EMERGENCY PLANNING AND RESPONSE FOR PEOPLE WITH DISABILITY IN AUSTRALIA

A joint response from the **Centre for Disability Research and Policy** and **Centre of Research Excellence Disability and Health** to the *Issues Paper: Emergency Planning and Response, Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability*

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Question 1: What needs to be done by governments to increase the safety and wellbeing of people with disability during an emergency such as the COVID-19 pandemic or the Black Summer bushfires?

The emergency situation in Australia during the 2019-2020 bushfire season and the ongoing COVID-19 pandemic together have brought into sharp relief Australia's *lack of preparedness for severe to catastrophic emergencies affecting the nation.*

While this impacts all Australians, the impact is evidentially higher on people with disability.

They are more likely to be vulnerable due to:
- *social isolation* from the broader population whether because of community attitudes or their need for communication, language, mobility, emotional or other supports;
- residing in *closed or segregated settings, geographical remoteness* (and consequent lack of access to available, affordable and accessible information, support and services);
- relying on particular services and supports for daily activities and care and for access to services and less likely to have the flexibility to adjust to disruptions or closure of the supports needed for everyday routines;
- *age-related additional vulnerabilities* for children and young people with disability relying on family and for older persons with disability who may no longer have family to whom they can turn for support;
- *impairment-related vulnerabilities* for example, people with intellectual disability or autism who rely on stable, consistent supports and routines which will be disrupted;
- in pandemics, *inability to physically distance and multiple close contacts* because of reliance on personal care for activities of daily living for some people with disability;
- in pandemics, particular health conditions that lead to specific vulnerabilities if the person becomes infected or ill (unrelated to the pandemic); and,
- in natural hazard disasters such as bushfires and floods, *particular health conditions* that lead to specific vulnerabilities in reaction to, for example, poor quality air and smoke hazards, or inability to access treatments that they rely on.

The situation is magnified for Aboriginal and Torres Strait Islander people with disability.[1] Aboriginal people are over-represented in the national rates of chronic health and disease, with other disabilities coexisting with mental health problems at a higher rate than the rest of the population.[2] However Aboriginal people are often left out of health system responses to serious mental illness and disasters.[3]

The diversity among people with disability and their particular vulnerability (or resilience) during an emergency immediately suggests that what needs to be done will have to take into account diversity of need and particular vulnerabilities.

The lack of preparedness on the part of governments in Australia to adequately consider people with disability is evidenced in:

- The shortcomings of the Australian Government's ongoing implementation of the Convention on the Rights of Persons with Disabilities (CRPD) and specifically Articles 9, 11 and 25. *The Concluding Observations of the Committee* (2019)[4] drew attention to Australia's lack of progress on full accessibility for people with disability (Article 9); and their concern that Australians with disability are in significantly poorer health and have less access to information and to adequate, affordable and accessible health services and equipment (Article 25).

- Critically, the Committee observed that Australia lacked *nationally consistent emergency management standards that ensure access to disability-specific and disability-responsive support before, during, and after emergencies* (Article 11).

- Further, the Committee reiterated its concern with regard to Australia *'that there are no permanent or effective mechanisms to ensure the active participation of persons with disabilities, through their representative organisations, in the implementation and monitoring of the Convention'* (General Principles and Obligations).

The Royal Commission has already observed the requirements of the Sendai Framework for Disaster Risk Reduction (DIDRR)[5] for governments 'to engage in inclusive engagement and partnership, and investing in women and people with disability to lead and promote the design and implementation of accessible disaster risk policies, plans and standards'. The Concluding Observations of the Committee attest to Australia's lack of progress in meeting these requirements.

Government typically draws attention to the two Australian frameworks to prepare for disasters: the National Disaster Risk Reduction Framework (2018)[6] and the Australian Disaster Preparedness Framework (2018)[7]. Both were generated in the context of disasters arising from natural hazards and produced by the Attorney General's Department as the responsible department for emergency preparedness. There is also a Australian Department of Health (2019). *Australian Health Management Plan for Pandemic Influenza (AHMPPI)*.[8]

Not one of the two national natural disaster frameworks or the only pandemic response framework (disconnected from the other two) provide for disability-specific and disability-responsive support during emergencies. On the rare occasions when people with disability are mentioned, disability is considered only as a risk factor. The frameworks do not reflect the active participation and agency of people with disability in matters which affect their lives; yet, these concepts have been in force since Australia ratified the CRPD in 2008 and released the National Disability Strategy 2010-2020 in 2011. These principles are also outlined in the Sendai Framework for Disaster Risk Reduction 2015 - 2030. Namely that, "persons with disabilities and their organisations are critical in the assessment of disaster risk and in designing and implementing plans tailored to the specific requirements, taking into consideration, among other things, the principles of universal design." (Para v.36.iii, p.23)[5].

Disability specific and disability responsive approach

Much emphasis is given in natural hazard disaster frameworks to 'first responder' agencies and their workforces: police, ambulance, fire services, health workers and hospitals, and so on. This does not reflect the experience of those involved in sudden onset catastrophic natural disasters where the first responders are the person themselves and those standing next to them. They are the ones

confronted with the immediate situation and if fortunate, they may be assisted by the very stretched trained personnel from relevant agencies as for example in the Black Summer bushfires. The lesson is that each and every person (or their advocate -see below) needs to be well-informed and prepared in the context of their situation and willing to work with the authorities as directed.

