

**Submission: Royal Commission into Violence, Abuse,
Neglect and Exploitation of People with Disability:
*Emergency Planning and Response Issues Paper***

QDN

QUEENSLANDERS WITH DISABILITY NETWORK
NOTHING ABOUT US WITHOUT US

Submitted to the Disability Royal Commission
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About Queenslanders with Disability Network (QDN)

Queenslanders with Disability Network (QDN) is an organisation of, for, and with people with disability. The organisation's motto is "nothing about us without us". QDN operates a statewide network of over 2,000 members and supporters who provide information, feedback and views from a consumer perspective to inform systemic disability policy and disability advocacy. This submission is informed by the lived experience of our members and supporters.

Introduction

QDN welcomes the opportunity to make a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability's (Disability Royal Commission) Emergency Planning and Response Issues Paper (Issues Paper).

In making our submission, QDN supports the human rights-based approach to this inquiry, in particular, Australia as signatory to the Sendai Framework for Disaster Risk Reduction (DRR) (2015-2030) (UNISDR, 2015) that outlines responsibility to find ways to ensure everyone is well prepared for disasters. QDN also acknowledges Australia's commitments to upholding the United Nations Convention on the Rights of Persons with Disability (CRPD) and the National Disability Strategy 2010-2020. The Sendai Framework established, for the first time, that people with disabilities are to be regarded as contributing stakeholders in DRR noting that, "Persons with disabilities and their organizations are critical in the assessment of disaster risk and in designing and implementing plans tailored to specific requirements, taking into consideration, inter alia, the principles of universal design" (Para.V.36.iii, p. 23). Upholding Australia's commitments to international frameworks and conventions (e.g., the UN Convention on the Rights of Persons with Disability) requires the inclusion of people with disability in the prevention, preparedness, response and recovery of disasters.

More than 4.4 million people in Australia have disability. This equates to almost one in five Australians.

It is broadly acknowledged that people with disability face additional risks, barriers and impacts in emergency planning and response. This relates not only to their health and disability needs, but is also impacted by individual and contextual factors such as age, gender, socio-economic status, family environment, where someone lives, whether they are Aboriginal or Torres Strait Islander and whether they are from culturally and linguistically diverse backgrounds.

The COVID-19 pandemic has shone a light on a broad range of service and system gaps that have existed for people with disability over many decades. COVID-19 has also driven a rapid and collaborative policy and system response to put in place a number of key policy, strategies and initiatives to ensure people with disability could continue to access essential day to day disability supports, food and nutrition, housing, health care and other essential services.

COVID-19 has also seen a number of people with disability already in closed and isolated environments and systems become further isolated because of government health directives and measures that have been put in place to slow the spread of the virus.

QDN supports the call for improved emergency planning and responses by, with and for people with disability. People with disability need to be included from the beginning in the planning, design, delivery and evaluation of emergency planning and response

It is critical that governments set nationally consistent standards to ensure the access and inclusion of people with disability in DRR and emergency planning.

It is critical that frameworks are in place to provide a roadmap for people with disability, community and disability support services, and local disaster management to work together to co-design emergency and disaster innovations, implement, and evaluate their impact on decreasing risk and increasing the resilience of people with disability to disaster.

It is also critical that people with disability can access information, tools and resources that are focused on individual disability functional-based supports. This ensures people with disability can have person-centred planning conversations to make a plan and communicate this with their support network before, during and after a disaster or emergency. This aligns and reinforces the capability approach and enables people with disability to be empowered.

These individual person-centred emergency plans also provide important information for decision makers to understand individual and collective needs, and be able to develop responses and quickly implement targeted strategies that are reflective of individual and collective needs.

Personal emergency planning for people with disability must go hand-in-hand with organisational preparedness and business continuity planning of the services that support them.

QDN's response to the Issues Paper is informed by Queenslanders with disability, including QDN's 2,000+ strong membership and support base and QDN's 20 Local Support Groups across the state. QDN's submission is also informed by QDN's work as a key partner in the Queensland Disability Inclusive Disaster Resilient Queensland projects across phase one and phase two, 2019-2021.

