

A voice of our own

Realising our right to be safe in emergencies

Submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability in response to the Emergency Planning and Response Issues Paper (15 April 2020)

About PWDA

People with Disability Australia (PWDA) is a leading disability rights, advocacy and representative organisation of and for all people with disability. We are the only national, cross-disability organisation - we represent the interests of people with all kinds of disability. We are a non-profit, non-government organisation.

PWDA's primary membership is made up of people with disability and organisations primarily constituted by people with disability. PWDA also has a large associate membership of other individuals and organisations committed to the disability rights movement.

We have a vision of a socially just, accessible and inclusive community, in which the human rights, belonging, contribution, potential and diversity of all people with disability are recognised, respected and celebrated with pride. PWDA was founded in 1981, the International Year of Disabled Persons, to provide people with disability with a voice of our own.

PWDA is a NSW and national peak organisation and founding member of Disabled People's Organisations Australia (DPO Australia) along with Women With Disabilities Australia, First Peoples Disability Network Australia, and National Ethnic Disability Alliance. Disabled Peoples Organisations (DPOs) are organisations that are led by, and constituted of, people with disability. The key purpose of DPO Australia is to promote, protect and advance the human rights and freedoms of people with disability in Australia by working collaboratively on areas of shared interests, purposes, strategic priorities and opportunities.

Postal address:

PO Box 666 Strawberry Hills NSW 2012 **Street address:**

Level 8 418a Elizabeth Street Surry Hills NSW 2010

Phone: 02 9370 3100 Fax: 02 9318 1372 Toll Free: 1800 422 015 NRS: 1800 555 677 TTY: 02 9318 2138

TTY Toll Free: 1800 422 016

TIS: 13 14 50

Email: pwd@pwd.org.au

ACN: 621 720 143



Contents

About PWDA	2
Response to DRC Issues Paper: Emergency planning and response	4
The impacts of climate change	5
Recommendation 1	6
COVID-19 Pandemic	7
Key findings from PWDA's COVID-19 Survey	8
Recommendation 2	10
2. Income support and expenses	10
Recommendation 3	11
3. Telehealth	11
Recommendation 4	11
Emergency response communications	12
Recommendation 5	13
Accountability measures	14
Recommendation 6	14
Conclusion	14



Response to DRC Issues Paper: Emergency planning and response

To the Commissioners, Royal Commission into Violence, Abuse, Neglect and Exploitation of people with disability.

Thank you for the opportunity to respond to the *Issues Paper on Emergency Planning and Response*.

Our response to the Issues Paper includes discussion of the impact of the two recent emergencies – Black Summer Bushfires (2019-2020) and COVID-19 (2020) – on people with disability, as well as our understanding about the overall disasters that our changing climate will bring. We have also attached our survey report that includes the voices of people with disability about the impact of COVID-19.

We would welcome the opportunity to appear before the Disability Royal Commission to speak to these concerns and practical ways in which Australian Governments can ensure that current and future emergency planning and response are inclusive of people with disability.

Your sincerely

Jeff Smith

CEO, People with Disability Australia



The impacts of climate change

Climate change will have disproportionate impacts on people with disability but we are often excluded from discussions about how to respond to the consequences of climate change, as well as any mitigation or adaptation measures.

Much of the law that has been developed to regulate the use of our environment, and to try to minimise the impact of climate change, has been built on a solid foundation of engagement with different communities. This commitment to public participation is firmly embedded in environmental legal frameworks at all levels – international, regional, national, state and at the local community levels. But people with disability, in all our diversity, have often been invisible in this space. This has to change.

Climate change is having an impact on everyone, including people with disability. Yet many questions remain:

- are we including people with disability in our disaster plans, or thinking about what people with disability will need to cope with increasing unpredictable and extreme weather, air pollution or heatwaves?
- are we including people with disability when we think about how to adapt to a changing world and how can people with disability be included in efforts to slow climate change?

Recently, the United Nations passed a resolution about human rights and climate change that includes "recognising that persons with disabilities are among the most adversely affected in an emergency, sustaining disproportionately higher rates of morbidity and mortality, and at the same time being among those least able to have access to emergency support".1

Human Rights Watch says that "Governments need to reach out and listen to people with disabilities, who are among those who feel, or will feel, more acutely the adverse effects of environmental change, and will be important leaders in fighting it." 2

PWDA is involved with local and international work to include people with disability in disaster planning, including in relation to climate change. As a member of the <u>Pacific Disability Forum</u>, we stand with people with disability in the Pacific, facing significant, immediate danger from the effects of climate change.

