



*Fighting for freedom of choice for
young people with high care needs*

Emergency Response Issues Paper:

*Effects of COVID-19 on the Disability
Community*

Executive Summary

The Royal Commission into the Violence, Abuse, Neglect and Exploitation of People with Disability (the Royal Commission) expressed interest in understanding how emergency planning and responses can include and support people with disability, and what should be done to prevent people with disability from experiencing violence, abuse, neglect and exploitation during emergency situations.

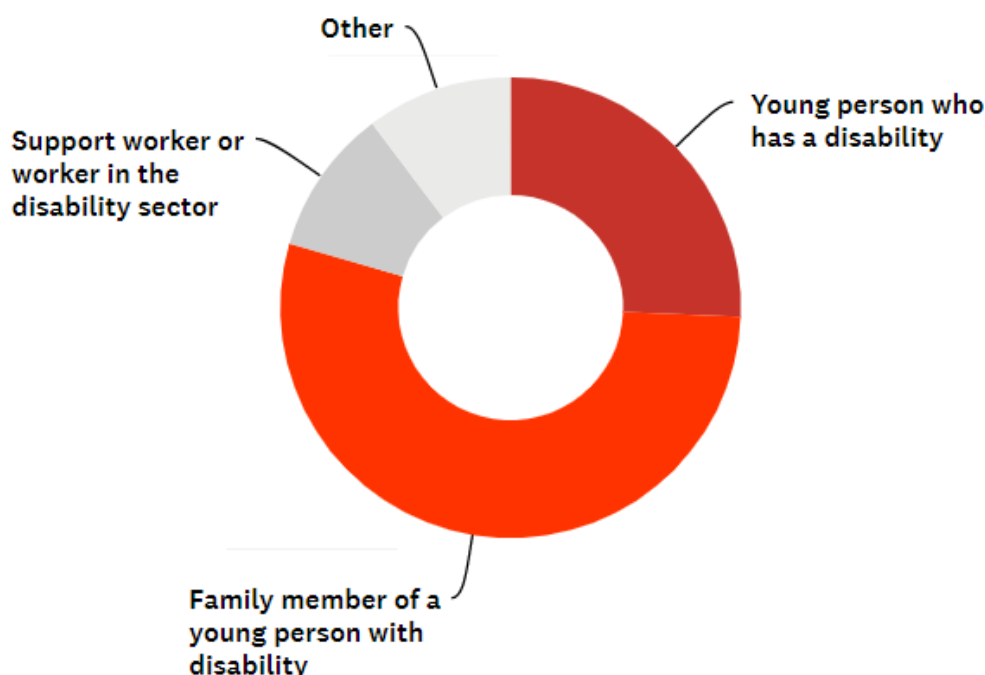
Youngcare's response includes data and feedback from young people living with disabilities (28.2%), their family members (56.4%) and support workers (15.3%). All responses were provided anonymously to ensure protection, and the survey was open from the 8/05/2020 – 5/06/2020.

Throughout this research, it was discovered the main areas for improvement centre around; safety, isolation, personal protective equipment (PPE) and other essential items, support, information, and access. It is our recommendation that by providing focus to these key areas, the Royal Commission can significantly reduce the risk to members of the disability community throughout emergency situations and day-to-day living.

Safety is a consistent, primary concern for young people with high care needs (YPWHCN), their families and their support workers. Emergent situations such as the COVID-19 pandemic or the Black Summer Bushfires act to not only introduce additional concerns in regards to safety, but exacerbate pre-existing issues.

This then leads to a dangerous and widening gap between what should be available to YPWHCN and what is provided to them to ensure their safety.

51% of survey respondents said they felt as though their safety had been compromised as a direct result of the COVID-19 pandemic. From these respondents the main reasons cited included: isolation, lack of Personal Protective Equipment (PPE), reduction in support services and a lack of information. These key areas form the basis of our recommendations.



Isolation

Many members of the disability community find battling isolation to be something they face on a regular basis, not just during an emergency. However, during situations such as the COVID-19 pandemic, isolation can quickly become a necessary and enforced reality.