Disability Inclusive Disaster Risk Reduction: Including people with disability in emergency planning and response

Internationally, it has been acknowledged that people with disability have been left behind in disaster preparedness and consequently, experience greater disadvantage and challenges. People with disability are disproportionately affected before, during, and after disaster triggered by natural hazard emergencies.¹

People with disability need to be included, and have a right to access information, support and planning tools and resources so they can be part of broader community emergency planning and responses. People

¹ Stough, L., & Kelman, I. (2017). People with disabilities and disasters. In H. Rodriguez, J. Trainor, & W. Donner (Eds.), *Handbook of Disaster Research* 2nd ed., pp. 225-242. Cham, Switzerland: Springer. https://doi.org/10.1007/978-3-319-63254-4_12

with disability rely on different levels and types of function based support every day and these must be taken into consideration in emergency planning and responses. People's disability support needs can be compromised during an emergency, so it is critical that people with disability are empowered so they can be prepared and know what to do, before, during and after an emergency. It is also important that people with disability can access the additional support, resources and advocacy they need during an emergency. People with disability experience challenges in getting the factual information they need about the emergency and therefore, being able to make a plan, and communicate that effectively with their support networks to ensure everyone can act together to minimise risks and maximise safety.

There are three principles which need to guide this work now and into the future:

1. Disability-Inclusive Disaster Risk Reduction (DIDRR) is a human rights issue.
2. DIDRR actions must be tailored to the function-based support needs of people with disability in emergencies.
3. Preparedness is a process, not a one-time event².

Australia's National Strategy for Disaster Resilience calls on individuals and community organisations to share responsibility with emergency managers by reducing their disaster risk and contributing to community resilience. Australia's National Disaster Risk Reduction Framework (Australian Government Department of Home Affairs 2018) further advocates the development of shared but defined responsibilities so that individuals and communities can contribute to DRR within their capabilities.

In 2019, in Queensland, the Queensland Department of Communities, Disability Services and Seniors partnered with the Centre for Disability Research and Policy at The University of Sydney, the Queenslanders with Disability Network (QDN), and the Community Services Industry Alliance (CSIA) to engage community stakeholders from the disability, community, and emergency services sectors in the collaborative co-design of tools, resources, and supports for enabling Disability Inclusive Disaster Risk reduction (DIDRR). Development of the DIDRR Framework and Toolkit was part of a larger, two-phase, project designed to guide the development and implementation of disability inclusive DRR in Queensland through local collaborative action. Phase one took place in four Local Government Areas (LGAs): Brisbane, Ipswich and surrounds, Rockhampton and surrounds, and Townsville. Each LGA has different demographics including core activities needing assistance, profile of community resources, local hazard risk, and experience of disaster.

The objective of this work was to provide actionable guidance to local disaster managers on how they can work together with community stakeholders, including people with disability and their representatives, to enable more inclusive approaches to DRR in Queensland communities.

To achieve this objective, we brought research on inclusive disaster risk reduction (DRR) together with a structured cross-sector process to facilitate the collaborative co-design of the DIDRR Framework and

² Villeneuve, M. Dwine, B., Moss, M., Abson, L., & Pertiwi, P. (2019). Disability Inclusive Disaster Risk Reduction (DIDRR) Framework and Toolkit. A report produced as part of the Disability Inclusive and Disaster Resilient Queensland Project Series. The Centre for Disability Research and Policy. The University of Sydney, NSW 2006.

Toolkit that can be implemented at the local level of communities, where disasters happen. Participating stakeholders from the disability, community, health, emergency management sectors, including government were invited to share their experiences and exchange knowledge about how to reduce risk and increase the resilience of people with disability to disasters.

The Queensland DIDRR Framework and Toolkit provides a roadmap for people with disability, community and disability support services, and local disaster management to work together to co-design DIDRR innovations, implement, and evaluate their impact on decreasing risk and increasing the resilience of people with disability to disaster³.

Phase two of this project is focused on implementing the DIDRR Framework and Toolkit, evaluating and showcasing DIDRR in action.

Key Issues

People with disability face a range of unique challenges in emergency situations, many of these highlighted by the ongoing 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.

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

- Human and Social Recovery Committee
- Queensland Clinical Senate
- Ministerial Housing Council
- Queensland Disability Advisory Council
- Queensland Transition Advisory Forum
- Queensland COVID-19 Health Working Group

³ Villeneuve, M. Dwine, B., Moss, M., Abson, L., & Pertiwi, P. (2019). Disability Inclusive Disaster Risk Reduction (DIDRR) Framework and Toolkit. A report produced as part of the Disability Inclusive and Disaster Resilient Queensland Project Series. The Centre for Disability Research and Policy. The University of Sydney, NSW 2006.

- 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

QDN also acknowledged the work of the Commonwealth Government and other jurisdictions to work collaboratively in this emergency planning and response to ensure that the needs of people with disability were considered, and appropriate actions and plans put in place to deliver much needed access to information, essential basic needs like food, essential support services across disability, health and housing and broader services and supports. QDN also acknowledges the formation of the Advisory Committee for the COVID-19 Response for People with Disability and convening of Australian Government Department of Health Cross Jurisdictional National Roundtable Disability COVID-19. This work within jurisdictions and nationally has enabled 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.