Similarly, during the COVID-19 pandemic much attention has been given to directives from national and state departments of health and appropriately so. The public health response however is only as effective in managing the pandemic as the preparedness and capacity of the service sector to respond and comply to these directives as well as the public's willingness to do so.

In the case of services and supports to people with disability, the service sector is distinct from government and operates as a market of providers (particularly for participants of the NDIS). The degree with which these providers were prepared for the COVID-19 (or any other pandemic) is questionable with many reports of providers – large and small – being ill-prepared to meet public health orders. Consequently, many had to rapidly close their services with few or no alternative supports on offer to their clients, resulting in complete -and anxiety producing - disruption of their daily routines.

The public health response is also only as effective as informal supports - family members and carers, neighbours and friends - knowing who to turn to for authoritative, trustworthy and disability relevant advice. Building the capacity of trusted organisations and networks such as disabled people's organisations to respond in emergencies is also required.

The lessons from the pandemic reinforce the need for a cross-sectoral, multi-level response. This has to include governments, service sectors, communities, neighbourhoods and individuals and their families. The concepts of community preparedness and resilience are understood in Australia with regard to natural disasters such as the Townsville floods of 2019, the Black Summer bushfires of 2020. There is a place for governments learning from this emergency management approach and applying it to pandemic preparedness and response. This requires governments to reach out to the community to ensure the best possible efforts in assisting each and every person with disability, their family and carers. Top-down, non-inclusive and one size fits all responses are notably ineffective in meeting the needs of people with disability.

The requirement that local government develops disaster and emergency management plans is laudable in this regard as these require this level of government to engage with emergency services and disaster welfare actors at the local level. However, this has been inconsistently implemented with varying quality across local governments nationally, with the inclusion of people with disability and their families and carers in many cases considered to be little more than tokenistic. There is much to be learnt by government working collaboratively with the community sector to ensure more effective and local, place-based preparedness and response in the future.

Disability-specific and disability-responsive means building on the knowledge of people with disability, working with people with disability, their families and carers (or others who stand as advocates with them) to build their preparedness capacity.

It also means requiring all 'first responders' for emergency situations to be adequately and appropriately trained to support people with disability in ways which are in their best interests rather than first meeting the interests of the government department, service agency, or their workforces.

For people with disability to be as well prepared as possible in the context of their situation, the Australian Government, as a matter of urgency, and in partnership with state and territory governments and at local government level needs to meet its obligations under CRPD and the Sendai Framework by:

1. establishing permanent and effective mechanisms to ensure the participation of persons with

disabilities, and through their representative organisations; and

2. developing nationally consistent emergency management standards that ensure access to disability-specific and disability-responsive support before, during, and after emergencies.

Question 2: What supports are required to ensure people with disability are not at risk of violence, abuse, neglect and exploitation during an emergency? For example:
- **Health support**
- **Financial support**

The papers released by the Centre of Research Excellence- Disability and Health (CRE-DH) on 16th March 2020, 24th March 2020 and 14th July 2020 are appended respectively as Atttachments 1-3. These papers provide details of mechanisms which, in our expert opinion, are needed to protect the health, wellbeing and safety of people with disability during the COVID-19 pandemic and in doing so, to reduce the risk of violence, abuse, neglect and exploitation.

There is an additional concern that for many people with disability living in congregate care or supported by formal providers there is nothing in place (individual plans, organisational records) that provide direction and guidance about when to seek medical or health assistance, at what stage, from whom, and how to put this in place in a timely manner. Many people with disability may have a family member, friend or advocate who ensures that their health needs are addressed in 'normal' times as well as during emergency situations. Many however do not. There is a yawning gap between what local housing/ disability providers know about a person's health and their capacity to address health needs; it is during emergency situations (when it may be too late) that the consequences of this gap become deadly.

There is also concern that many health facilities are ill-prepared to respond to people with disability; this situation can be life-threatening at any time and this is exacerbated in an emergency situation. Individualised health plans and the newly developed Department of Health advice, Coronavirus (COVID-19) hospital companion for people with disability[9], will go some way to assist communication between health workers and people with disability, if known about and used. In the early days of the pandemic, support persons were turned away based on inflexible rules about accompanying persons. In this situation, there is a serious risk of neglect or mistreatment if health personnel are not able to communicate effectively with the (very) unwell person with disability.

Evidence is mounting about the lack of capacity in the disability workforce to adequately respond to, and protect people with disability in the face of the COVID-19 pandemic. A fact sheet with findings from a rapid survey of disability support workers is forthcoming (Kavanagh et al., 2020) and will be shared with the Royal Commission. The initial government response to people with disability in the pandemic relied heavily on the NDIA, an agency responsible for around 10% of the Australian population of people with disability. It was evident that this agency and the provider disability workforce were not trained or adequately prepared to respond effectively to a public health emergency.

