



Submission to the Disability Royal Commission

Issues Paper - Emergency Planning and Response

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Who is the Physical Disability Council of NSW?

The Physical Disability Council of NSW (PDCN) is the peak body representing the 1,034,000¹ people living with physical disability across New South Wales. This includes people with a range of physical disability issues, from young children and their representatives to aged people, who are from a wide range of socio-economic circumstances and live in metropolitan, rural and regional areas of NSW.

Our core function is to influence and advocate for the achievement of systemic change to ensure the rights of all people with a physical disability are improved and upheld.

The objectives of PDCN are:

- To educate, inform and assist people with physical disabilities in NSW about the range of services, structure and programs available that enable their full participation, equality of opportunity and equality of citizenship.
- To develop the capacity of people with physical disability in NSW to identify their own goals, and the confidence to develop a pathway to achieving their goals (i.e. self-advocate).
- To educate and inform stakeholders (i.e.: about the needs of people with a physical disability) so that they are able to achieve and maintain full participation, equality of opportunity and equality of citizenship.

¹ Australian Bureau of Statistics, *44300DO001_2018 Disability, Aging and Carers, Australia – New South Wales, 2018* <<https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02018?OpenDocument>> accessed 7 July 2020.

Recommendations

Bushfire Emergency Preparedness

Recommendation 1:

That state and/or federal governments increase funding for local governments in 'at risk' areas, to coordinate advisory boards and develop disability inclusive disaster risk reduction plans.

Recommendation 2:

That state and federal governments provide funding for disability awareness training and AUSLAN training for frontline emergency services staff in at risk areas.

Recommendation 3:

That there are designated spaces for people with physical disability in Safer Spaces and Emergency Centres, and where this is not feasible, that people with physical disability are given priority in spaces and centres that are designated most accessible.

Recommendation 4:

That Federal and State Government commit to an evaluation of the effectiveness of emergency messaging specific to both the accessibility and content needs of persons with physical disability through consultation with people with disability, carers, the disability sector and the emergency services sector.

Recommendation 5:

Subject to the outcome of such an evaluation, Federal and State Government commit to investing in the development of clear and mandated processes around the provision of accessible information as an essential component of any national crisis communication strategy, and implement legislation to ensure that broadcasters comply with these requirements.

Recommendation 6:

That federal and state governments provide sufficient additional resourcing to suitably qualified NGO services in times of national emergencies to mobilise and produce targeted, accurate, high quality information for specific accessibility needs.

Recommendation 7:

That the federal government invest in increasing the capacity of the National Relay Service (NRS) and provide additional funding for AUSLAN interpreters in times of national emergency.

Recommendation 8:

That LGAs in bushfire prone areas conduct an accessibility audit of current designated Safer Spaces as a matter of priority to determine whether these premises are accessible; and if not, make the appropriate adaptations to these Safer Spaces to make them more accessible, or find alternative places with a greater level of accessibility to nominate as Safer Spaces.

Recommendation 9:

That Local Councils commit to providing and maintaining a list of regularly updated local accessible accommodation in accessible formats as part of the Council's emergency preparedness resources for residents.

Recommendation 10:

That Local Councils provide accessibility details of all designated LGA Safer Spaces and Evacuation Centres, (for example, ramp access, disabled bathroom facilities available, power available, level access) in emergency preparedness publications for residents.

Recommendation 11:

That Australia, in line with the UN's concluding observations, develop a nationally consistent framework for assisting people with disability in emergencies. The development of should involve people with disability, their families and carers, all levels of government, not for profits, advocates, and community groups in the planning.

Recommendation 12:

That LGAs and Emergency Services in bushfire prone areas be legislatively required to perform Bushfire Training Exercises at local level on a regular basis; and that similarly, the appropriate convening organisation of such an activity is provided with State funding to conduct these exercises.

Pandemic Emergency Preparedness

Recommendation 13:

That the protocols regarding the management of cruise ships during pandemic incidents be reviewed in relation to:

- *responsibilities for identifying on-ship illnesses,*
- *the risk ratings for liners; and*
- *processes around quarantining passengers exhibiting flu-like illness until diagnosis and*
- *Quarantining and treating passengers who are diagnosed as having pandemic illnesses.*

Recommendation 14:

That State and Federal Governments commit to ongoing pandemic preparedness exercises with a focus on working through various scenarios relating to transmission via international sea and air travel.

Recommendation 15:

That Federal and State Government commit to an evaluation of the effectiveness of public health messaging specific to both the accessibility and content needs of persons with physical disability through consultation with people with disability, carers, the disability sector and the health sector.

Recommendation 16:

Subject to the outcome of such an evaluation, Federal and State Government commit to investing in the development of clear and mandated processes around the provision of accessible information as an essential component of any national crisis communication strategy, and implement legislation to ensure that broadcasters comply with these requirements.

Recommendation 17:

That Federal and State governments provide sufficient additional resourcing to suitably qualified NGO services in times of national emergencies to mobilise and produce targeted, accurate, high quality information for specific accessibility needs.

Recommendation 18:

That the Federal government invest in increasing the capacity of the National Relay Service (NRS) and provide additional funding for AUSLAN interpreters in times of national emergency.