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.

Advocacy and support

QDN members have identified the importance of having access to independent, individual advocacy and support during this COVID-19 time. QDN also sees the importance of systemic advocacy in broader systems reform and systems change has been critical to informing and implementation of a range of actions, activities, policies and responses. Systemic advocacy is critical to bring about change to deliver improved emergency planning and responses by, for and with people with disability.

Emergency and disaster preparedness

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.

Further to this, cross-sector collaboration and responsibility is critical to delivering responsive, integrated strategies to deliver reduced risk and increased safety for all members of the community, and particularly for people with disability. To build the capacity and resilience of people with disability, they need to be included, and have access to the information, tools and effective mechanisms that support their full participation and work collaboratively with their support networks and broader services to deliver this. The reduced capacity of people with disability to take effective action in emergency situations increases their risks and also impacts upon recovery⁴. The vulnerability of people with disability is further increased because people with disability have not been included in community-level disaster preparedness⁵.

Local governments are primarily responsible for managing disaster events in their Local Government Area (LGA). According to the Queensland Disaster Management Guidelines (2018), LGAs are ideally placed to provide specific disaster management at the community level given their knowledge and understanding of local social, environmental and economic issues. For Local Government to best plan and respond to the needs of people with disability in emergency situations, it is important that people with disability are included in local DRR initiatives.

The needs of people with disability are best articulated by the direct involvement of people with disability and their representatives in local, district, and state disaster management committees and task groups. This enables all levels of government to better understand the requirements and support needs of people with disability in emergency situations, and more effectively respond to these needs. It is also critical that people with disability have access to tools that are designed to meet the needs of people with disability to undertake planning and preparedness. The Australian-designed Person-Centred Emergency Preparedness (PCEP) toolkit⁶ is a process tool for people with disability and their community based service providers to work in partnership to develop emergency preparedness through self-assessment, targeted actions, and advocacy relevant to the support needs that individuals will have in an emergency. The PCEP framework enables the identification of function-based support in eight areas: Communication, Personal Support, Social Connectedness, Transportation, Assistive Technology, Assistance Animals, Management of Health, and Living Situation. The PCEP was co-designed with people with disability and their service providers⁷. The

⁴ Adams, R., Eisenman, D., & Glik, D. (2019). Community Advantage and Individual Self-Efficacy Promote Disaster Preparedness: A Multilevel Model among Persons with Disabilities. *Int J Environ Res Public Health*, 16(15), pp. 2779. DOI:<https://dx.doi.org/10.3390%2Fijerph16152779>

⁵ United Nations Office for Disaster Risk Reduction (UNISDR/UNDRR). (2014). *UNISDR 2013 Survey on Living with Disabilities and Disasters: Key findings*. New York: United Nations Office for Disaster Risk Reduction. Stough, L., & Kelman, I. (2017). People with disabilities and disasters. In H. Rodriguez, J. Trainor, & W. Donner (Eds.), *Handbook of Disaster Research 2nd ed.*, pp. 225-242. Cham, Switzerland:Springer. https://doi.org/10.1007/978-3-319-63254-4_12

⁶ Villeneuve, M., Sterman, J., & Llewellyn, G.L. (2018). *Person-Centred Emergency Preparedness: A process tool and framework for enabling disaster preparedness with people with chronic health conditions and disability*. Centre for Disability, Research and Policy, University of Sydney, NSW 2006.

⁷ Villeneuve, M. (2019). *Increasing involvement of people with disability*. *Australian Journal of Emergency Management*, 34(4). Published online: <https://knowledge.aidr.org.au/resources/ajem-october-2019-increasing-involvement-of-peoplewith-disability/>

aim of the PCEP is to facilitate person-centred planning conversations; enabling people with disability to have a plan for how they will act together with their support network before, during, and after a disaster.

Disability service providers and community organisations are key in supporting a person-centred approach to individual emergency preparedness planning for people with disability. It is important that the capacity of the direct support staff is built to initiate and support person-centred planning conversations with people with disability. Disability service providers must also be encouraged to embed individual and organisational preparedness planning into staff induction and training programs, to develop capacity for DIDRR.

DIDRR is about ensuring that people with disabilities have the same opportunity to access emergency preparedness information, to participate in emergency preparedness programs in their community, and to be included as a valuable stakeholder in all phases (prevention, preparedness, response, and recovery) of local community disaster risk reduction. DIDRR depends on effective cross-sector collaboration between emergency managers and community services and disability support personnel working together with people with disability, their family and allies to remove barriers that stop people with disability from engaging with DRR activities through principles of accessibility, participation, collaboration, and non-discrimination⁸.