"The Pacific is also at the front lines of climate change, with increasing severity and more frequent occurrence of natural disasters, rising sea levels and other climate-

¹ United Nations General Assembly – Human Rights Council 41_{st} session 24 June to 12 July 2019 https://www.hrw.org/sites/default/files/supporting_resources/hrc41_climate_change_and_disability.pdf ² Human Rights Watch https://www.hrw.org/news/2019/07/15/un-climate-resolution-emphasizes-protection-disability-rights



related challenges. These circumstances create a need for community-based approaches which foster inclusion and resilience."3

It is vital that people with disability have a direct say in the way that Australia manages the climate crisis, and that we are involved, as experts about our lives, in all measures to reduce our emissions.

Recommendation 1

That the Australian government in partnership with state, territory, and local governments reviews its framework approaches to emergency response planning to ensure that people with disability are included at every level of the emergency response planning and implementation. Key steps will include:

- engaging meaningfully with people with disability and their representative organisations in all levels of the planning and response processes across government portfolios in an ongoing and systematic basis (not simply reactively when the emergency strikes)
- ensuring that emergency planning and response strategies include mainstreaming
 of disability-inclusive practices into both mainstream response efforts within health,
 housing and community services but also amongst the emergency services and
 combat agencies. Approach also need to include developing tailored and specific
 measures to address the diverse needs of people with disability
- establishing and resourcing an ongoing and formal engagement mechanism that allows people with disability and their representative organisations to be central and active partners in Australia's planning and response to emergencies.

³ Pacific Disability Forum SDG-CRPD Monitoring Report 2018 http://www.pacificdisability.org/getattachment/Resources/Research/PDF_SDG-CRPD-Report.pdf.aspx



COVID-19 Pandemic

The COVID-19 pandemic has had a profound impact on people with disability across Australia and around the world.

We note that the Disability Royal Commission has referenced our Open Letter to National Cabinet, endorsed by over 70 disability organisations and individuals, in the Emergency Response issues paper.⁴ This letter distils many of the concerns that people with disability have about the way the pandemic has been handled, and the disproportionate impact many of the measures have had on people with disability.

The key concerns highlighted in the Open Letter covered areas such as:

- Guaranteeing continuity of supports for all people with disability
- Expanding the case definition for COVID-19 testing to include people with disability and their support persons
- Urgently improving communications so they were inclusive for all people with disability
- Removing barriers to healthcare for people with disability
- Ensuring effective measures were in place to recognise and respond to violence, abuse, exploitation and neglect of people with disability
- Extending the Coronavirus Supplement to the Disability Support Pension
- Preventing the discrimination of students with disability in education provision
- Ensuring the rights of people with disability living in congregate settings
- Adequately resourcing Disabled Peoples Organisations and Disability Representative Organisations, to enable support of, and advocacy for, people with disability.

Continuity of support was a key issue for many people with disability, who reported to trusted organisations, such as PWDA, that NDIS service providers were withdrawing essential supports, and not providing alternatives, in contravention of their Code of Conduct.

Our direct practice, intake and communications staff all reported hearing directly from a wide variety of people with disability that disability support providers had changed their supports without consultation, or had stopped them entirely. Our direct practice staff worked with people with disability to ensure they had access to food and medication, as well as regular time outside their homes.

Since the onset of the COVID-19 pandemic, significant and consistent barriers to our safety and wellbeing have existed. These include access and availability of personal protective equipment (PPE), as well as a lack of accessible testing. In July 2020, both these issues have resurfaced with the new outbreaks of COVID-19 in Victoria, and must to be addressed urgently.

4 https://dpoa.org.au/an-open-letter-to-the-national-cabinet-immediate-actions-required-for-australians-with-disability-in-response-to-coronavirus-covid19/



We also conducted a survey during May 2020 on COVID-19. We received over 200 responses from people with disability and their families, detailing their experiences during the COVID-19 crisis. The report about the survey findings is attached to this submission.5

1. Key findings from PWDA's COVID-19 Survey

People with disability said they had faced increased expenses (91%), reduced disability supports (40%) and had also used telehealth to access healthcare and allied health appointments.