Health departments at state and territory level were generally much quicker in understanding and responding appropriately to people with disability as a significant part of their client base (not only those who are NDIS participants). It took some time and much advocacy for the government to realise the need for, and provide a health related response for people with disability through a dedicated team in the Australian Department of Health, and setting up the Advisory Committee for the COVID-19 Response for People with Disability to provide advice to the Chief Medical Officer and report regularly to the Australian Health Protection Principal Committee.

Question 3: What is the experience of people with disability in getting assistance and information in an emergency? How does a lack of assistance and information expose people with disability to violence, abuse, neglect and exploitation?

We refer the Commission to the reports by People with Disability Australia[10] and Children and Young People with Disability Australia[11] (and there are other inquiries and reports in process) in which these organisations sought the experiences of their members in getting assistance and information in relation to COVID-19.

There are also a series of reports that share what has been learnt about the experience of people with disability before, during and after natural disasters in Australia. These reports clarify the situation for people with disability and provide evidence of the exclusion of people with disability from mainstream disaster risk reduction programs and education that are designed to keep everyone in the community safe. Importantly, these reports put forward recommendations that come from the voice and perspective of people with disability. These reports can be accessed here: https://collaborating4inclusion.org/disability-inclusive-disaster-risk-reduction/queensland-reports/. The Townsville report[12] for example, provides confronting illustration of the consequences of exclusion from information and support following the 2019 monsoonal flood event.

In the COVID-19 situation, the government pandemic response was particularly slow in providing targeted information resources such as Easy Read and ensuring Auslan on all occasions. As noted earlier, the CRDP Committee has called Australia to account for its lack of progress with regard to accessibility for people with disability.

Inconsistency in information has been widely commented upon by the general community; for people with disability and their families; the inconsistent information across state and federal level has been identified as particularly problematic (see for example https://www.cyda.org.au/resources/details/161/more-than-isolated-the-experience-of-children-and-young-people-with-disability-and-their-families-during-the-covid-19-pandemic)

While the mental health needs of the general population during COVID-19 have received significant attention, relatively little attention has been paid to people with psychosocial disability, despite evidence suggesting that they have been more severely impacted.[13,14] Review of health system use in previous pandemics has shown that people with psychosocial disability may conversely avoid care, meaning that their mental health declines.[15] They are also less likely to be able to access regular informal supports.

A recent Victorian report identified inaccessibility, financial barriers and not wanting to use telehealth as the primary reasons for this population ceasing to continue accessing their mental health services during this COVID-19 pandemic period.[16] Lack of access to healthcare and supports means that they are at risk of declining mental health, admission to an inpatient unit, and resulting social exclusion furthering entrenched disadvantage.[17,18] Generic approaches to preparedness by health and social care systems will not address the layering of disadvantage (isolation, poor housing, poverty, chronic illness). Failure to address this individually puts people with psychosocial disability at risk in disasters, including COVID-19.[15,18,19]

Question 4: Will an emergency hotline service help people with disability keep safe and informed during an emergency? What other communication measures might be helpful?

Emergency hotline services need to be resourced and connected so that they can be in a position to act appropriately where an individual needs assistance. Although there is now an emergency hotline for people with disability commissioned by the Department of Social Services and hosted by IDEAS, the availability of this hotline has not been widely communicated beyond the disability sector or more broadly to the community. This has been particularly apparent in health providers' lack of awareness about this hotline. Poor cross-sectoral communication and lack of cross-sectoral collaborative responses put people with disability at risk. It is also unclear what quality standards are required in relation to training and authoritative knowledge for this emergency hotline.

The high regard with which Lifeline is held nationally is testament to quality standards in recruitment, initial and ongoing training, provision of networks, resources and supports to ensure knowledgeable and supportive volunteers available to offer information and ensure callers are safe. Emergency hotline services have to operate in this way to be trusted enough to be used and to ensure consistency of information as endorsed 'providers' of advice.

Multiple communication methods need to be implemented to ensure people with disability are informed during an emergency. First, this is because of the diverse needs of people with disability which may be for captioning or Auslan or for large print or for Easy Read or many other communication strategies. In the context of the Black Summer bushfires the need for (almost) moment by moment information relevant to specific location was scarcely met in NSW by the Rural Fire Service Fires Near Me application which was not accessible to many people with disability.

Second, an emergency hotline service assumes a robust, ongoing, available and accessible telecommunication mechanism during an emergency situation. This was not the case in areas of Australia under the severe conditions of the Black Summer bushfires when the NBN and telecommunications providers were unable to maintain services, with no or limited services in some places for several days or more.

Third, reliance on any technical solution is always subject to technical interruption or breakdown. Disruption to transmission of information for even a short period of time may have deadly consequences. It seems unlikely that technical solutions, no matter how accessible these become, will ever ensure safety of people with disability.

An alternative approach is for people with disability at risk in emergency situations and wishing to avail themselves of additional assistance are 'paired' with an advocate to ensure their best interests are addressed. By advocate is meant a person who can stand beside the person with disability and

ensure their health, wellbeing and safety needs are met. Many people with disability have family, friends and neighbours who take on this role. Many do not. In some communities volunteers from organisations such as the local Neighbourhood Centre have taken on this advocacy role for people with disability in the community at risk of being 'overlooked' by the formal services or unable to access their usual supports.

