

Committee Secretary
Health, Communities, Disability Services and Domestic and Family Violence Prevention
Committee
Parliament House
George Street
Brisbane Qld 4000
Sent via: health@parliament.qld.gov.au

3 July 2020

Dear Committee

Queenslanders with Disability Network (QDN) welcomes the opportunity to make a submission to the Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee's (the committee) Inquiry into the Queensland Government's Health Response to COVID-19.

QDN is an organisation of, for, and with people with disability with over 2,000 members and supporters across Queensland. QDN operates a state-wide network of members who provide information, feedback and views from the lived experience of people with disability to inform systemic policy feedback to government and peak bodies.

People with disability continue to face unique challenges as a result of the COVID-19 pandemic. Not only are many people with disability at higher risk from COVID-19, but the pandemic has exposed and exacerbated pre-existing inequalities and barriers for people with disability.

QDN acknowledges COVID-19 has created an unprecedented health crisis and that all parts of the community, including government, business and the community sector, have had to adapt rapidly during a time of global uncertainty.

The Queensland Government have demonstrated a commitment to the safety and wellbeing of people with disability during this time, and also worked collaboratively across government to ensure the voice of people with disability and their experiences have informed the planning, design, implementation and evaluation of responses and actions. QDN has also observed a strong working relationship across jurisdictions and with the Commonwealth to deliver targeted responses and approaches for people with disability.

QDN also recognises the Queensland Government's efforts across multiple departments to bring together and rapidly respond to the needs of key stakeholders. Throughout the pandemic, QDN representatives contributed to many State and Commonwealth Government committees and working groups, including:

- Human and Social Recovery Committee

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- Queensland Clinical Senate
- Ministerial Housing Council
- Queensland Disability Advisory Council
- Queensland Transition Advisory Forum
- Queensland COVID-19 Health Working Group
- Queensland COVID-19 Disability Working Group
- Department of Housing COVID-19 Homelessness Housing Group
- Queensland Transition Advisory Group
- Domestic and Family Violence Disability Consultative Working Group
- Australian Government Department of Health Cross Jurisdictional National Roundtable Disability COVID-19

QDN acknowledges the development of State and Commonwealth Disability Health Plans to guide the health sector response for people with disability as an important step and action during this worldwide pandemic. These key documents include Queensland Health COVID Disability Plan and the Management and Operational Plan for People with Disability: Australian Health Sector emergency Response Plan for Novel Coronavirus (COVID-19) April 2020.

The issues and recommendations outlined in this submission have been developed to assist the Queensland Government's ongoing preparation, response and recovery in this ongoing public health emergency. COVID-19 presents a particular challenge to disaster planning and preparedness that prevention, preparedness, response and recovery are being delivered in parallel and concurrently as we respond to this moment in history.

QDN also sees there are a number of critical issues with regards to the immediate healthcare of people with disability in COVID-19 and some areas that will have longer term health impacts on individuals and health systems that need consideration.

At the beginning of the COVID-19 outbreak in Australia, the rights of people with disability to access health care, get information about how they could stay safe and continue to access essential disability supports were critical to consider in Queensland's response to this pandemic.

In Australia, people with disability have rights enshrined in the United Nations *Conventions on the Rights of Persons with Disabilities, the Rights of the Child, and against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, and the *Disability Discrimination Act (Cth) 1992*. These help to ensure that people with disability receive the same level of healthcare as other persons, that healthcare workers promote the dignity and autonomy of people with disability, including their freedom to make their own choices, and that health care services are free from bias and/or discrimination.

For 10% of Queenslanders with disability, their access to funded disability supports is through the National Disability Insurance Scheme (NDIS), managed by the National Disability Insurance Agency (NDIA) and quality and safeguarding oversight by the NDIS Quality and Safeguards Commission. Both these Commonwealth agencies have played a

key role in working collaboratively as key issues for people with disability have emerged and worked to address these both locally and nationally.

The specific health needs of Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse people with disability is also a key consideration with access to services, information, and supports.

Some key areas emerged as critical to Queenslanders with disability during this pandemic which can be framed within the following areas:

Preparedness:

- emergency planning by and with people with disability for the specific COVID-19 public health emergency;
- having access to user-friendly public health information about the virus, preventing the spread and knowing what to do to stay safe;
- having access to digital technology and knowing how to use it to be able to get information, access essential disability and health services and stay socially and emotionally connected with family, friends and networks of support;
- targeted focus for people with disability who have been assessed as medically safe to leave hospital, to transition and be discharged from hospital to live and receive care and support in the community, and;
being able to make informed decisions about the use of the COVID-19 Safe App.