Recommendation 19:

That State and Federal Health Departments ensure that any public health messaging in relation to risk factors and vulnerabilities, continues to be updated throughout pandemic events in response to increases in knowledge of a pandemic virus AND as different stages of a pandemic response are enacted.

Recommendation 20:

That the Federal Government, as a matter of priority, expand provision of supplies via the NMS to individuals at increased risk of Covid19, who cannot otherwise access PPE via the private market – and change NMS guidelines accordingly.

Recommendation 21:

That an audit of NMS supplies be conducted post pandemic with a view to critically assessing quantities of various supplies held and the spending allocated to each line item with a view to increasing supplies of personal protective equipment (PPE).

Recommendation 22:

That, as part of the audit into the NMS, the Government critically assess current suppliers and manufacturers with a view to diversifying supply streams.

Recommendation 23:

That the Federal Government investigate the possibility of being granted special powers during pandemic events to appropriate domestic supplies of PPE, as necessary, to be channelled to key priority groups.

Recommendation 24:

That the NSW Department of Health commit to engaging with key stakeholder groups, including the disability sector, in the preparation of a health services protocol to guide the distribution of ICU resources at times where demand exceeds sector capacity.

Recommendation 25:

That the Federal Government reconsider its current plan to cut the Coronavirus Supplement and Jobseeker Payments in September.

Recommendation 26:

That the Federal Government retain Jobkeeper and Jobseeker payments (at the current levels) for persons who are able to work (or their carers) where there increased risk to that individual to resume normal work/mutual obligation requirements means that they may not be able to do so, for as long as necessary.

Recommendation 27:

That the Federal Government increase the DSP, Carers Payments and Aged Pension as a matter of urgency by an amount that is not less than the income gap identified across these households via the NATSEM report and backdated this increase to 27 April 2020.

Recommendation 28:

That the Federal Government permit persons receiving the Carers Allowance who are otherwise ineligible for the Jobkeeper Payment, to access Jobseeker without the need for mutual obligations.

Introduction

A duty to ensure protection and safety in situations of risk

PDCN appreciates the opportunity to provide a submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability's Issue Paper on Emergency Planning and Response. Australia, as a nation, has specific commitments to people with disability during national emergencies. The United Nations Covenant on the Rights of People with Disability, of which Australia is a signatory, states:

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.²

This commitment sits alongside general obligations, also provided under the UNCRPD to ensure that all persons with disability have access to information, communications and other services, including electronic services across a variety of accessible formats³ as well as rights under Federal and State Anti-discrimination legislation.

Since emergency preparedness is a broad concept extending across many scenarios, PDCN has focused its submission around the two most recent national emergencies to occur within Australia – the Black Summer Bushfires and the Covid19 Pandemic. We will address the two emergencies as separate case studies, focusing on both National and State responses to these emergency situations.

Response

² United Nations, *Convention on the Rights of Persons with Disabilities and Optional Protocol*, <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> accessed 9 July 2020, p.11.

³ *Ibid.*, p.8.

Black Summer Bushfires

Background

The recent Black Summer bushfires of 2019 – 2020 devastated Australia. The bushfires began in September, continuing into the early months of 2020 and did not end until the onset of storms, which in some areas caused similar levels of destruction.

Australia is experiencing longer, dryer and hotter summers than ever before⁴. According to the Bureau of Meteorology, 2019 was Australia's hottest year on record, following a long period of drought conditions.⁵ In addition, scientists believe the risk of bushfires has increased by 30%.⁶ As a result, more planning is needed to ensure people who may need extra assistance during an emergency are supported. This includes people with disability, people with mobility impairments, and the elderly.

Our submission will not answer the questions directly, rather it will speak to some of the key issues identified by the Disability Royal Commission as they relate to our cohort - people with physical disabilities, their families and carers.

The key issues that have come out of PDCN's research and consultation with members is that involving people with disability in the planning process is vital, and that good, clear communication is essential.

Emergency planning is a human right

Article 11 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) stipulates that state parties must "*ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.*"⁷ It sets out clear criteria to judge the conduct of signatories by, and Australia, who ratified the convention in 2008, has a duty to comply and carry out its obligations.

Emergency planning however does not exist in isolation – when considering emergency planning, it has to be done within the context of local humanitarian and human rights laws. The UNCRPD sits alongside Federal and State anti-discrimination laws. Emergency planning has obligations under both the CRPD and anti-discrimination laws at a Federal and State level.

Australia has a responsibility to provide emergency planning for people with disability. State and Federal governments have a responsibility to provide accessible information and assistance when it is needed. There should be plans in place to ensure people with disability, the elderly and people with mobility impairments can get the information or help they need. The government has a responsibility to ensure that *nobody gets left behind*.