Access to information

Access to information about emergencies that is presented in an accessible, user-friendly way, is critical for people with disability to plan for and respond to emergencies when they occur. This includes local hazard warning mechanisms and preparedness information, as well as ongoing state and national emergency advice.

Many people with disability have reported that existing information (e.g. local hazard warnings and preparedness information) is not accessible to their needs. This impacts on the capacity of people with disability to understand the mechanisms in place, and develop emergency preparedness plans and respond effectively in emergency situations. As an example, QDN have had feedback about local disaster management information not meeting accessibility needs (e.g. unable to be read by screen-readers). Local, state and national government can address this by working closely with people with disability to identify accessibility needs in preparing any disaster preparedness information.

For people with disability, access to information about COVID-19 in user-friendly and accessible communication methods remains critical. As the emergency unfolded, people with disability reported a range of experiences and barriers to getting factual information about COVID-19, what it meant for them and what they needed to do. In the current situation, where we are seeing outbreaks and greater

⁸ Villeneuve, M. Dwine, B., Moss, M., Abson, L., & Pertiwi, P. (2019). *Disability Inclusive Disaster Risk Reduction (DIDRR) Framework and Toolkit*. A report produced as part of the *Disability Inclusive and Disaster Resilient Queensland Project Series*. The Centre for Disability Research and Policy. The University of Sydney, NSW 2006.

community transition in some states and territories, this fundamental need for accessible, user-friendly information continues to be critical.

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. QDN acknowledges that disabled person organisations, advocacy organisations and other key allies have played an important role across not only Queensland but all other states and territories as key informers, able to quickly mobilise to develop and deliver user-friendly, accessible content for people with disability. This has been essential to getting accurate information out to people with disability who are digitally connected.

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. Digital inclusion is recognised as one of the key social justice challenges facing policy makers and communities worldwide.

QDN acknowledges that there are a significant number of people with disability who are not digitally connected or have low levels of digital literacy. Community and disability services industry providers have played an important role in ensuring people with disability who access their services get information, however it is also important to recognise that this workforce may also experience challenges in understanding the information, interpreting the directives and therefore communicating these to people in user friendly ways. The community and disability services workforce also need to develop their skills and knowledge in digital literacy and digital inclusion.

QDN had feedback that some people with disability were receiving inaccurate and untruthful information that forced them into isolation measures that were not consistent with other members of the community. This imbalance of power and exploitation of power has significant consequences on the lives, well being and rights of people with disability.

This is a critical and ongoing need that will need to be addressed. As health and other essential services continue to 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.

However, for many people with disability, digital access and inclusion won't be possible, and there will be an ongoing need to have flexible ways of providing information to people, through trusted sources and trusted support networks, either verbally, visually or in print.

QDN acknowledges the Australian Government's communication, including the Department of Health national information and website for people with disability, that has been produced a range of measures, including a national information hotline for people with disability to be able to access people that they can ask questions about COVID-19. However, this information was not available quickly and took some time to work with relevant stakeholders to mobilise.

This pandemic has highlighted the importance of strong and resourced local and national disabled person organisations, to deliver independent information, synthesise individual and systemic needs by and for people with disability, and be able to provide advice to Government on a key range of issues. This pandemic has also highlighted the need for people with disability to be able to access independent advocacy and raise and ask questions about what is happening and what they need to do.

Communication is key. There are lots of people with disability who do not have the information they need, in the way that they need it to be able to make decisions and/or supported to make decisions and understand what they can do to minimise their risks and maximise their safety. All levels of Governments have a role in ensuring this information is communicated in multiple ways and multiple formats that is accessible to broad range of communication needs for people with disability.

During disaster and emergency response, Local Government play a key role in their work with State Government to deliver locally based responses. Going forward, it is important that mechanisms are in place to include people with disability and their lived experiences in the planning, design, implementation and evaluation of these. Current place based action research work being undertaken in Phase Two Workstream Three of the Disability Inclusive Disaster Resilient Queensland Project, led by University of Sydney, funded by Queensland's Department of Communities, Disability Services and Seniors and in partnership with Queenslanders with Disability Network and Community Services Industry Alliance is focused on this important area of work and research.

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 is the 'Person Centred Emergency Preparedness Planning for COVID-19: A Guide to assist you to develop your own emergency preparedness plan for COVID-19'. 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 to build the capacity and skills of people with disability to lead disaster preparedness across a broad range of disasters and emergencies. This work has made clear the capacity of people with disability to lead DIDRR individually, within their community and alongside their peers with disability. With the right resources and support, people with disability are in the best position to understand and assess their own individual needs and challenges in an emergency situation. This, alongside an understanding of the process of developing an emergency preparedness plan, is invaluable in supporting others through person-centred emergency preparedness conversations. The value of peer approaches to emergency preparedness has been demonstrated through this project so far, with Peer Leaders in a unique position to support others with disability to understand emergency preparedness planning and lead the development of their own plans. A peer-to-peer approach to emergency preparedness could be supported through increased training and support to people with disability in using tools and resources such as the 'Person Centred Emergency Preparedness tool', supported by Disabled People's Organisations. With support and training, people with disability can lead training and conversations around emergency preparedness to others with disability, alongside Local Government and State Government emergency personnel.