Our strong focus is on local, place-based responses so that individuals with disability are not overlooked, neglected or intentionally or otherwise 'violated'.

There are many aspects to local, place-based responses. All require the local officers of larger state-based services from health, disability, and emergency response sectors to work collaboratively with local community owned and based services (e.g. library, neighbourhood centres, information centres, day centres, local businesses) to plan, prepare and respond appropriately to the needs and demands of the local context. Too often many services 'rush in' and respond with 'one size fits all' programs with inevitable overlaps, shortfalls and ineffective solutions. The different messages provided by agencies within the same sector and across sectors can be very confusing and not at all helpful to people in the community as was the case in the fatal 2015 Dungog NSW flood.

Importantly we recommend that local community emergency coordination teams ensure that each household with a person with disability is assigned one person they can contact for advice at any time avoiding problems with multiple, mixed and confusing communication from many different agencies and people. The volunteer model to achieve this has been used successfully for people with disability in natural disasters through disability advocacy groups in Queensland and neighbourhood centres in NSW.

It is noteworthy that local government in some jurisdictions are instituting emergency Dashboards as a key source of truth on disaster information and access to resources for the whole community. These Dashboards are a critical source of accurate information but they are typically inaccessible to people who need to access information in alternative formats. Development of the Dashboard requires investment in universal access to be useful to people with disability.

Question 5: How can people with disability be included in emergency planning and responses to ensure strategies that reduce risk of violence, abuse, neglect and exploitation?

The response to Question 1 addresses this question in part. The first approach is at a government level. The nationally consistent emergency standards referred to in response to question 1 can only be disability-specific and disability-responsive if developed with people with disability and their representative organisations. Practical guidelines[20] have been developed for emergency services and community organisations to effectively engage with people with disabilities to learn about their diverse and situation-specific needs in natural disaster preparedness. (see *Local emergency management guidelines for disability inclusive disaster risk reduction in NSW* at http://sydney.edu.au/health-sciences/cdrp/projects/Emergency%20Preparedness_brochure_August2017_WEB_ACCESS.pdf).

Secondly, people with disability and their support networks can engage in active and participatory person-centred preparedness planning activities.[21] These activities focus on the person in their context, family, friends, neighbours, community and the person's functional support needs and capabilities relevant to the emergency situations they are likely to encounter. The person with disability then has a fully developed plan which is maintained and updated as needed. Pre-planning, a written and accessible plan, involvement of other supporters and networks all work to reduce the risk of violence, abuse, neglect and exploitation before, during and after an emergency situation.

Resources for doing so have been co-designed with people with disability. A Person Centred Emergency Preparedness Workbook[22] that enables people with disability to tailor emergency preparedness to their support needs has been developed. This is available from the Department of Health website Coronavirus and advice for people with disability at https://www.health. gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/advice-for-people-at-risk-of-coronavirus-covid-19/coronavirus-covid-19-advice-for-people-with-disability. There are also additional resources to enable service providers to engage in person-centred emergency preparedness[23.] Further information and resources are provided for people with disability and service providers from Culturally and Linguistically Diverse Communities at www. collaborating4inclusion.org/pcep/.

In relation to pandemics individualised health care planning in consultation with a relevant health care professional is also required. This needs to cover strategies for prevention and testing aligned with public health advice and tailored to meet the needs of the person with disability and their support person/s. Written plans also need to be in place about what to do and who is responsible if the person with disability tests positive, becomes sick and /or requires hospitalisation. As noted previously there is concern that many people with disability living in congregate care or supported by formal providers have nothing in place in individual plans or in organisational records that provide direction and guidance as to when to seek medical or health assistance, at what stage, from whom, and how to put this in place in a timely manner.

Question 6: How are people with disability in closed facilities and segregated settings placed at increased risk of violence, abuse, neglect and exploitation during emergencies? What is needed to ensure people with disability in these settings are safe if facilities are locked down or evacuated?

There is a real risk for people with disability in closed facilities and segregated disability and mainstream settings (for example child protection, juvenile justice) because of the lack of natural safeguards from families or visitors (formal and informal) to these settings. Closure of community visitor programs before and during the pandemic and stopping on-site visits in official visitor programs has meant that the natural safeguards and oversight afforded by these programs are no longer in place.

The isolation of older people in congregate care has received a great deal of attention, including the concerns of families and regular volunteers about lack of oversight when 'outsiders' are not permitted inside. The same attention has not been given to the many closed facilities and segregated settings in which people with disability reside. Many of these settings include people with intellectual disability with additional needs requiring complex support who at real risk in 'normal' times, a risk seriously exacerbated by their further isolation from 'outsiders' imposed by the pandemic.

Question 9: How effective have initiatives by businesses been in supporting people with disability through the pandemic, such as dedicated supermarket shopping hours or home delivery services? What else can be done?