Response:

- access to 'essential' disability supports on a day to day basis to ensure continuity of care
- continuity of essential primary and acute health care that were impacted by Chief Health Officer directives;
- access to Personal Protective Equipment (PPE) for people with disability, the disability workforce and carers and training in how to use it;
- a need for priority testing for people with disability and the disability workforce
- targeted responses required for people with disability to maintain their 'non-essential health care needs' that are actually critical to maintaining their ongoing health and well-being;
- ethical decision making about the health care and treatment of people with disability within hospital settings;
- clear instructions and guidance for patients with disability to access to their authorised decision makers during hospital stays and for end of life care decisions, and;
- reasonable adjustments within disability support and hospital operating environments to deliver safe COVID practices for people with disability, particularly vulnerable people who need support persons with them for communication and situations where total self-isolation is impossible because of individual disability support needs.

Recovery:

- access to supports and services that enable people with disability to transition from isolation to inclusion;
- focus on building resilience and well-being of people with disability, including specifically mental health and well-being services;
- rehabilitation of individuals who may contract COVID-19 and any ongoing complications, and;
- ensure the role and voice of people with disability to contribute to the recovery process is planned and integrated.

Queensland Government response: People with disability

Governments play a vital role during disasters and emergencies to ensure all members of the community can access the information they need to;

- assess their risk;
- understand and make a plan for the steps they need to take to ensure they can stay safe, before, during and after a natural hazard or other emergency;
- make informed decisions about the actions to take during the emergency, and;
- take care of their health and well-being and adapt to the impact of the disaster and know where to go for help if they need it.

The Queensland Government, particularly the Department of Communities, Disability Services and Seniors, Department of Health, Department of Housing and Public Works and relevant Ministers and key statutory bodies have worked collaboratively with QDN through out this public health emergency to date to engage, consult and respond to the needs and supports of people with disability. Investment has also been provided to QDN to deliver a range of specific activities to assist with preparedness, response and recovery phases by and for people with disability.

The Queensland Clinical Senate also undertook a range of engagement and dedicated work with health consumers, people with disability and older persons through the peaks of Health Consumers Queensland, QDN and Council on the Ageing Queensland to inform their decision making and planning and this enabled a strong consumer voice and collaborative partnership across clinicians and consumers which aided Queensland's response.

QDN also established a COVID-19 Disability Advisory Working Group funded by the Department of Communities, Disability Services and Seniors during the peak of the pandemic, which comprised of a range of people with disability with diverse disability to provide lived experience perspective to inform direction and strategy that QDN has provided feedback to government.

Public health information:

For people with disability, access to information about COVID-19 in user-friendly and accessible as part of the public health promotion information was critical. People with

disability reported as the emergency unfolded, a range of experiences and barriers to getting factual information about the coronavirus, what it meant for them and what they needed to do.

QDN was able to rapidly produce user-friendly information about COVID-19 both in written and video formats, which were publicly shared on 24 March 2020 so that Queenslanders with disability had access to user-friendly information in the early phases of the declared worldwide pandemic and state of emergency.

QDN has regularly provided updates to people with disability during this time as Chief Health Officer directives came into force, communicating changes to restrictions in user-friendly, accessible formats. These accessible updates were then made available on QDN's website, shared on Facebook and communicated with relevant government departments.

Through Queensland Health, and informed by the Health Disability COVID-19 Working Group, ongoing planning and implementation of key information for people with disability is continuing to be considered.

COVID-19 Emergency Planning Resources and tools:

People with disability needed to have a plan for COVID-19 that covers their disability and health care needs for two scenarios:

- to stay at home, or;
- if they or someone who supports them gets sick and they need to either receive in home healthcare or hospital-based care.

Through funding provided by the Department of Communities, Disability Services and Seniors, QDN partnered with the University of Sydney to develop a guide to help people with disability to get the facts about COVID-19 and make a plan for how they will manage the impact of this situation. This tool uses the Person-Centred Emergency Preparedness (PCEP) Toolkit (Villeneuve et al., 2019). The PCEP helps people with disability to tailor emergency preparedness planning to their capabilities and function-based support needs. The PCEP was developed by researchers at The University of Sydney through a co-design process involving people with disability and the services that support them. The toolkit is available here: <https://qdn.org.au/home/covid-19/make-a-plan/pcep/>

QDN has worked with Queensland Government Departments and allies and partners to distribute this resource broadly so people with disability could access it. QDN also emailed this resource to all Queensland Members of Parliament for distribution to their constituents.