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 adapt this into a national resource. The link to the tool is on the Commonwealth Department of Health's [website](#).

Personal emergency planning for people with disability must go hand-in-hand with organisational preparedness and business continuity planning of the services that support them. People with disability need to be given the information and support they need to undertake this emergency planning, communicate it with their support network and organisations, and governments need to be able to use this information to make informed plans and responses to emergency situations. People's support workers across NDIS and community services industry need to support people in their emergency planning where

needed to enable people to be prepared and know what they can do, have the supports they need and others around them can respond to minimise risk and maximise safety.

Systems and complexity

People with disability are often engaged in multiple systems and have a range of complexity in their lives as a result of the intersection of these systems at different stages of their life. This includes housing and homelessness, justice system, cultural and identity diversity, socio-economic disadvantage, early life and child protection system, and disperse geographical spread across Queensland.

Access to health care

QDN also sees there are a number of critical issues needing consideration, regarding 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.

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 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.

The Management and Operational Plan for People with Disability: Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19) April 2020 is a key document to guide the national response, and demonstrates a collaborative and integrated multi-stakeholder response across jurisdictions, inworking together to develop and implement this document.

Queenslanders with disability experience barriers to accessing health across preventative, primary, sub-acute and acute health settings, and QDN members have reported a range of experiences a spectrum of violence, abuse, neglect, exploitation and discrimination. Particularly during COVID-19, these impacts have been heightened.

In recent times, disability service provision has shifted away from the institutional medical model, which has historically dominated disability service provision. Instead moving to a person-centred approach, which focuses on the multi-dimensional needs of people, including their social wellbeing and inclusion. While this shift has resulted in many positive outcomes for the quality of life of people with disability, it has also resulted in less interactions between the health system and disability system. Consequently, this has seen a reduction in health literacy in the disability workforce, and a reduction in disability literacy within the health workforce. During COVID-19, we are seeing the real day to day impacts that this has on people's life and their access to quality health care. Across the State, Territories and Commonwealth, Health

Departments and Health Systems and Disability Departments and service systems were acknowledging the need for 'specific expertise' to assist in the formation of plans and responses across these two systems that were most affected by COVID-19.

QDN members have identified the challenges they experience in navigating the health system in a way that acknowledges them as individuals and takes into consideration their disability needs, and during COVID-19, being able to access the health system in a timely, equal way to other Australian citizens has been a challenge for many people with disability. People with disability often face issues communicating with health professionals and their health and disability support team in order to receive the right care and support in a way that meets their needs and upholds their rights. With restrictions and need for infection control procedures in place, people with disability have identified that this is a challenging experience, and often their need for support people and have family have been denied due to COVID-19 requirements and inconsistent implementation of guidelines.

Having patient information that not only shares clinical information but also about people's support needs has been a key gap here in Australia. Whilst some individuals may have this information, that has often been developed in response to their individual interactions and driven by their needs, there is no consistent national approach to collecting and sharing people with disability's health and disability information in a way that can be easily used by frontline medical and hospital staff.

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.

Decision making

QDN members have also raised challenges when they are not supported to be involved in the range of healthcare and health decisions, including decisions about end of life decision making, including advanced health directives, statements of care and end of life palliative care. People with disability have a right to be supported and involved in their health care, and to be given the information they need to think through these issues in a sensitive and respectful way. People with disability need the information and support to make considered decisions about their health care, and to plan for a situation where they may not be able to communicate their wishes, particularly in the COVID-19 environment.

Data

Through QDN's work we are aware of the significant impacts of no nationally consistent approach to collecting data about disability and health, which has clear individual and systemic consequences. The lack of jurisdictional or nationally integrated and consistently collected data in primary and acute health care settings reduces the understanding of systemic health issues and their impacts and limits capacity to inform the development of good public policy based upon evidence and data. This has been particularly challenging in terms of planning for this COVID-19 emergency, and understanding the range of needs and vulnerability of people with disability, being able to make informed evidence based decisions about planning, resources etc including PPE, broader public health resourcing and staffing.

COVID-19 testing

QDN has been made aware of cases where people with complex disability needs have been unable to access COVID-19 testing because of there are significant barriers to them accessing hospitals/their GP. For these complex cases, there needs to be provisions for at-home testing.