There needs to be a coordinated, whole of government approach to planning for people with disability in emergencies, such as bushfires – it needs to be looked at from many angles, with many people

⁴ Henriques-Gomes, L. *Climate crisis cutting short Australia's winters and extending summers*, The Guardian, 2 March 2020, <https://www.theguardian.com/environment/2020/mar/02/climate-crisis-cutting-short-australias-winters-and-extending-summer#:~:text=Australia's%20summers%20are%20getting%20longer,report%20from%20the%20Australia%20Institute.&text=%E2%80%9CIf%20it%20feels%20like%20Australian,are%2C%E2%80%9D%20the%20report%20said.> accessed 29 April 2020

⁵ Readfern, G. *2019 was Australia's hottest year on record – 1.5C above average temperature*, The Guardian, 2 Jan 2020, <https://www.theguardian.com/australia-news/2020/jan/02/2019-australia-hottest-year-record-temperature-1.5c-above-average-temperature>, accessed 29 April 2020

⁶ Pallab, G. *Climate change boosted Australia's bushfire risk by at least 30%*, BBC News, <https://www.bbc.com/news/science-environment-51742646>, accessed 9 July 2020

⁷ United Nations, *Convention on the Rights of Persons with Disabilities*, Article 11, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-11-situations-of-risk-and-humanitarian-emergencies.html>, accessed 9 July 2020

involved so all bases get covered. Extensive consultation and involvement of people with disability in the planning process is vitally important.

Preparing for a bushfire

People with disability, as well as people with mobility impairments and the elderly or frail aged need extra support in the event of an emergency such as a bushfire, and it is vital that they are given the support to prepare for one. Emergency services, such as the NSW Rural Fire Service (RFS) are able to assist people leave in an emergency, but people are still encouraged to make their own plans, and for people with disability who are at higher risk, leaving early is considered the safest option. People with disability are experts in their own lives, but they still need support to make an informed decision based on their own needs. This kind of preparation can include:

- Clear and appropriate information to make informed choices around emergency situations.
- Help and support to make plans that suit their needs/capabilities. Making a list of what they will need to take with them, eg: medications, important documents.
- Deciding where they will go, how they will get there, and who they will let know they have left their home.
- Assistance to prepare their home for bushfires, for example checking that smoke alarms are working, cleaning up debris outside the home and ensuring entry and exit points are clear
- A back up plan with a place of last resort, remembering that Safer Places are places of last resort.
- A list of relevant phone numbers/apps/websites to get the most up to date information and support by emergency personnel if their plans fall through.

Accessibility is a human right

Article 9 of the UNCRPD stipulates that state parties must ensure people with disability have equal access to information, communications, transportation and the physical environment.⁸ However, what we can ascertain from the experiences of people with disability emergencies, such as the recent bushfires, is that equal access is often not provided in practice. One PDCN member, who lives on the NSW, is a wheelchair user and chair of his local council's access committee, shared his concerns with us:

"As chair of the local access committee, I'm concerned about people with disability being looked after. My local area does not have a detailed listing of suitable accommodation for people with disability. Also, a list of numbers people could call for assistance or information. This could be available." – Peter, person with disability, South Coast*

In addition, there seems to be an expectation from emergency services that people with disability need to leave early – but they may need assistance to do this, and emergency services do have a responsibility to provide this assistance. As Louise⁹, a RFS volunteer told us:

"We really need to highlight that they shouldn't be waiting for someone to come and get them, as we just might not have the resources available at the time. I think as a brigade we definitely need to know what vulnerable people are in our communities so yes, it is good if we can have some involvement in helping them to develop their plans. I think my point is that, as with all community members, we should really be assisting and empowering them to make plans that include them leaving early and without RFS assistance."

Anecdotal evidence from PDCN members reveals that access to information and suitable accommodation was not always equal. There is an expectation that whatever services and supports are offered to people who are able-bodied should also be offered to people with disability - it is discrimination not to. For example, if not all evacuation centres are accessible, then they are not equal, which goes against articles 9 and 11 of the CRPD. No other cohort would accept anything less than

⁸ United Nations, *Convention on the Rights of Persons with Disabilities*, Article 9, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-9-accessibility.html>, accessed 9 July 2020

⁹ NB: All names have been changed.

100% accessibility, yet people with disability are continually left behind when it comes to accessible facilities in emergencies. For example, during the recent bushfires, a woman with disability and her elderly mother, also a person with disability, left an evacuation centre and returned to an 'at risk' environment, because it was not accessible or suitable. This is unacceptable and demonstrates a lack of planning for people with disability.¹⁰

Omission as a form of neglect

People with disability are at greater risk, and more likely to encounter challenges, in times of disaster.¹¹ Emergency planning, therefore, needs to involve people with disability. However this is not always the case; people with disability are often the last to be included, or are forgotten.¹² Dr Michelle Villeneuve at the University of Sydney's Centre for Disability Research and Policy, has been researching emergency planning and preparedness for years, and her research shows that it is evident there continues to be a lack of planning for people with disability. Her current project, *Disaster Risk Management Practices that Leave nobody Behind*, is focused on person-centred emergency preparedness. Dr Villeneuve and her team have developed numerous resources to assist both individuals and government undertake disability inclusive disaster risk reduction – but people with disability continue to be forgotten.

As one PDCN member told us, during the recent bushfires, there was information and assistance available for every group considered vulnerable – except people with disability. Simply put, people with disability are being overlooked – and this is a form of neglect.

"I have an expectation that whatever facilities are available to my able-bodied counterparts will be available to me. But this doesn't happen in practice... There is no publicly available information for people with disability. Effort is made for other groups, but not for people with disability." – Ben*, person with disability, South Coast

Another PDCN member's experience highlights the challenges faced by people with disability in an emergency, and how failure to plan can lead to neglect, and putting lives at risk.

