.

For further information, please contact:

Jacqui McKim

Diversity and Inclusion Advisor, genU

Email: jacqueline.mckim@genu.org.au

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