That people with disability have to rely on business to respond is unsatisfactory. The example of shopping hours and home delivery services is noted yet there were delays in instituting these 'adjustments' which caused significant stress. Where a business provides what is an essential service for a person with disability the government has to guarantee supply and be in a position to act as the supplier of last resort to maintain the service or services.

Individualised planning needs to take place so that continuity of essential services and supports – and these may differ depending on the individuals – are offered in a way that is accessible for all people with disability. An example of a good approach which is sometimes not accessible because of the nature of a person's disability is telehealth. People who are deaf and blind are unable to access these services. Some people with psychosocial disability have been unwilling to engage in telehealth because of the nature of their illness, with some clinicians moving to telehealth only services that therefore then become inaccessible to those that need to continue to use them.[16] This inaccessibility of services can lead to a decline in an individual's mental health. Proactive, individualised planning would ensure that there was continuity of care available in such a situation so that individual needs could be accommodated and support offered by means other than telehealth.

Question 10: How can people with disability, including those in closed and segregated settings, be supported to maintain social and community connections during emergencies?

Digital technologies can be useful to keeping individuals connected during emergencies. We have seen a wide uptake in video conferencing applications (e.g. zoom) as people can be facilitated to keep in touch with friends and families. Other technologies such as virtual reality and online games can also be used to engage people. Virtual reality allows individuals to feel as though they are outside their closed or segregated settings, without necessarily leaving that area, see for example https://edition.cnn.com/2020/07/14/health/virtual-reality-seniors-assisted-living-wellness/index. html

Many aged care providers in Australia report implementing similar creative solutions to decrease the loneliness and isolation of older people and to provide some relief from their ongoing fears and anxieties about the pandemic. It would be a particularly useful contribution if the NDIA and/ or National Disability Services could collate a compendium of such activities to provide more widespread adoption of creative solutions by disability providers.

Question 11: Is there anything else we should know about the experiences of people with disability during emergencies and responses that are needed?

There is a sound knowledge base emerging on disability inclusive disaster risk reduction (DIDRR) primarily addressing natural disasters and more recently pandemics. This work has been driven by the additional vulnerability of people with disability in Australia because there is no clear line of government responsibility to address the unique needs of people with disability in disasters [20,21,22,23] and pandemics. Attachments 1-3

DIDRR is an approach that directs attention to the support needs of people with disability in interaction with their environment, and the factors which create or restrict capabilities around

emergency preparedness and action during any emergency. DIDRR depends on effective cross-sector collaboration between emergency managers (including health and ambulance) and community services personnel to remove barriers that stop people with disability engaging with disaster-risk reduction activities through principles of accessibility, participation, collaboration and non-discrimination.[20,21,22,23] As such DIDRR is cross-sectoral, local and place-based to focus on the needs of, and supports required by people with disability where they live.

DIDRR Principles for Action in Natural Disasters

There are three principles for action on DIDRR.

1. DIDRR is a human rights issue – people with disability have the right to access disability risk reduction information, to participate in emergency preparedness programs in their community and to be included as a valuable stakeholder in all phases of local community disaster risk reduction. DIDRR brings to the fore the requirements of Article 32 of the Convention on the Rights of Persons with Disabilities to ensure that people with disability lead pre-planning efforts.[20]

2. To ensure full inclusion, DIDRR actions must be tailored to the function-based support needs of people with disability in emergencies – the Australian-designed Person-Centred Emergency Preparedness (PCEP) Toolkit[24] is the first to classify the function-based support needs of people with disability in emergencies.

Within a human-rights framework, the PCEP Toolkit offers a new approach to data- informed decision making about the capabilities and support needs of people with disability in emergencies. Consistent with the SFDRR5, the PCEP advocates a *"a more people-centred preventative approach to disaster risk"* (p.5).

3. Preparedness is a process, not a one-time event – the Disaster Risk Management Cycle is defined in terms of how governments and emergency service agencies anticipate and manage disaster risk. However, DIDRR requires cross-sector collaboration to ensure meaningful inclusion of people with disability and their support networks in DRR. The DIDRR Framework and Toolkit22 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 disaster.

Conclusion

This submission has addressed emergency response and planning in relation to natural hazards disasters such as the Black Summer bushfires and the current pandemic of COVID-19. We submit that the foundational principles underpinning disability-inclusive disaster risk reduction developed for natural disasters are equally applicable to pandemics. These principles require that all emergency planning and response is disability inclusive and disability-responsive.

Overwhelmingly, our experience is that emergency preparedness planning at all levels of government including with the community is more highly developed with regard to natural disasters than in relation to pandemics. This also applies to the slow but steady progress in disability-inclusive and disability-responsive approaches in natural disaster emergency preparedness planning.

The lack of attention to emergency planning with regard to people with disability and pandemics at all and particularly using disability-inclusive and disability-responsive approaches has become evident in the country's response to managing the current public health emergency.

Many of the strategies and actions found effective in preparedness and response to natural hazard disasters are being applied in the face of COVID-19.[23] The benefits of these approaches will become clear as research reports on COVID-19 and responses for, by, and with people with disability become widely available. Inevitably there will also be some limitations that will need to be addressed. First and foremost, the imperative remains to ensure the safety and wellbeing of people with disability during any emergency. Nationally consistent emergency management standards that ensure access to disability-specific and disability-responsive support before, during, and after emergencies (Article 11, CRPD) are urgently needed as one step in the right direction to keeping people with disability safe from violence, abuse, neglect and exploitation during emergency situations.