QDN's peer support groups, led by people for people with disability have hosted a series of virtual meetings across the state during this time to support people with disability with information about how they can make their own COVID-19 individual plan and were able to give practical tips and support to people about important things to think about in their plans.

QDN's 23 Peer Leaders have also been engaged in a Disability Inclusive Disaster Risk Reduction project, led by the University of Sydney to build the capacity and skills of people with disability to lead disaster preparedness across a broad range of disasters and emergencies.

As part of QDN's role on the Australian Government Department of Health Cross Jurisdictional National Roundtable Disability COVID-19, QDN was able to share this resource nationally. As a result, the Australian Commonwealth Department of Health worked with University of Sydney and QDN to now adapt this into an Australian resource. The link to the tool is on the Commonwealth Department of [Health's website](#).

Access to digital technology and digital literacy:

It is well acknowledged that people with disability are rated one of the groups who have the lowest rating on the national digital inclusion index. They have poorer accesses to technology and lower skills and digital literacy. QDN, therefore, sees an urgent need for training and support to enable people with low digital literacy skills to access online and virtual tele-health and allied health therapies.

This is a critical and ongoing need that will need to be addressed. In the post COVID-19 environment, as health and a range of other essential services move to more virtual models of care that rely on digital devices, equity of access to service will be at risk for people with disability.

Further to this, as well as 'having' a device, people with disability will also need the skills and knowledge to know how to use this device, how to access their essential services and in some cases where they receive funded supports, have a workforce with the skills and knowledge to support people with disability to develop their digital capacity.

Feedback to QDN in the COVID-19 environment indicated the need for greater access to devices and data to enable people with disability, in particular more socially disadvantaged or marginalised people, to remain connected and have their essential needs met and social connections maintained. QDN has been working with GIVIT, a non-profit organisation set up to assist Queenslanders with goods and services, especially in natural disasters and emergencies.

QDN subsequently engaged with the Minister for Disability Services around this matter and the department connected QDN and GIVIT together – the aim being for GIVIT to secure the devices and data, and QDN to be able to identify people with disability who need digital supports. To date, QDN has received 34 devices and has allocated over half of these to people with disability who fit the criteria agreed upon with GIVIT. Some of the recipients of devices include:

- one iPad has been sent to Normanton to connect people with disability in this remote community;
- one iPhone has been given to a person with disability with an acquired brain injury leaving hospital;

- one iPhone has been given to a person with disability near Boonah to be able to be part of telehealth appointments, and;
- one iPad to a 40-year-old man not eligible for the NDIS (New Zealand citizen) living in a nursing home who is under stricter isolation requirements due to his living arrangements.

Access to essential disability and health services:

COVID-19 has given Queensland, and more broadly Australia, an unexpected and once in a lifetime opportunity to disrupt the way we deliver both disability and health services.

Throughout this time, the innovation and implementation of agile, adaptive models of service delivery across our service systems has been rapid and unprecedented and delivered positive outcomes and change for a number of people with disability.

For many people with disability, calls for more responsive, accessible, virtual models of care, and 'closer to home' care models have been ongoing over many decades. Whilst it is not a one size fits all, many QDN members have reported positive benefits and outcomes from these changes to the way health services have been delivered over the past four months.

People with disability have been receiving health care in other ways during COVID-19 for treatment and appointments with GPs, therapists, nurses or specialists. This includes:

- Telehealth;
- Virtual wards, and;
- Hospital in the home

Some QDN members who have received care in these ways reported positive experiences, benefits and outcomes, including:

- protecting people from contracting COVID-19;
- saving time and money;
- reducing the stress of getting to appointments, and;
- better accessibility outcomes as people have been able to coordinate and manage their own support needs for access.

QDN members have reinforced that it is important to note that e-health does not meet everyone's needs and that there is a need for ongoing choice in the way health care is delivered (e.g. a range of face-to-face or by telehealth services).

Access to ongoing care to have regular health care needs met is critical, and for some QDN members, as 'non-essential' health care was ceased, this had significant impact on their day to day functioning and pain management. For some people with disability, their fear of contracting the virus also played a factor in staying away from accessing their 'regular' health care supports and treatments. Longer term health impacts may need to be considered where people with disability had reduced access to a range of allied health and therapeutic

supports. These 'non-essential' health care services play a key role in meeting people's day to day needs and will need to be more thoroughly considered to reduce the impact on people with disability's physical and mental health.