Sophie is a paraplegic living in the Blue Mountains. She has her own vehicle and the ability to drive, but no close family. She needs assistance to prepare her home for a bushfire but received no support from the local RFS. During the recent bushfires, she did not feel comfortable at the local evacuation centre, so planned to stay with friends temporarily. However, for more long-term accommodation, Sophie needed a wheelchair accessible hotel that could also accommodate a companion dog. She did not know how to find one. Sophie called both the local council and her insurer, but neither could help. She relied on her neighbours for assistance, but believes that in this situation, it would be useful for the local council to have a list of vulnerable people and contact them in an emergency.*

¹⁰ Young, E. *What it's like to experience a bushfire evacuation while living with a disability*, SBS News, 8 January 2020,

<https://www.sbs.com.au/news/what-it-s-like-to-experience-a-bushfire-evacuation-while-living-with-a-disability>, accessed 29 April 2020

¹¹ International Committee of the Red Cross, *People with disabilities in emergencies*, 7 May 2015, <https://www.icrc.org/en/document/people-disabilities-emergencies>, accessed 29 April 2020

¹² Op. cit, note 9

Where does responsibility lie?

As the CRPD states, Australia has a responsibility to ensure the protection and safety of people with disability in emergencies.¹³ In order to do this, emergency planning in consultation with people with disability must be carried out. PDCN members who live in areas recently affected by the bushfires do not believe this is happening in practice. There is information out there, and a disparate array of services available, however what PDCN has observed is that people with disability are making their own plans, without assistance from emergency services. These individuals however, are by their own admission, competent, capable and connected – they know who to call in an emergency, and they can rely on friends and family to help get them out. These people are still reliant on the government or emergency services providing accessible information and, in the case of bushfires and evacuation, on accessible accommodation.

This is where PDCN members feel the system is falling down – people with disability are simply not being considered when it comes to information or emergency accommodation. This begs the question – what about those people who live alone, have no familial support nearby, may be frail, have mobility impairments, or vision or hearing impairments – *who is helping them?* A lack of information and education can lead those responsible – or even just assisting – to make decisions that discriminate against people with disability in emergency situations. People with disability are often treated as second-class citizens or not as important as others, they often get “left behind”¹⁴

Emergency response in NSW involves various organisations, services and levels of government, including Fire and Rescue NSW, NSW Rural Fire Service (RFS), local government, State Emergency Service (SES) and NSW Police. The NSW Government has emergency management arrangements for NSW, details of which can be found on the NSW Resilience website¹⁵, and these arrangements outline the different levels of responsibility in the event of an emergency. The following section of this submission will not go into to great detail of the structure, however it will comment on how the current structure affects our cohort, people with physical disability, and how the structure may have left PDCN members at risk of neglect during the recent bushfires.

NSW Rural Fire Service

The NSW Rural Fire Service (RFS) is a volunteer fire service that provides emergency and fire services to the residents of NSW. It is also considered the ‘combat agency’, along with Fire and Rescue NSW, for primarily controlling the response to bushfire emergencies.¹⁶

One service it offers is a program that can assist vulnerable people with preparing their homes for a bushfire – the AIDER (Assist Infirm, Disabled, Elderly Residents) Program. AIDER is designed to assist people who have limited support available to them to prepare their home for a bushfire.¹⁷ It can assist with gutter clearing, tree trimming, removing vegetation and leaf debris from around the home and mowing long grass. However, it is a one-off service and subject to budget availability – whereas this type of maintenance needs to occur more frequently.

The Rural Fire Service sees itself as having a responsibility to inform the public on how to prepare for bushfires through community education and community consultation. Community education resources are provided either online, in hardcopy form or via electronic format, for example, the Fires Near Me app. The Rural Fire Service also runs annual events for communities at risk – the Get Ready Weekends – to promote community awareness and encourage people to prepare for fire seasons months in advance.

¹³ Op. cit, note 6

¹⁴ Kilham, S. *Bushfire planning leaves behind people with disabilities*, The Conversation, 232 January 2014, <https://theconversation.com/bushfire-planning-leaves-behind-people-with-disabilities-21792> accessed 1 May 2020

¹⁵ Resilience NSW, Emergency Management for NSW, , <https://www.emergency.nsw.gov.au/Pages/publications/guides-factsheets-brochures/emergency-management-arrangements/arrangements.aspx#:~:text=At%20the%20LOCAL%20level%2C%20the,have%20experience%20in%20emergency%20management.> accessed 3 July 2020

¹⁶ibid

¹⁷ NSW Fire and Rescue, AIDER Fact Sheet, <https://www.rfs.nsw.gov.au/plan-and-prepare/aider.> accessed 3 July 2020

Fire and Rescue NSW

Fire and Rescue NSW is the government agency responsible for providing fire, rescue and hazmat services in NSW.¹⁸ In NSW's emergency management structure, it is the other 'combat agency' responsible for organising the response to bushfire emergencies.¹⁹ Fire and Rescue NSW similarly sees itself as having a role in assisting the community with pre-emptive planning through the provision of community education and resources.