They also reported significant challenges in maintaining vital daily supports which indicated that people were both at risk of and experiencing systemic neglect and marginalisation. The following quotes from the survey highlight the challenges that people with disability have been living through during the COVID-19 pandemic. And now that the pandemic has reached a 'second wave' in some parts of Australia, we need to remember that these are not short-term or one-off experiences, these experience are continuing and ongoing:

"All my costs have expanded, from having to make multiple trips to the shops to get the basics or having to pay 100% inflated prices online as people are hoarding the medical supplies I need, but I need them, so I must pay for it."

"The way the supermarkets managed the priority grocery delivery service was a disaster. They cancelled normal delivery with having nothing in place. Coles took several weeks to arrange their service, but in the meantime, Woolies were very unresponsive and kept losing peoples forms. I was genuinely scared I would starve, in an affluent country like ours!"

"I'm completely isolated...no one has rang to see how I'm going. I have no outside family."

"I lost all NDIS supports, and am now barely alive, I do believe I could die from this. I have had huge issues trying to get any food, food delivery from supermarkets, very patchy. I have no family or friends or informal supports and rely on paid supports to keep me alive, how much longer I live is beyond me. I do not have the technology I need or require or assistance to access it."

"Much easier for me to access telehealth services from GPs, specialists and allied health workers, some I didn't have access to at all before COVID."

"I am deaf but don't sign and the move to Zoom and telehealth has been extremely difficult for me. I used my NDIS money for captioning in Zoom meetings as the sound quality was so terrible. It was also hard communicating with the doctor for telehealth sessions."6

The experiences in this report show clearly the extreme anxiety and dread that people with disability felt as the COVID-19 pandemic began to unfold and how we were not included in the narratives and initiatives for the emergency response planning.

⁶ https://pwd.org.au/experiences-of-people-with-disability-during-covid-19-survey-results/



⁵ https://pwd.org.au/experiences-of-people-with-disability-during-covid-19-survey-results/

In mid-March 2020, PWDA wrote to the relevant Ministers: the Minister for Health, the Hon. Greg Hunt MP; Minister for Families and Social Services, Sen. Anne Ruston; and the Minister for the NDIS and Government Services, the Hon. Stuart Robert MP. We highlighted our concerns and called on the following initial steps to be undertaken.

Here is an extract from our letter:

According to the Australian Bureau of Statistics (ABS), one in five people across Australia have disability. For older Australians this increases to one in two people. At the same time, only 10% of people with disability under the age of 65 are eligible to receive supports through the National Disability Insurance Scheme.

This means most of us rely on mainstream services, such as the health system, just like everyone else. However, our daily experiences and current research show that many parts of our health system are inaccessible. We face barriers in seeking health and medical treatments due to a range of factors including: negative cultural attitudes towards us, limited staff training in disability awareness and limited to poor accessibility of health premises, such as GP clinics and hospitals.

To ensure that the people with disability are properly, appropriately and respectfully considered in the face of the COVID-19 health epidemic, we are asking you to ensure that people with disability are included in the planning, implementation and monitoring of responses to COVID-19 as the emergency unfolds.

The initial steps we urge you to take are:

- update the Australian Health Sector Emergency Response Plan for Novel Coronavirus COVID-19 to include the needs of people with disability
- provide representation of people with disability and their representative organisations on the major Federal Government planning and consultative mechanisms to respond to the spread of COVID-19
- ensure that essential supports continue for people with disability with NDIS plans, and that the NDIA has contingency and communication plans in place so that people with disability know what to do if their support workers are sick, or need to self-isolate, as well as how to access extra support if they need to remain at home
- ensure all communications about COVID-19, including the new national campaign, are accessible to people with disability. We need to see Easy Read material widely available, as well as Auslan and captions used in all emergency broadcasts
- provide information for people with disability on where to get essential supplies to keep themselves safe, such as hand sanitiser, particularly when they are running low and if there is a need to self-isolate.

We note and acknowledge that through March, April and May 2020, the Australian Government, as well as States and Territories, did put in place a number of initiatives and mechanisms to better address the specific and diverse needs of people with disability.



However, what the COVID-19 pandemic has revealed is that provisions for people with disability are not embedded within Australia's policy framework for emergency planning and response and that this must be significantly improved.

It is urgent that people with disability and our representative organisations must be involved on an ongoing basis in the broad planning and response processes across government portfolios. As we moved through the COVID-19 pandemic, key lessons are that we must be involved meaningfully in the next stages and the recovery process, and that we have much to offer.