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PEOPLE WITH DISABILITY AND COVID-19

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3DN DEPARTMENT OF DEVELOPMENTAL DISABILITY NEUROPSYCHIATRY

Leading health and disability researchers are calling for *urgent action* **from State and Federal governments to develop a targeted response to COVID-19 for people with disability, their families and the disability service sector.**

A recent example in China where a 16-year-old boy died from starvation because his father was quarantined in hospital for COVID-19, suggests a number of measures can be implemented to reduce the likelihood of this happening in Australia. Although this is an extreme example there are also a number of other potential consequences that may emerge.

Context
Australians with disability are a vulnerable population in the COVID-19 pandemic because they are at elevated risk of morbidity and death due to underlying health conditions. This is frightening because:

- The *health sector* is under-prepared to meet the urgent health care needs of people with disability.

- The *disability service sector* will not be able to meet the care needs of people with disability.

- Information on what to do is not easily accessible. For example, some people may not understand why there is disruption to their usual daily care routines.

The Government has a targeted response for the aged care sector, but not for the disability sector. Both sectors have many similarities including congregated settings, a precariously employed and inadequately trained care workforce, and families and carers who may face significant challenges meeting the care needs of people with disability in Australia.

We recommend that governments take immediate steps including:

1. **Rapidly scale up the health care sector's capacity to care for people with disabilities by:**

- Ensuring all clinics providing testing and services related to COVID-19 are completely accessible and that this is communicated clearly to people with disability and their carers.

- Providing extra resources such as video conferencing and telephone consultations to existing specialised medical services for people with disability.

- Creating a dedicated hotline for people with disability, disability services and families.

- Ensuring sufficient support for people with disability with the most complex needs, particularly if quarantined

- Making information accessible (including Easy English, Auslan, large print, captioning in all community languages) and disseminating this information through disability services, advocacy bodies and the National Disability Insurance Agency.

2. Rapidly increase capacity of the disability care workforce to respond to the pandemic and its consequences. The government must ensure that disability services stay open otherwise the lives of people with disabilities are at risk. This can be done by:

- Rapid upskilling of disability care workforce in infection control.

- Developing standby capacity that will allow rapid recruitment and expansion of the disability workforce sector by drawing on students of allied health including occupational therapy, physiotherapy and social work.

- Increasing capacity to process Working with Children and Police checks so a new workforce can be mobilised quickly.

- Providing more financial resources to services so they can rapidly scale up their operations when there are closures to schools, day services and other programs. This could be done through the NDIA.

- Ensuring that services that provide specialist supports such as employment and therapy remain financially sustainable if they experience a downturn because their operations need to cease temporarily.

- Allowing the disability service sector, like the health and aged care sectors, to have priority access at no cost to personal protective equipment including masks, hand sanitisers etc.

- Ensuring the needs of people with disability who self-manage are met as they may find it harder to access new workers and to get access to personal protective equipment.

- Ensuring continuity of support for people with disability with the most complex needs.

- Providing strong local coordination, potentially through Local Area Coordinators, to triage disability services so that as workers become infected or are exposed to infection, the most critical services are staffed and kept open.

- Providing financial compensation from the NDIA for casual and self-employed disability workforce (an increasing component of the sector) who need to self-isolate to avoid them coming to work if sick placing people with disability at risk of infection.

- Compensating family and carers of people with disability who need to take time off work to care for their loved one. This could include paying family members for a strict time limited period for support provided during normal working hours.

- Developing a coordinated plan, implemented through the National Quality and Safeguards Commission, to address the potential for increased violence, abuse and neglect against people with disability because of social isolation and disruption of daily routines, particularly in congregated settings such as group homes.

- Providing emergency support to families who are caring for family members who have behaviours of concern that may pose a risk to the person with disability and/or family members.

- Liaising with Aboriginal and Torres Strait Islander advocacy groups and communities to ensure that their needs are met.

- Ensuring that people who have not yet transitioned to the NDIS and people with disability who do not qualify for the NDIS, but may be vulnerable to COVID-19, receive the services and the supports they need.

There is a need for action at the highest levels of government, across the National Disability Insurance Agency and National Quality and Safeguards Commission to prevent the deaths of people with disability in the coming weeks and months.

- **Professor Anne Kavanagh,** *Chair in Disability and Health and Academic Director of the Melbourne Disability Institute, University of Melbourne; Co-Director CRE-DH*

- **Associate Professor Gemma Carey,** *Research Director, Centre for Social Impact, UNSW; Chief Investigator CRE-DH*

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POLICY ACTION TO PROTECT PEOPLE WITH DISABILITY AND COVID-19

COVID-19: POLICY ACTION TO PROTECT PEOPLE WITH DISABILITY

24 March 2020

There is an urgent need for the disability and health sectors to develop a coordinated response that protects the health of over 4 million Australians with disability.