NSW State Emergency Service

The State Emergency Service (SES) is a volunteer-based organisation providing emergency and rescue services. It is considered the 'combat agency for floods, storms and tsunamis', however it does assist with other disasters, such as bushfires. For example, in the recent bushfires, the SES assisted with door knocking and providing information, and manning information centres. SES also produces publications and resources and conducts community education.

Local government

As the level of government with the closest contact to the community, local government has always played an interesting role in providing services to the community. In emergency management, its role is to participate on the Local Emergency Management Committee (LEMC). Local government also has a role in providing governance and support, and also a role in providing community services during the recovery. PDCN spoke to a senior manager at a local council in one of the bushfire affected areas. Her view of the role of local government is twofold – they are an advocate, and they are also a conduit between the community and community services or emergency personnel.

State WelFAC

The State Welfare Services Function Area Coordinator (State WelFAC) is responsible for disaster welfare services in response to emergencies.²⁰ It is tasked with implementing the NSW Welfare Services Functional Area Support plan, which includes immediate financial assistance, accommodation, catering, personal support, aid, chaplaincy, and disaster relief grants. It is designed to work with emergency services, local council and participating organisations to coordinate the aforementioned welfare services. The participating organisations are ANGLICARE, Adventist Development and Relief Agency (ADRA), Australian Red Cross, The Salvation Army and Uniting Church in Australia.

Difficulties with the current system

PDCN spoke to number of people either working or volunteering for emergency services, and it was evident from these informal conversations that the current system is not designed around pre-planning. It's a top down approach – information is fed down the chain of command, particularly to volunteer based services such as the SES, and this means that groups like such as the SES don't necessarily have processes in place for assisting people with disability. Emergency services personnel are able to get someone out of a potentially hazardous situation – they wouldn't leave anybody behind - however they are not trained to assist all types of disability, nor is there specific plans on how to assist a person with disability.

¹⁸ NSW Fire and Rescue, <https://www.fire.nsw.gov.au/page.php?id=45>, accessed 3 July 2020

¹⁹ Op. cit., note 9

²⁰ NSW Government, Welfare Services Functional Supporting Plan, <https://www.emergency.nsw.gov.au/Documents/plans/supporting-plans/Supporting-Plan-Welfare-Services-Functional-Area.pdf>, accessed 3 July 2020

PDCN spoke to an SES volunteer with over 10 years experience, who assisted in the recent bushfires. They indicated that SES volunteers do not receive specific training on assist a person with disability. In emergency management, the SES volunteers relying on information coming from a higher level – they are given a task and would expect all the relevant information to be included in the briefing. If they were being asked to evacuate a person with disability, the expectation is that the info will be included in the briefing. If they happened to encounter a person with disability who needed assistance, they would simply have to work it out, or call for help. If the SES member did not know what to do, or assistance was a long time coming, it might place the person with disability in serious danger. While no one, including PDCN, would understate the important role the SES plays in emergency management, it does highlight an important issue – that people with disability are at risk of neglect because they are not being included in emergency planning.

PDCN also spoke to a number of RFS volunteers, who all iterated that while they can assist people when needed, people should not always rely on this happening, and they do encourage individuals to make their own evacuation plans – and to leave early where they can. However, this raises two concerns and reiterates two early points – the first, that there are people with disability who are in a position to make plans, and in the event of a bushfire, evacuate, but what about those people who need extra assistance? And secondly, there needs to be clear accessible communication to ensure people who live alone, or are hearing impaired, are notified with enough time to leave. And even for the ones who have got plans, they need to know where they are going will be accessible – and this isn't always the case. It also raises the question – what happens when you don't get enough warning and can't get out? There needs to be a safety net so people with disability, the elderly, frail, and people with mobility impairments, are not left behind.

It was apparent during the 2019-20 bushfires that these services, despite working well together, were stretched. It was a very long fire season, and services were constantly moving and changing. This meant that other organisations – such as local government – took on some of the roles and responsibilities for emergency services. For example, during the recent bushfires Bega Valley Shire Council took on a communications and welfare role because the services usually responsible were stretched so thin. Councils have strong links with vulnerable people in the community, and in this instance, the Council saw a gap in services and were able to jump in and help – despite this not being its role and not being funded to do so. Governments needs to invest more at the local level – for example in local government, to coordinate with local services and groups to establish databases of people at risk and also suitable evacuation centres. People with disability have a right to the same services as everyone else, but their needs are different and these must be taken into consideration.

Recommendation 1:

That state and/or federal government increase funding for local governments in at risk areas, to coordinate advisory boards and develop disability inclusive disaster risk reduction plans.

Recommendation 2:

That state and federal governments provide funding for disability awareness training and AUSLAN training for frontline emergency services staff in at risk areas.

Access to essential supports

Despite bushfires becoming an increasingly more common occurrence in certain areas of New South Wales, not to mention Australia, they are still highly unpredictable events. No matter how much planning you do, it is still hard to know precisely when a bushfire will occur, or how long it will last. Certainly no-one could have predicted the Black summer bushfires to have lasted as long as they did. This is why it is so important to ensure the infrastructure is in place to ensure people with disability have the supports they need both before and during a bushfire. The importance of a government-led whole of sector approach to planning cannot be understated.

The key supports identified by PDCN are communication and accommodation support.