It is essential for these members of our community who feel isolated to retain connections to the outside world; where face to face meetings are not possible, video calls or FaceTime should be implemented and made accessible depending on specific situations and abilities. These initiatives will decrease knock-on effects of feelings of isolation and aim to increase a sense of normality throughout, what can often be, distressing situations for YPWHCN.

"I think those living with a disability are often very isolated anyway and will continue to be, pandemic or not."

A more empathetic, community support approach needs to be adapted to support those with disability, and their families. Companionship, check-ins and inventive ways to connect with other people are vital to maintain mental health, especially when YPWHCN are isolated in a facility away from their loved ones and cannot have visitors. It is essential to provide not only physical but emotional support during these times.

"People with disabilities in hospital were left without volunteers to visit, without being able to interact with people, no real access to video chat with family."

Initiatives such as Telehealth which were introduced and more heavily relied upon throughout COVID-19 can be taken further to incorporate other services, for example social Telehealth activities, virtual lessons, meetings with peer groups or other ways of facilitating communication to feel connected.

"Isolation is a problem ALL THE TIME and not just during a crisis."

Personal Protective Equipment (PPE) and Essential Items

Lack of access to Personal Protective Equipment (PPE) and other essential items have been heavily discussed throughout the pandemic. This is perhaps the most glaring issue that presented itself for YPWHCN and their families, and it is an issue that is the difference between life and death.

73% of respondents indicated that they had experienced a lack in essential items during the COVID-19 pandemic. 41.5% of respondents stated that they experienced a lack in PPE, 19.5% experienced disturbed access to medication and 12.2% stated that their access to food declined.

"Lack of PPE meant I had to risk having support worker's inches away from my face to help me shower properly, without face masks. I felt, and feel, vulnerable to infection this way."

Some respondents explained how lack of access to certain foods and medications impacted their loved ones and clients; in cases where individuals have sensory issues, bowel intricacies and/or behavioural problems, they noticed an increase in aggression caused by changes to routine. This was further exacerbated for individuals with behavioural problems by the inability to go outside, or in cases where individuals were not living at home, a ban on visitors coming into their facility.

It is hard to estimate just how much disruptions such as these impact on YPWHCN,

but from anecdotal evidence it can be assumed that for these exceptionally vulnerable individuals, there need to be measures in place to reduce or remove manageable interruptions to routine.

"[The shortages] made me fearful, anxious and put my health at risk. There needs to be measures in place to stop shortages of essentials during crisis."

Australia's response to these shortages was fairly fast, however let us consider the dangers this poses for YPWHCN if a different kind of emergency situation arose. In the case of a natural disaster where individuals are cut-off, how quickly can essential food and medication be made available for particularly vulnerable individuals.

Support Services

100% of respondents stated that they or their family had changed the way they accessed support. 37.5% voluntarily self-isolated, 35% reduced their in-home support services, 22.5% cancelled all support services and 5% started self-managing their support. The fear of workers coming in and out of the house, as well as a mistrust in the care sector to adequately provide training and equipment to support workers resulted in individuals and families choosing to limit outsiders wherever possible.

"I have cancelled most supports, reduced some in home supports as well. I am mainly self-isolating due to compromised immune system."

This change in support has had a multitude of knock-on effects for YPWHCN, their families and support workers. Increased behavioural changes due to changes in routine have put family members and support workers at greater risk. The move from formal support, by way of carers, to informal support, provided by family members, has seen an increase in the presentation or exacerbation of injuries due to increased stress on the body. This, in turn, has negative impacts on YPWHCN. Their level of care is compromised due to the ailments of their family members, and mental health and wellbeing declines for both parties, due to a lack of support, stimulation, visitors and community access.

"The risk was to our health as we had to provide 24/7 care to a profoundly disabled 32-year-old male with behavioural issues."

Fatigue, disempowerment, loss of motivation and lack of accountability are some key emotions cited by family members providing support to their loved ones in their home throughout this time.

"We had to give up all external support. If anything had happened to us; this would have severely compromised [our son's] care."

To help ensure the safety of YPWHCN, family members and support workers have engaged in some precautionary measures. 61% increased sanitation practices, 26% changed staffing ratios and 12% reduced their consultation times. With sanitisation still being the highest concern, a lack of PPE and other supplies has led to heightened anxiety and stress for those welcoming carers into their homes.