On 15 March we made recommendations to government for significant measures to protect people with disability and the disability support workforce in the COVID-19 pandemic. While we welcome the outcomes of the *Disability Reform Council* (28 March) and the media release of *Minister Robert* (21 March), there are still many areas of concern that threaten the wellbeing of people with disability, their families and the disability support workforce.

In particular, we note the apparent lack of an integrated disability and health service response.

The **health sector** is still underprepared to meet the health care needs of people with disability. Our concerns are:

- the lack of accessible testing and health care services and no plan for people with intellectual and development disabilities

- the lack of support for clinicians providing services to people with disability to upscale their telehealth activities to enable high-level health care for people with disability.

Government has mobilised a cross-sectoral approach in aged care and health, but has not paid the same sort of attention to the disability sector. The response so far has largely focussed on changes to NDIS processes.

> We strongly recommend that a National Cabinet organises a Committee of expert advisers knowledgeable in disability and health service provision.
> *This would include academics, clinicians, advocates and government representatives from disability and health sectors, to facilitate rapid evidence-informed decision making that protects the health of people with disabilities, their families and the disability care workforce. This expert committee should report to the Australian Health Protection Principal Committee (AHPPC) who then advise National Cabinet.*

Recommendations for healthcare and people with disability

1. That a **new MBS item** is introduced to develop COVID-19 health care plans with children and adults with complex disabilities, so they know how to implement social distancing and hygiene measures and how to access testing and treatment. Health practitioners should remain a single point of contact during the pandemic for COVID-19 and other health care matters.

2. That the recently introduced **Medicare item for telehealth** consultations with primary care and specialist providers be extended to children and adults with disability (who are not included in the current definition of vulnerable populations). They do not qualify for access to these services unless they are in self-isolation or quarantine.

3. A dedicated **Coronavirus Health Information Hotline** for children and adults with disability, families and disability services staffed by people with a deep understanding of disability issues and health co-morbidities. This hotline should operate alongside the existing hotline and share resources.

With respect to the **disability care workforce,** a number of issues that remain and are likely to undermine the safety, social and economic wellbeing and health of children and adults with disabilities, their families and the disability care workforce. We note the commitment of the Federal government to enable extension of plans, telephone planning, plan flexibility, commitment to ensuring the ongoing provision of essential services and supports, new measures to source workers displaced from other industries and proactive outreach to people with disabilities with complex needs.

It is unclear how these measures will be implemented including how continuity of services can be guaranteed when service gaps arise. Participants are simply referred to the standard 1800 number.

Recommendations for the disability workforce

1. **Immediate access to personal protective equipment** (PPE) to prevent transmission as a prevention strategy. There is a lack of recognition of the need for workers to access personal protective equipment to prevent transmission to the people they support. Because many of these workers see several disabled people in one day, they are very likely to acquire and transmit COVID-19. However, personal protective equipment is only available if they are supporting someone with COVID-19 or suspected COVID-19 infection.

2. **Guarantee the incomes of families and carers** who need to take time off to provide care. In light of school and day service closures in some states and territories, many participants will rapidly need to have changes made to their plans, including a large injection of funds, so that essential supports can be provided. We previously recommended that family members should be paid for providing supports in the pandemic, so families are not placed under undue distress.

3. That the **NDIS rapidly reach out to self-managed participants** particularly those using online platforms, unregistered providers or directly employing support staff to ensure they don't experience a disruption of supports and have access to PPE for staff when it becomes available

4. That **disability support** is considered and clearly **defined as an essential service** alongwith other services such as supermarkets and petrol stations.

> We welcome the opportunity to speak with Commonwealth and State and Territory governments at the highest level, the NDIA, and the National Quality and Safeguards Commission to ensure that disabled Australians receive the care and support they require during the COVID-19 pandemic.

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Disability and Health

STOP THE SPREAD

SAVE LIVES

RECOMMENDATIONS FOR A TAILORED COVID-19 RESPONSE FOR PEOPLE WITH DISABILITY

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What has happened in Melbourne over the last two weeks is a serious warning for all Australians about the potential for coronavirus to spread and the ongoing risks for people with disability.

We have moved from a situation where State and Territory government responses are relatively consistent to one where there are differentiated responses even within the same State or city. This raises new questions about how to respond to the **health, educational and social care needs of people with disability** living in areas with high rates of infection, at the same time as how people with disability in other areas might be encouraged to return to pre-COVID-19 activities. It also shows the importance of planning so coordinated responses to emerging outbreaks can be rapidly mobilised, no matter where these occur.

With community transmission escalating this month, the Victorian government has implemented Stage 3 restrictions across metropolitan Melbourne and Mitchell Shire. Hard lockdowns of high-rise public housing estates have also occurred in response to outbreaks in these environments. Importantly, there are now multiple clusters including a large outbreak in a school in Melbourne's outer west as well as infections reported among aged-care workers. The situation is rapidly changing and it is critical that governments are able to respond to the needs of disabled people, as a priority.

We commend the Victorian government for its actions to protect and support residents now under lockdown in a highly complex environment requiring multicultural, health, mental health, aged care and family safety responses, as well as support for people with disability, their families and carers.