Communication support

The most common form of support identified by PDCN members was the necessity for good communication. Both about the level of risk of bushfire, so that, where possible, people can make the decision to leave early, based on their specific circumstances, and during bushfires incidents themselves.

Bush fire danger ratings are used by the RFS to rate the risk of fires if they were to ignite based on predicted conditions, such as temperature, humidity, wind and dryness of the landscape.²¹ These ratings are designed to enable the community to make decisions as to whether to stay or leave early and in some cases, provide a timeframe for leaving, for example, the catastrophic rating states that people should *'leave bush fire prone areas the night before or early in the day – do not just wait and see what happens'*.²² It is vitally important that people with physical disability know of the ratings at any given time (via accessible communication means) and that they understand what the ratings mean in terms of the level of risk so that they are empowered to act in the way that best suits their requirements. It is also essential that as much consideration is given to the timeliness of communications as possible (and we note that this is often hard to determine in advance), given it can take a person with disability longer to leave.

At the same time, it is important that there are strong lines of communication and clear information available during critical incidents because if there isn't, this can put people's lives at risk and health in danger. The following story from one PDCN member illustrates this point. (All names have been changed.)

Anne is a wheelchair user and lives in Bermagui. During the recent Black Summer bushfires, she was evacuated at 4.30am to the evacuation centre (the local surf lifesaving club). While there it was suggested that she and her carer move to Narooma. They did so, however the situation was worse there, so they returned to Bermagui, only to discover that there was no longer room for them at the evacuation centre. They then moved to a friend's house on the beach, and eventually to a cave on the beach, where they waited out the fire for three days. Anne did not have access to food or water and became severely dehydrated due to an underlying medical condition. Once the roads reopened, Anne was admitted to hospital.*

As Anne said, the communication she received led to her moving from one evacuation centre to the next, risking her health and life. Had Anne remained at the first evacuation centre, she would have received water and food and most likely avoided the need to go to hospital. This illustrates a serious breakdown in communication, particularly in reference to Anne's needs, which placed Anne at risk of neglect. Anne suggests what is needed is a specific area set aside for people with disability in every evacuation centre, to ensure there is space for everyone... *and no one gets left behind.*

Recommendation 3:

That there are designated spaces for people with physical disability in Safer Spaces and Emergency Centres, and where this is not feasible, that people with physical disability are given priority in spaces and centres that are designated most accessible.

During the recent bushfires, members of PDCN reported that they relied on a combination of methods, including local ABC radio (which, in rural, regional and remote areas, is considered vital and we note is currently facing a restructure, including a restructure of its emergency broadcasting, due to funding cuts), the Fires Near Me app, Facebook and the Rural Fire Service app. They rely on good, clear

²¹ NSW Rural Fire Service, <http://www.rfs.nsw.gov.au/fire-information/fdr-and-tobans?a=1421>, accessed 3 July 2020

²² *ibid*

communication for information regarding the whereabouts of fires, and it is imperative that this information is accessible, or available in accessible formats. Auslan interpreters, for example, should be on hand at evacuation and information centres. Emergency services personnel could also be trained in basic Auslan. One member PDCN spoke to, Claire*, who is profoundly deaf, told us that she was very concerned about how she, and other people with hearing impairments, would be contacted during the bushfire emergency. To Claire, text messages are paramount in an emergency, although they are only effective during the day when she can see them. Claire suggested an information line that people can call or text for information or assistance would be useful during an emergency. Other members of PDCN supported this, and also suggested a priority number that people could call or text if they need assistance would be of use. Claire also believes a register of people living alone, or who may need extra assistance, would be useful during an emergency.

It is also worth noting the reliance on live captioning by people with hearing impairments during emergencies. PDCN is a member of the Australian Communications Consumer Action Network (ACCAN), and we received feedback from ACCAN that people from the deaf community were frustrated with the quality of live captioning of emergency broadcasts during the Black Summer bushfires, including errors in live captioning and a failure of live captions to flow on to other platforms, such as social media. We understand that ACCAN is making a submission to this issues paper, and are in support of its recommendation to update the Broadcasting Services Act “to require more hours of captioning, and to also require broadcasters to provide captioning and Auslan interpreters on emergency warnings/broadcasts”.²³

ACCAN, as the peak representative body for telecommunications consumers in Australia is better placed than PDCN to comment on the telecommunications issues that arose during the bushfires. However, as a member of ACCAN, PDCN supports the work that it does, particularly in regard to accessible communications, and supports its submission to the Royal Commission. We also make note of ACCAN’s submission to the Senate Standing Committees on Finance and Public Administration inquiry into lessons to be learnt in relation to the Australian bushfire season 2019-20 and encourage the Royal Commission to read it if it has not already done so.

Recommendation 4:²⁴

That Federal and State Government commit to an evaluation of the effectiveness of emergency messaging specific to both the accessibility and content needs of persons with physical disability through consultation with people with disability, carers, the disability sector and the emergency services sector;

Recommendation 5:

Subject to the outcome of such an evaluation, Federal and State Government commit to investing in the development of clear and mandated processes around the provision of accessible information as an essential component of any national crisis communication strategy, and implement legislation to ensure that broadcasters comply with these requirements;

Recommendation 6:

That federal and state governments provide sufficient additional resourcing to suitably qualified NGO services in times of national emergencies to mobilise and produce targeted, accurate, high quality information for specific accessibility needs.