"I, as the primary carer, had to provide education to some of the support workers and some support workers did not want to follow instructions. I think stricter guidelines in all workplaces should be in place and agencies need to train their staff in proper cleaning practices to ensure safety."

Lack of access to sanitisation products due to 'panic buying' by the public has significant impacts on the disability community. In some cases, families were providing their own sanitisation products to workers at their own expense, and in other cases where shortages could not be navigated YPWHCN and their families had to continue in fear.

"When we realised the danger and sourced hand sanitizers, gloves and mask; it was too late."

Information

When asked if they had found it easy to access information and updates relevant to them throughout the crisis, 77.5% of respondents said yes. However, we must examine this point through the lens of the 28.2% of total respondents who are YPWHCN. Examples of where communication to YPWHCN, family members and support workers has worked are; through support coordinators and service providers, schools, and local and state government updates. Many people turned to the news or online for information on general COVID-19 updates.

"At the facility, families of patients were told about visiting restrictions, but the clients weren't told. So who was supposed to tell the client?"

67.5% of respondents did not feel as though they were ever at a greater risk because of a lack of information. This is, again, where we need to consider how YPWHCN access information and technology.

32.5% of respondents did feel more at risk due to the lack of disability specific information and updates, unclear communication from agencies to YPWHCN and family members, and a perceived lack of education to support workers providing services.

"A person with a disability is often disconnected from the media and social media. If someone does not update them on the restrictions, then this could have consequences."

85% of respondents preferred method of communication was by email, 34% preferred social media or the internet, and only 25% indicated that they would like to be contacted by phone.

YPWHCN rely heavily on their family or support workers to pass on information. Not only is it imperative to utilise avenues that YPWHCN prefer and have access to, it is also essential that family members and support workers are well-educated and confident in supporting YPWHCN to ensure they are equipped with appropriate information.

Access

In some areas, access for YPWHCN and the disability community was extended during COVID-19. 52.5% of respondents stated that they had accessed the disability specific grocery store hours which were introduced amidst the pandemic. This, along with home delivery, provided a huge amount of support to people who were isolated at home.

However, of those who visited the store at the allotted hours, many cited that the time of day was difficult to manage. For many YPWHCN's this was not possible without a carer, and support for someone with severe disabilities was difficult to organise for that time of morning.

Additionally, due to peak 'panic buying' times, members of the community accessing these initiatives stated that they were still unable to acquire everything they needed. Others called for the disability specific hours to be extended past the pandemic to be available throughout the year.

"I think there should have been a fairer system to delegate supplies such as food "staples" and toilet paper to the elderly and the disabled."

Other services such as Telehealth, On-Call Doctors, and phone calls by agencies to check in on vulnerable members could be considered for continuation into the future. Most importantly, it is about asking what measures would benefit YPWHCN and having an involved conversation to inform measures aimed to serve them.

Additional Information

7.1 Visibility of People with Disability

Many individuals saw coverage about the impacts on elderly people in the community during the COVID-19 pandemic. Within QLD there was a “Care Army” initiative launched, which aimed to ensure the wellbeing of the local elderly population. In the future, and in general, there needs to be a greater focus on promoting visibility for people with disability in the media and the community.

“I was disappointed that the Leaders didn’t mention the risks for people with a disability during this time. No consideration was given to us; all the coverage was for elderly people. It makes me feel like I don’t matter.”

Increased representation of People with Disability across mainstream media can also be used as an educational tool. For YPWHCN and the wider disability community to be protected, the general public need to understand how their actions will affect vulnerable members in society.

Instances of violence, abuse, exploitation, and neglect are more likely to increase in an emergent event such as COVID-19. It is essential that people pay more attention during these times, stay educated and have access to appropriate resources in order to protect YPWHCN and reduce their vulnerability.

“The case under the spotlight at the moment involving a woman with Cerebral Palsy who died at the hands of her care providers, I believe a good starting point.”

7.2 Schooling

Greater support has been called on by parents with school aged children with disability. Across the board, School’s need to be better prepared and equipped to assist children with disability access appropriate and timely education materials. There also needs to be special consideration on a case by case basis to determine how a child with disability will benefit from remaining at home or attending campus.