Greater guidelines are needed for health professionals who are required to test people with disability who are presenting with challenging behaviours, including guidelines for the use of sedation and restrictive practices. There is also a need for the Commonwealth Government to guarantee COVID-19 testing for disability support workers regardless of symptoms in identified hot-spot areas.

Hospital visitation

QDN is aware of multiple cases of people with disability in hospital for non-COVID-19 related reasons that have been prevented from accessing their regular support workers to provide critical support. There is varying directives and policy implementation across state and territory jurisdictions and actions need to ensure people with disability still have access to important supports that allow them to maintain their physical and mental health whilst in hospital.

Personal Protective Equipment (PPE)

QDN members are still reporting significant issues with accessing PPE. Only 10% of people with disability access the NDIS, and whilst there are provisions in place for people with NDIS plans to access the national stockpile, for some this has not effectively addressed this issue. During the pandemic, QDN members have reported emailing the national stockpile and receiving no response over a number of weeks. People with disability and their support workers need access to PPE and Support workers also need additional and consistent training on the correct use of PPE to keep people safe, and at home, avoiding hospital settings.

Health workforce capacity and communication

Doctors, clinicians and health professionals report that as part of their professional learning, there are nil to limited opportunities for training and skill development to equip them with the skills to deliver appropriate specialist health care to people with intellectual disability. The focus on people with intellectual disability in university medical and nursing school curricula is very low, with a median of only 2.6 hours of compulsory content found across 12 medical schools (with one university standing out with 12 hours⁹).

Disability workforce capacity and communication

The disability workforce broadly has limited knowledge, understanding and training in health literacy, in understanding the specific health impacts for people with disabilities, their role in recording and assisting individuals to maintain information and records about their day to day health conditions, and specialist information and training to deliver quality disability supports that are cognisant of people's health and wellbeing needs. During this COVID-19 period, this need for capacity and training is highlighted and is an ongoing need going forward.

⁹ Trollor, J.N., B. Ruffell, J. Tracy, J.J. Torr, S. Durvasula, T. Iacono, C. Eagleson, and N. Lennox, *Intellectual disability health content within medical curriculum: an audit of what our future doctors are taught*. BMC Medical Education, 2016. 16(1): p. 105.

Mental health and well-being

Mental health and well-being will continue to be a national health crisis in the ongoing response and recovery to COVID-19. This needs to be a critical area of consideration for people with disability, particularly people with intellectual disability who experience higher rates of mental health issues and dual diagnosis than the general population.

Access to essential services, food and supports

QDN had reports during COVID-19 where people with disability experienced withdrawal of a range of supports by their disability service providers, impacting on their day to day supports and essential services.

Unclear information and directions about what was and wasn't an essential service, particularly in the early days/weeks of response to the pandemic in Australia, made it difficult for disability and community service providers to provide direction and implement planning for the continuity of care and services. This left many people with disability in very vulnerable positions, without access to a range of essential supports and services to them. People with disability reported that they had a range of services withdrawn like support to do their grocery shopping with instructions to 'go online' and do it, often with the person having no understanding or access of how to do this independently. As a whole range of 'face to face' support services were withdrawn for people, this left them in challenging situations of having to rely on family and friends to assist with basic things like meal preparation.

Going forward, it is critical that measures are put in place to ensure that services and organisations have undertaken organisational preparedness and business continuity planning for the essential services that need to be delivered to their service users. Where lock down measures are in place, broader planning and evidence based actions are needed to ensure situations like the Victorian social housing towers is not experienced by others across the country.

Personal centred emergency preparedness COVID 19 emergency planning for people with disability is key to helping individuals and their support networks understand what they need across the eight capabilities and function-based support needs areas of the Person Centred Emergency Preparedness Planning for COVID-19: A Guide to assist you to develop your own emergency preparedness plan for COVID-19.

<https://qdn.org.au/home/covid-19/make-a-plan/pcep/>

Access to housing

Accessible and affordable housing is a significant issue for people with disability that was made more challenging during the COVID-19 emergency period.

A range of measures were brought into place to address the economic impacts of COVID-19 on renters including the Queensland Government's *Renter Protection Package*, and these measures assisted in keeping many people with disability safe in their private rentals, particularly for individuals who had lost income or were self-isolating for health reasons. Some QDN members expressed distress, anxiety and confusion when required to communicate or provide documentation directly to landlords or real estate agents. There is a significant power imbalance in the relationship between a tenant and landlord. People

with disability can be particularly vulnerable if forced to negotiate a reduction in rent directly with landlords, with a number of disability and housing advocacy services over capacity as a result of COVID-19.