We outline some immediate actions that Victorian and Commonwealth government agencies could do for **people with disability,** some of which may already be underway.

1. We recommend proactive community outreach to households:
This could be coordinated through local councils and community organisations who could actively refer people to services. The outreach would identify all people who require additional supports, whether or not they are NDIS participants or identify as a person with a disability.

Community workers could reach out to individual households and:
- assess immediate health and social welfare needs including personal care, mental health and behavioural support
- develop a plan for each person with disability and household on what would happen if one or more family members becomes infected and needs to self-isolate or if their current living situation is untenable (e.g. at risk of abuse and neglect)

- provide information in Easy Read and/or Easy English and community languages
- provide emergency contact numbers including disability hotline, mental health services, family violence services and health care professionals with specialist expertise in disability to assist them if they become unwell or need further information
- ascertain whether they have access to phone and internet to contact services and receive information, and organise internet access if they do not have access
- provide face-to-face training on infection control and use of face masks
- assess whether they have access to essential medicine and health care and ensure that they receive their medicines and access to health care by contacting relevant providers.

We recommend that community workers undertake welfare checks on households at least every second day, so emergent issues can be identified and problems can be averted. *We recognise that not every person or household will want such a comprehensive response and that many may choose to opt out.* We also believe that these measures provide some safeguarding for people with disability at risk of violence, abuse and neglect in the pandemic, something that has already been reported.

We suggest that the response is coordinated through local government, local residents' groups and community services with sufficient resourcing. Trained community workers and educators, with deep knowledge of local communities, employed through community organisations (e.g. Multicultural Centre for Women's Health, Disabled People's Organisations) could be used. Volunteers with a background in disability and medical and health sciences students (e.g nursing, social work and occupational therapy) could also be deployed. **Importantly we recommend that each household is assigned one person they can contact for advice at any time avoiding problems with communication.** The volunteer model has been used successfully for people with disability in natural disasters through disability advocacy groups in Queensland and neighbourhood centres in NSW.

2. Specific health care and social welfare initiatives could include:
- where taking nasopharyngeal swabs is difficult or impossible, ensure that saliva testing is available
- ensure doctors and nurses testing patients have the resources to communicate with people with a range of disabilities and, where necessary, are accompanied by community workers with appropriate background in disability
- as recommended in the Commonwealth Government's [Management and Operational Plan for People with Disability,](#) develop health care specific plans for people with disability covering testing, health and hospital care and advanced life saving support which can be presented to health care providers unfamiliar with their care
- reach out to the Office of the Public Advocate, Disability Services and Mental Health Commission and Family Safety Victoria and other related State and Commonwealth agencies to assist with identifying the most 'at risk' people quickly

- for people who rely on others for informal support for personal care and mental health needs, enable their supporters to be able to continue that care provision in a safe manner and where this is not possible arrange for alternative support to be provided
- provide for people with disability for whom confinement to home is very challenging to be able to go outside, with appropriate safety standards in place
- community workers and volunteers work alongside police and other services such as child protection so they respond appropriately to the particular needs of people with disability
- identify emerging issues for people with disability, their families and carers, by actively monitoring social media and respond quickly to concerns raised.

3. In terms of the provision of disability services we recommend:

- that the National Disability Insurance Agency and Local Area Coordinators reach out to all participants and assess whether an urgent plan review is required
- that the Victorian government, National Disability Insurance Agency (NDIA) and NDIS Quality Safeguards Commission (NDISQSC) proactively work with disability services in the affected areas to provide support to residents (whether NDIS participants or not) in a safe way. Detailed directives from these agencies are required, rather than leaving these critical decisions to individual service providers
- ensure that NDIS participants are able to access all the services they require irrespective of whether they have sufficient funding in their plans, and provide alternative support if services such as day programs are closed
- reach out to NDIS participants in affected areas to offer rapid plan review if required
- pay family members who provide additional support to a person with disability because formal support is reduced or ceased
- extend temporary visas and increase the number of hours international students can work if they are providing disability support
- provide compensation for support workers who have to cancel shifts because they are sick and do not have paid leave
- ensure personal protective equipment (PPE) is available and being used appropriately
- audit services to ensure they are complying with public health directives.

4. In relation to the health of children and young people with disability returning to education we recommend:

- where students cannot return to school, have their school facilitate opportunities to engage with friends and classmates on a social basis
- provide alternative transport options to school buses to enable physical distancing and other infection control measures
- provide school staff with training in infection control
- audit schools to ensure they are compliant with public health directives
- encourage families and schools to develop individualised return to school plans for children who have underlying health conditions which place them at risk if they are infected with COVID-19. Templates for plans are available on the Commonwealth government Department of Health website.
- ensure schools and disability services need to have pandemic plans that are actively audited.

We recommend that all State, Territory and Commonwealth governments reach out to local communities to develop tailored community responses, proactively plan with people with disability, families and carers and identify someone that can be contacted if the need arises.

We are happy to work with the government, the community and advocates to help tailor the response for people with disability. We believe action is urgent to prevent the terrible outcomes for people with disability seen in other parts of the world, including preventable deaths from COVID-19 and cases of abuse and neglect during the pandemic.

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