Recommendation 7:

That the federal government invest in increasing the capacity of the National Relay Service (NRS) and provide additional funding for AUSLAN interpreters in times of national emergency.

²³ Lea, M. *Draft Issues Paper: Emergency Planning and Response*, Australian Communications Consumer Action Network (ACCAN) submission to the Disability Royal Commission, July 2020

²⁴ NB: Recommendations 4 – 7 are the same as recommendations 15 -18 as we believe they apply equally to both bushfire emergency and pandemic planning.

Accommodation support

During an emergency such as a bushfire, accessible accommodation is essential. Bushfires can impact communities for days at a time, and people who are required to evacuate need somewhere to go - for people with disability, those places need to be accessible and be appropriate to their needs, e.g. ability to access electricity etc.

Evacuation centres or Safer Spaces should be places of last resort for people in bushfire situations. There is a view that evacuation centres are safe spaces, but Safer Spaces within communities that are under threat of bushfire are not guaranteed to be safe, particularly for people with disability.

As conditions change, there is potential to have to move people multiple times, this is a problem if you are fairly immobile. PDCN member Anne* was evacuated from her home five times during the recent bushfires. This is incredibly exhausting on anybody, but particularly for people with disability or mobility impairments who cannot simply 'get up and go'. There is also no guarantee that temporary accommodation will be suitable.

For example, during the South Coast fires, beaches were often designated as places for people to evacuate to – for persons using mobility devices, sand and uneven ground pose logistical challenges. Similarly, these places are exposed to smoke and heat and lack essential resources – access to electricity, food and water.

Many people do not have relatives or friends that they can stay with during bushfires, particularly if they may need to remain away from home for extended periods of time. For people with physical disability, who may live in homes that are modified to their specific needs, an additional complication is finding accommodation that is both accessible and comfortable for them to stay in.

It is for this reason that PDCN members believe there is a need for a list of appropriate places people with disability can go in the event of an emergency – this is something that local government and community services/peaks can work together on – and why it is so important that people with disability are consulted BEFORE the emergency – so that plans can be put in place – and also goes back to communication and consultation being key.

Recommendation 8:

That LGAs in bushfire prone areas conduct an accessibility audit of current designated Safer Spaces as a matter of priority to determine whether these premises are accessible; and if not, make the appropriate adaptations to these Safer Spaces to make them more accessible, or find alternative places with a greater level of accessibility to nominate as Safer Spaces.

Recommendation 9:

That Local Councils commit to providing and maintaining a list of regularly updated local accessible accommodation in accessible formats as part of the Council's emergency preparedness resources for residents.

Recommendation 10:

That Local Councils provide accessibility details of all designated LGA Safer Spaces and Evacuation Centres, for example, ramp access, disabled bathroom facilities available, power available, level access in emergency preparedness publications for residents.

Including people with disability in the planning

Consultation is key

In its concluding observations 2013, the UN advised that Australia, as a party to the UN CRPD, must *"consult with people with disabilities to establish nationally consistent emergency management standards to be implemented across all three levels of government, ensure inclusivity across diverse disabilities and cover all phases of emergency management preparation, early warning, evacuation, interim housing and support, recovery and rebuilding. The Committee further recommends the inclusion in national plans of emergency response schemes for persons with disabilities."*²⁵ This recommendation was reiterated in the UN's concluding observations 2019, as the UN is concerned about the increased risk to vulnerable people, including people with disability, in natural emergencies and disasters. The UN stated that it was disappointed Australia had not developed nationally consistent emergency management standards.²⁶

PDCN concurs with the UN and believes that any emergency management standards must be developed with the direct involvement of people with disability. Without their involvement, they are at risk of being neglected. Neglect is often a result of discrimination, which in turn can be a result of misinformation/lack of education – it's not always done with malicious intent, and that is why it is vital that emergency preparedness plans are put into place with the person whom the plan is for. Most councils have access and inclusion committees, and these should be utilised, as they are great resources and are great way to include people with disability in the process from the outset. However, it is vital that these are made up of people with disability or their carers, not support workers or other representatives as it's important people with disability be involved directly in the planning stages, and are also present at any post emergency discussions. There is no other way to ensure their needs are considered. Often, during planning sessions, the needs of people with disability are not considered until it becomes obvious that the plan being considered would be ineffectual for people with disability. When planning, consideration would need to be given to:

- The needs of people within each disability type.
- Equipment needed to evacuate, eg wheelchair, hoist.
- Basic AUSLAN training for emergency personnel.
- List of contact numbers for people with disability to contact in emergency, including numbers that will accept text messages.
- Evacuation centre requirements: access to interpreters, trained support personnel (nurses, personal care, technology support), accessible bathrooms, power etc

The Black Summer Bushfires, as one of the harshest bushfire seasons on record, provides an opportunity for assessment of current emergency preparedness strategies within LGAs as well as an opportunity to assess gaps in these strategies to address the needs of vulnerable groups, including people with physical disability. We understand that there has been an inquiry into the period, which will no doubt identify a number of systemic areas of improvement, however we also consider that there should be assessment at a local level, involving LGAs, RFS, Fire and Rescue and all other emergency services to reflect on opportunities for improvement.