In Queensland, a range of rapid responses were put in place to ensure people experiencing homelessness were safe and had priority access to emergency housing as the COVID-19 pandemic hit. The success of these measures shows that addressing homelessness requires more than just bricks and mortar, but wrap around social services. It is important that as the needs and support levels for people with disability who are homeless changes, that people are not forced back into unsafe situations and people are not forced back into insecure housing.

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.

Transition and outbreak planning continue to be an important part of emergency planning and response, including identification of 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 to enter and only allowing residents to have one or two family members approved to visit for less than an hour. 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 services they can access. Severely restricting people's ability to see others, 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.

It is important that 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.

Non-COVID emergency housing in disasters

For many people with disability, the lack of accessibility across local evacuation centres is a critical issue. Reports of people with disability choosing to stay in housing at high risk (e.g. during the recent Townsville floods) because of the lack of accessible evacuation options is a significant issue. For people with disability with limited social connectedness, alternative options for evacuation are minimal, putting them at high risk in emergency situations. This is also true for many people with disability who do have social supports, as many of the houses of family or friends are identified as inaccessible and inappropriate for shorter or longer term sheltering. This is a significant gap that needs to be addressed. QDN recommends government continue to undertake 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 emergencies. An understanding of the individual circumstances of people with disability is also needed, to better identify those who may require alternative accommodation during an emergency situation. This understanding can be achieved through collaboration with people with disability, disability and community services and government.

Economic impacts and income security

QDN members reported a significant increase in their cost of living as a result of COVID-19. This has only exacerbated the financial disadvantage many people with disability already face. Even before the pandemic period, 45% of people with disability in Australia lived in poverty, which is more than double the OECD average (22%).

From delivery fees, shortages of and access to everyday groceries and increased prices for personal protective equipment (PPE), the cost and availability of vital goods became a major issue for people with disability during the peak of the crisis.

The public 'panic buying' of essential items like toilet paper, flour and non-perishable goods, including pasta and rice, left many people with disability without access to affordable items that they rely on to ensure they have enough food within their budget. Additionally, public stockpiling of items like hand sanitizer and masks, left people with disability without critical PPE they use regularly. 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.

Many QDN members reported that the financial impact of increased costs for essential goods was compounded by the emotional and social impact of a significant reduction in their contact with formal disability supports. However, both the Carers Payment and the Disability Support Pension (DSP) were excluded from the Commonwealth Government's Coronavirus Supplement of \$550 per fortnight.

QDN received a large volume of calls and emails from members who are confused and distressed by the exclusion of DSP recipients from the Coronavirus Supplement, which was given to recipients of the JobSeeker Payment, Youth Allowance Jobseeker, Parenting Payment, Farm Household Allowance and Special Benefit.

While the Commonwealth Government's two \$750 economic stimulus payments provided much needed financial relief to people on the DSP, the lack of ongoing financial supplements made many people with disability feel "forgotten" or "left behind", adding to the feeling of isolation during an already difficult time. QDN recommends that in the event of a future emergency, governments work collaboratively to ensure that people with disability are not financially disadvantaged and have access to additional support.

Many QDN members, including those on the DSP, also report losing work during the COVID-19 crisis, which had previously supplemented their income support. This has led to difficult decisions between purchasing food, medication or accessing health services. These workers will require additional support to find employment in the COVID-19 recovery phase. QDN recommends governments develop and implement a dedicated disability COVID-19 employment strategy with direct input from people with disability and disability advocacy organisations. The strategy should specifically look at ways to promote the benefits of hiring people with disability and address some of the outdated attitudes that lead to greater unemployment for people with disability.

Domestic and family violence

QDN understands that people with disability experienced a rise in domestic and family violence during this COVID-19 time. It has been very important that people with disability, including women with intellectual disability have been able to access the range of supports, including specialist supports like WWILD-SVP to support them during this time. There has been an increased need for safety measures like first phones for many that haven't had access to digital technology and also second phones for individual safety from perpetrators during this time of lockdown where people have been forced into closed settings with the people who perpetrate the abuse.

Safeguards, oversight and isolation

Many people with disability rely on their access to external supports and services to act as a safeguard and provide oversight from people outside of their environment. COVID-19 has meant that the closed systems that many people live in have become even more closed and some people with disability have become even more isolated. This heightens the risk of abuse, neglect, violence and exploitation that people experience and have been experiencing during COVID-19.

Even as people's health and allied health services have shifted to online 'telehealth', this has meant that there is one less person who can act as another set of 'eyes and ears' in a person's life, to monitor what is happening and another level of safeguard.

As direct services for 'non-essential' services like community access, some supported employment services were not being delivered, the range of people in an individual's life has become smaller and smaller.