“Not either of my son’s schools offered in school learning, my son is remarkably autistic and has an intellectual disability, he should have been allowed at school at least one day a week to learn”

7.3 Funding

The NDIS were fast acting to create flexibility in individuals plans. There is evidence of repurposing of plans to allow for communications devices which were essential to keep individuals connected, accessing telehealth, and doing their shopping. Additionally, SDA panels met regularly to assist timely discharge from hospital to allow room for potential COVID-19 cases and medium term housing was implemented to alleviate the strain on hospital systems and negate admissions to aged care.

It is our recommendation that the NDIS retain this sense of urgency for YPWHCN in all cases to ensure quick responses and timely alterations to plans. YPWHCN can find themselves in an emergency situation day-to-day and it is essential that their funding is able to be accessed and allocated where it is needed most, and avoid lifelong inappropriate situations such as residing in aged care or other institutions.

Recommendations

Implement activities that increase access for YPWHCN permanently:

Keep the dedicated grocery store hour but consider moving the time to later in the day so that it integrates to people with disability's schedules. Continue home delivery access for people with disabilities, even when there are service disruptions. Continue telehealth where clients choose to opt-in and consider alternative options to ensure that YPWHCN can access goods and services without putting themselves at greater risk.

Ensure essential supplies are stockpiled:

Send essential items to families and individuals when supplies are in surplus, allowing where possible stockpiles to be established. This will reduce strain on hospitals and support workers/agencies, it will also reduce risk of individuals who cannot cease care workers in their home. Supply lines need to be reactive and replenished quickly – there are simply some items that YPWHCN cannot go without for any extended period of time.

Allow priority access to essential services:

Using information from the NDIS, identify individuals and triage access of essential items depending on the type of emergency. YPWHCN and their families are incredibly vulnerable to changes in routine and access, for this reason they need to be highly visible in emergency response plans.

Research and develop connective technology:

Introduce technology to hospitals, rehabilitation centres and other facilities to allow clients/patients to communicate with family or friends in the event of a lockdown. Understand that not all YPWHCN have the cognitive or physical ability to engage in telephone or email communication without assistance, and in some cases are isolated with little, to no explanation of why they are no longer able to see their loved ones. This results in an increase of behaviours which put the individual and others at risk.

Establish clear communication plans:

In the event of an emergency it is imperative that people with disabilities are top of mind. YPWHCN are an extremely vulnerable section of the cohort and are heavily reliant on their families or support workers to convey information that will ensure their safety – develop clear communication channels to ensure the right information can get to the right person in a timely fashion. It is unacceptable to assume that an email with no follow up will be adequate in explaining the complexity of an emergent situation.

Develop community response measures:

Ensure that YPWHCN feel connected to their community, and that members of the community are educated in how to be empathetic and supportive for people with disabilities during an emergency situation. Instances of violence, abuse, neglect and exploitation are more likely to slip under the radar while people are distracted and looking the other way. Throughout this pandemic we have seen outstanding examples of communities, local business and Government coming together to provide support. It is only when people work together as a community that our most vulnerable can be protected.

Conclusion

"Nothing about us, without us." – South African disability activist Michael Masutha, 1998.

The above quote first appeared in Poland political traditions in 1505. It was then picked up by the Western disability community in the 90's. Even today, this quote remains a relevant and poignant cry for members of the disability community and other human rights movements.

Young people with high care needs, as part of the disability community, are some of the most vulnerable members of society. This statement becomes truer when emergency situations, such as pandemic's or natural disasters, are introduced to the equation.

Safety concerns and isolation for these individuals can only ever increase throughout an emergency, but this does not mean that measures cannot be put in place to reduce disruption throughout these events and in day-to-day life.

By increasing accessibility, connectedness and communication, young people with high care needs, their families and support workers will be able to nimbly respond to emergencies and reduce manageable impacts on individuals.

This is not an issue that is able to be solved in isolation; an acceptable solution requires industry, community, government, and advocates to come together to look for empathetic, humanitarian responses.

By starting simple and growing outwards it is our aim to see people with disability considered in initial response planning. It is essential that the wider community listens to the needs of people with disability and develops appropriate and suitable solutions in accordance with the disability community.

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