Our survey report also reveals that people with disability routinely experience marginalisation and social segregation and that emergencies like COVID-19 serve to heighten these experiences. Furthermore, our survey report showed that people with disability did not feel included, and/or were only included after significant efforts around advocacy and representation were made. Concerns covered supports for basic needs such as access to food, PPE, health care and continuity of supports.

In response to the Open Letter, the Minister for Health, the Hon. Greg Hunt MP, announced and convened an advisory group on 3 April 2020. The advisory group was tasked with developing and implement an immediate response plan focusing on the health needs of people with disability during the coronavirus pandemic.

PWDA participated in this advisory group, and the Management and Operational Plan for People with Disability was released on 6 May 2020.7

Recommendation 2

That Australian Governments ensure that all forms of emergency planning response (whether that be a public health crisis, natural disasters (fires, floods, storms) or major accidents or emergency incidents such vehicle accidents, train crashes, building and house fires and collapses) make full and proper provision for people with disability at every level of the planning and response process.

2. Income support and expenses

Another key area that remains unresolved is income support and the lack of a full policy response for income support for people with disability during the COVID-19 pandemic. People with disability have experienced, and will continue to, experience higher costs of living and disability costs during the pandemic. PWDA received considerable feedback from our members about the impact this was having on their wellbeing and capacity to respond to the COVID-19 crisis.

In addition, the survey report reveals the need for wholesale review of the income support framework for people with disability. People with disability rely on a variety of income support payments, including the Disability Support Pension and JobSeeker. For those people with disability who have the capacity to work, they are also experiencing

 $^{{\}scriptstyle 7\ https://www.health.gov.au/resources/publications/management-and-operational-plan-for-people-withdisability}$



disproportionate pressure compared to our non-disabled peers in the current labour market due to the multiple barriers that people with disability face in the job market.

However, unlike people without disability, people with disability will continue to be at highrisk and most likely to experience adverse and long-term impacts as we enter the next phases of the COVID-19 pandemic. Considering this, we believe that the following measures are needed to support people with disability in the next phases.

Recommendation 3

That the Australian Government:

- reviews mutual obligations for people with disability to ensure people are not putting their health at risk due to the requirements to meet mutual obligations
- extends the Coronavirus Supplement to the Disability Support Pension for the remainder of the duration of the pandemic
- reviews the Disability Support Pension impairment tables, noting this has been recently recommended by the Senate Committees on Community Affairs in their report on the Adequacy of Newstart and related payments (April 2020)
- permanently increases the DSP to reflect the true costs of living and disability expenses.

3. Telehealth

People with disability also reported in our survey that they had made use of telehealth to access medical and allied health appointments during the pandemic. This has been a welcome move to ensure that more people with disability can access the healthcare they need, but we are concerned at recent changes to restrict access to telehealth.

We are concerned about the narrow availability of the recent changes to telehealth access. The requirement to have an existing relationship with the doctor/health care provider will put up barriers to people with disability accessing health services.

This doesn't make sense when the spread of COVID-19 is increasing. Many people with disability will remain in lockdown for a long time, so putting restrictions on accessing healthcare is impractical, inequitable and counter-productive.

We believe that it is vital that telehealth access is improved, beyond this initial stage, to ensure equitable healthcare for people with disability.

Recommendation 4

That the Australian Government removes barriers to accessing healthcare for people with disability during the COVID-19 pandemic and beyond by lifting the restrictions on access to telehealth.



Emergency response communications

Communications are a vital aspect of robust and effective emergency responses, and have a particular impact on people with disability. During both the recent Black Summer bushfires, and the COVID-19 pandemic, the availability of accessible and accurate information has been a significant barrier for people with disability to make decisions about their individual disaster responses.

During the bushfire crisis, PWDA, alongside Disability Advocacy Network Australia (DANA), Inclusion Australia and IDEAS, called for urgent funding for disability advocacy and information services, as we were playing a vital role in assisting people with disability on the ground in evacuation centres, and to connect with the supports they needed.8

We also called for all disaster-related communications to be accessible for all people with disability, including people with intellectual disability, through Easy Read, Auslan, plain English and other accessible formats.

PWDA, alongside other disability advocacy and information services, quickly collated information from a variety of sources, prioritising accessible formats such as Easy Read and Auslan. Disability advocacy and information services were relied on heavily during this time as trusted organisations by our communities. PWDA advocates also directly supported people with disability to navigate through the different levels of government, and the sometimes contradictory and often inaccessible information that was present at the time.