QDN has also been part of work, funded by Queensland Health to provide independent information, support, advocacy and guidance to patients with disability and their families who are leaving hospital during COVID-19.

Impacts of costs of living and people's access to health supports and health care:

QDN members reported a significant increase in their cost of living as a result of COVID-19, that included delivery fees, shortages of and access to everyday groceries and increased prices for personal protective equipment (PPE), became a major issue for people with disability during the peak of the crisis. Additionally, public stockpiling of items like hand sanitizer and masks, left people with disability without critical PPE they use regularly as part of their day to day infection control procedures during their support in their home. QDN members reported instances where the price of hand sanitizer more than tripled during the peak of the pandemic. For people with disability, these items are essential to manage basic daily tasks like eating and personal hygiene practices.

QDN recommends that the Queensland Government works in collaboration with the Commonwealth Government, major retailers and people with disability to develop plans to ensure people with disability have priority access to essential, affordable food items and PPE in a crisis environment. Developing these plans will give people with disability greater certainty and reduce confusion in the event of a future health emergency event.

Currently, less than 10% of the population of people with disability in Australia are supported by the NDIS and are therefore unable to access and pay for the additional supports and services they may require during this unprecedented crisis. For people with disability who don't have access to funded supports and services, the establishment of the Community Recovery Hotline to assist people with disability and the Care Army was a responsive approach to an emergent need.

Protections for people in congregate settings:

As we continue to monitor the COVID-19 situation nationally, people with disability in group homes and supported accommodation facilities remain particularly vulnerable. If a resident in one of these settings contracts COVID-19 there could be an urgent need for alternative accessible housing, which is currently in short supply across the country.

Moving forward, QDN recommends that the Queensland Government continues to undertake transition and outbreak planning on how to best identify and locate short-term housing options across social housing, private rentals, specialist disability accommodation, respite facilities and supported accommodation facilities to accommodate people with disability during a public health emergency.

Throughout the COVID-19 period, QDN received numerous reports of congregate housing settings, including supported accommodation facilities and group homes, restricting the rights of people with disability beyond what was required under public health directives. This included not allowing outside support staff who deliver essential disability services to enter and restricting visits by family members. Of concern to QDN was that many of these conditions were being more strictly enforced even as COVID-19 restrictions for the general public were being eased.

It is essential that people with disability continue to have some level of choice and control in their homes during an emergency, particularly when it comes to the essential services they need to live their day to day life. Severely restricting people's access supports and leave the home not only erodes people's basic rights, but also has the potential to increase the risks of challenging or harmful behaviours.

QDN members reported significant inconsistencies in how public health directives were being implemented in congregate settings and more broadly what was considered an 'essential service'. People with disability received different advice on what support workers were 'essential' depending on which service providers they spoke to. In extreme cases, this left some people with disability without any formal disability supports during the peak of the pandemic.

QDN recommends that the Queensland Government look at specific and detailed scenario outbreak planning to better inform how public health directives should be implemented in congregate housing settings and what services are considered 'essential'. It is vital that the development of these plans includes people with disability and their families.

People with disability: recovery moving from isolation to inclusion

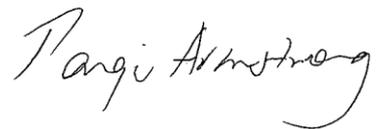
Moving forward into the next phase of response in COVID-19, a recovery that includes people with disability in the planning, design, delivery and evaluation is critical. A focus on moving people with disability from isolation to inclusion and builds people's resilience and well-being is key. People with disability have played a key role in informing, shaping and leading work, by and for people with disability. This has resulted in more inclusive and responsive actions to keep people with disability safe during this time, and ensure people can stay informed and connected with essential services and supports.

Notwithstanding the recommendations outlined in this submission, QDN acknowledges and respects the efforts of the Queensland Government to seek out the lived experience of how this unforeseen pandemic has impacted the everyday lives of people with disability.

Many people with disability require a more considered and gradual return to the 'new normal'. Many QDN members have reported that they will not consider resuming their routine community activities until a vaccine is made widely available, it will be important to ensure that their voices continue to be heard and they are not left behind, and they are supported to continue to access the essential health and disability services they need.

QDN looks forward to continuing to provide a platform for the voice of people with disability to be heard.

Yours sincerely

A handwritten signature in black ink that reads "Paige Armstrong". The signature is written in a cursive, flowing style.

Paige Armstrong
Chief Executive Officer
Queenslanders with Disability Network