Going forward, it is critical that people with disability continue to have a broad range of safeguards and oversights in place and protective and investigative mechanisms for follow up to ensure people are free from abuse, neglect, violence and exploitation and safe.

COVID-19 has given the broader Australian community a brief insight into some of the current and historical experiences of people with disability to live in isolated, closed environments, where their movement, connection and engagement with others is restricted and shut out.

The COVID-19 pandemic also provided some tangible examples of the fine line between protecting the health and safety of people with disability and impinging on their rights to freedom of movement and access to the community.

Different governments across the world have approached this issue in a variety of ways. This has included more restrictive approaches like legislation that precludes service providers from civil or criminal liability for locking gates, doors or windows to prevent an adult with intellectual or cognitive disability from breaching the home confinement direction or another public health direction. Other countries have made adjustments to chief health officer directives in response to the needs and challenges that people with disability face, because of their disability to restrictions of movement, within broader considerations of public safety based upon the situation.

For example, in some countries it has been recognised that some persons with disabilities, such as persons with psychosocial disabilities and people with autism, might not be able to cope with strict confinement at home. Short and careful outings throughout the day are key for them to cope with the situation. The United Kingdom of Great Britain and Northern Ireland¹⁰ have relaxed initially strict confinement rules and introduced exceptions to permit autistic persons and other persons with disabilities to go outside. France has introduced similar measures¹¹. It is very important that policy decisions, legislative changes and directives made during COVID-19 do not have any unintended consequences that impinge on the rights of people with disability, particularly people with intellectual disability or cognitive impairment. Additionally, it is critical that there are provisions in place for external reporting and oversight, especially for individuals who are being subjected to restricted practices under the guise of following chief health officer directives. External scrutiny, timeframes for how long measures can remain in place and monitoring of outcomes is important, and involving people with disability in consultations where there is risk of potential harm, exploitation and abuse for people with disability.

The risks posed by expedited policy changes are also exacerbated by the overall discrepancy in how services and supports are interpreting general COVID-19 restrictions and policies, which has created unnecessary confusion and stress for people with disability and their families.

Going forward, it is important to have national and state level strategies, specifically for people with a disability to help explain the “COVID Alert Levels”. This strategy should include the development of Easy Read resources and clear guidance for parents of children with disability returning to school.

Going forward, assisting people with disability to be prepared, safe and have a plan for their supports in COVID-19 will be critical. Access to digital technology and skills to use technology will also be critical.

¹⁰ See United Kingdom of Great Britain and Northern Ireland, Coronavirus outbreak FAQs: what you can and can't do, section 15

¹¹ See Secrétariat d'Etat auprès du Premier Ministre chargé des personnes handicapées, at <https://handicap.gouv.fr/autisme-et-troubles-duneuro-developpement/infos-speciales-coronavirus/article/information-covid-19-et-confinement>

Conclusion

Moving forward into the next phase of response in COVID-19, inclusive emergency planning and response, 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, building 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. However, it has also highlighted a range of experiences for people with disability that have been unacceptable, and identified gaps and issues in system and individual level responses that need to be addressed, and lessons learnt.

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 a range of outcomes and change for people with disability. Going forward, it is important that these do not place people with disability at risk of abuse, neglect, violence, and exploitation.

It is important to acknowledge the role and work of nationally and locally based disabled person and advocacy organisations during this pandemic, who have been able to not only mobilise and respond to individual need, but also provide a range of important supports and services to people with disability particularly those who don't access formal services. It is also important to acknowledge the work and dedication of industry and peak bodies, as well as direct service providers who have worked to quickly mobilise business continuity plans and be able to deliver continuity of supports.

The collaboration of State and Territory and Commonwealth Governments and their respective Departments, and the work and dedication of people to deliver what is needed for people with disability during this time is also acknowledged.

Across all systems and at all levels, the work and support has not necessarily delivered what was needed for every person, and there have been many people with disability who have experienced levels of abuse, neglect, exploitation and violence during this pandemic as a result. However, there have been some important lessons learnt, and some important actions, policy changes and work undertaken that provide insight and learnings for what is needed going forward.

Further research is required to unpack a nationally consistent framework and how such requirements could be developed and governed in Australia, particularly given the diverse context of service delivery, funding models, and roles of service providers in the community, health, and disability sectors.

QDN supports the call for improved emergency planning and responses by, with and for people with disability. People with disability need to be included from the beginning in the planning, design, delivery and evaluation of emergency and disaster responses. It is important that frameworks, tools, information and resources deliver collaborative, inclusive and multi-stakeholder responses that enable decision makers to make informed decisions that are responsive to individual and collective needs of people with disability.