PWDA collated information into a bushfire hub on our website, and shared that with our community through social media (Facebook, Twitter, Instagram), email (newsletters and member emails), as well as posted information by mail as needed, and provided hard copy information to our advocates to use in local communities.9

Auslan interpreters were used for emergency press conferences and announcements, but were frequently cropped out of the frame, despite direct advocacy from a variety of disability and Deaf organisations. Captions were not always provided for video and audio formats. Emergency information was generally not made available in Easy Read formats. At a local level, most information was not made available in accessible formats at all, nor take into consideration the needs of a diversity of people with disability.

Following directly on from the bushfire crisis, the COVID-19 pandemic and the associated response again challenged PWDA, and other disability advocacy and information services, to quickly provide accurate and accessible information for our communities. This was particularly acute for people with disability, as there was a severe lack of accessible

8 https://pwd.org.au/media-release-people-with-disability-must-be-part-of-bushfire-plans-and-recovery/9 https://pwd.org.au/bushfire-and-emergency-information/



information, as well as information about the specific circumstances for different communities of people with disability.

Information was very difficult to find about personal protective equipment, disability services, accessible testing and the details of the lockdown rules for disability support. In addition, the restriction of access to mainstream services, such as grocery delivery, was very confusing and difficult to clarify for people with disability.

In our initial statement, with other disability advocacy organisations, we highlighted the urgent need for accessible information for a variety of disability communities. These included:

- Aboriginal and Torres Strait Islander people with disability
- Culturally and linguistically diverse people with disability
- Deaf, Deaf/Blind communities
- Blind and low vision communities
- People with intellectual disability.10

Communications staff from a variety of state, territory and national disability advocacy organisations came together to share resources and work together to provide as much information as we could to our communities.

Staff met weekly, and shared information via social media with each other. We developed a variety of original material in accessible formats, and helped to ensure that the latest information from all levels of government were made available as quickly as possible.

As in the bushfire crisis, much Government information was often released without captions, and with Auslan interpreters cropped out of the frame. There were even times when some Premiers were making public announcements without Auslan interpreters.

Information was not released in Easy Read formats in a timely way, putting a huge stress on disability advocacy organisations to produce accessible resources. Online resources were often produced in PDF format only, which remains inaccessible to many communities.

Both of these disasters, and the associated responses to them, highlighted the urgent need for a robust communications planning protocols for emergencies, that centres people with disability and our organisations. Disability advocacy and information services were provided with no resources to provide accessible communications, so the work our organisations have been doing has come at a significant cost to staff and budgets. Many of our communications staff are also people with disability who were affected by both of these recent emergencies, and used their direct experience and communications expertise to serve our communities very well in a time of crisis.

Recommendation 5

That all emergency response plans include robust communications plans and protocols that centre people with disability.

10 https://pwd.org.au/covid-19-plan/



That the communications plans are co-designed with people with disability and their representative organisations and recognise the high-level expertise that communications professionals from the disability community have to offer.

Accountability measures

PWDA has significant concerns about the shortcomings in the accountability and oversight mechanisms that could have assisted people with disability during these disasters. We had many reports, through a variety of staff and sources, that people with disability were experiencing increases in violence, as well as withdrawal of essential supports during the COVID-19 period.

However, people with disability often didn't feel safe to make complaints, or know where to make a complaint. In addition, for people with disability who have NDIS plans, there appeared to be limited to no monitoring of whether disability support providers were abiding by the Code of Conduct, or any penalty for withdrawing supports from people with disability during a time of crisis.

This urgently needs to be urgently examined by the Disability Royal Commission so these issues are addressed for the long term. As more regions and states go back into lockdown, it is essential that people with disability aren't left without the key supports we need.

Recommendation 6

That the Disability Royal Commission investigates the oversight, accountability and safeguarding measures as they were applied during the COVID-19 pandemic.

Conclusion

2020 has been a hard year for many people with disability, who have lived through bushfires, then coped with a pandemic. For many people with disability, the lockdown will be in place well into 2021 or until a vaccine is developed.

As the peak body for people with disability, run by and for people with disability, we experienced the impacts of the COVID-19 pandemic directly, as well as working with people with disability across Australia. Many of our staff, Board and members were affected by both the bushfires and by the COVID-19 pandemic.

It is urgent that people with disability have a seat at the table in all emergency planning, and are genuinely consulted and listened to about what we need to manage disasters. This must include a diversity of disabled people's voices to ensure that we are including all people with disability.

People with disability are equal citizens in Australia, and we must not be left behind in emergencies.







A voice of our own