Such assessments should be conducted with public consultation involving key stakeholder groups – including people with physical disability and Disabled Persons Organisations - with a view to identifying gaps in addressing the needs of particular community cohorts and working to address these gaps as a community.

²⁵ United Nations, *Convention on the Rights of Persons with Disabilities Concluding Observations*, 21 October 2013, <http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkGIId%2FPPrICAgHk7yhsnzSGoIKOaUX8SsM2PfxU7tjZ6g%2FxBVYsYEv6iDyTXyNk%2BsAB%2FHgrVpAKHcEYTB%2B1t%2FH3HX1F%2F%2Bo%2Bk3O4KhxfhPoTQZ3LeS75n8PHidYHE3>, accessed 9 July 2020

²⁶ United Nations, *Convention on the Rights of Persons with Disabilities Concluding Observations*, 15 October 2019, https://tbinternet.ohchr.org/_layouts/15/treatybodyexternal/Download.aspx?symbolno=CRPD/C/AUS/CO/2-3&Lang=En, accessed 3 July 2020

We also consider that there is great value in communities at risk undertaking Bushfire Planning Exercises on a regular basis, where emergency preparedness systems are tested, and emergency services have an opportunity to work alongside each other outside critical incidents. Planning exercises like these have been useful in other emergency contexts, such as preparing for national pandemic threats, and may offer an opportunity to refine localised responses to future bushfire events as well as determining the responsibilities of different services during emergencies, as a major issue appears to be a lack of clear delineation of roles.

Obviously, such exercises require investment of time and resources – we consider that it should be the responsibility of the State to fund such operations.

Recommendation 11:

That Australia, in line with the UN's concluding observations, develop a nationally consistent framework for assisting people with disability in emergencies. The development of should involve people with disability, their families and carers, all levels of government, not for profits, advocates, and community groups in the planning.

Recommendation 12:

That LGAs and Emergency Services in bushfire prone areas be legislatively required to perform Bushfire Training Exercises at local level on a regular basis; and that similarly, the appropriate convening organisation of such an activity is provided with State funding to conduct these exercises.

Moving forward

Australia's summers are getting longer and hotter, and the risk of emergencies such as bushfires is increasing.²⁷ Australia, as a signatory to the UN CRPD, has a responsibility to ensure the safety and protection of all its citizens in the event of an emergency. To that end, PDCN believe there needs to be a more coordinated approach to emergency planning, preparation and implementation, particularly for people with disability. A one size fits all approach cannot be taken, as people's needs are very different, however there is an expectation that in an emergency, assistances and support will be provided on an equal basis for all. During the course of our research, PDCN identified the primary issues during the bushfires for its cohort - people with physical disabilities - were a lack of communication, and a lack of consideration of their needs, particularly accommodation.

This brings us back to the importance of a coordinated, whole of government approach to planning, as the UN concluding observations 2019 stress. Without this kind of approach, in which people with disability themselves are directly involved in planning, we are simply not meeting our obligations under the CRPD and failing up to 50% of our population (people with disability, the frail and aged.)

²⁷ Op. cit., note 3

Covid19 Pandemic

Physical Disability and Covid19

The Covid19 pandemic represents a major health threat to Australia as a nation, however the epidemiology of the virus means that some groups of people are more vulnerable to Covid19 than others. Across PDCN's membership, whilst many people with physical disability are at limited risk of mortality from Covid19, it has been recognised that the virus may represent a greater risk to those with tetraplegia or high paraplegia level injury, those with existing lung or breathing issues²⁸ and those who are immunocompromised.²⁹ Older persons (65+) with physical disability may also be at increased risk due to the physiological and immune changes that occur with age³⁰, and the increased likelihood that older persons will have existing chronic health conditions.³¹

For people who have the conditions above, Covid19 is a very real and palpable risk to their lives. Many people at high risk chose to self-isolate early, even before the Government enacted social distancing provisions, and will continue to do so. For others, self-isolating has not been possible, for instance, where they live in supported accommodation or have high care needs requiring outside support. In such cases, members have had to rely heavily on the safeguards put in place by service providers.

Regardless of the inherent risk factors they face as individuals, and the safety mechanisms they have had to employ, people with physical disability have seen massive changes to disability service delivery, reduced capacity to carry out basic day to day activities, as well as isolation from their supports, including family, friends and carers. They have had to deal with additional household costs, limited supplies of essential products and difficulties accessing personal protective equipment. Some members have also had to manage with decreased household income due to job loss or reduction of working hours.

'Carers are going shopping for me, but they are reluctant to expose themselves and also questioning whether they are able to go shopping for me during the disability/aged care window on my behalf if I'm not there. So that is an issue. Plus, if there's stock that's low, they have to go out on multiple trips to get the same groceries'.

Although we appear to have seen the worst of the pandemic and are now entering a winding down period, there is still significant anxiety for many people with physical disability, especially now that social distancing measures are relaxed, for fear of a 'second wave' of infections, such as we are seeing in Victoria. Many people with physical disability are confused about when to reduce social isolation measures, while some believe that they will not be safe until a vaccine is developed.

Wellbeing checks conducted by PDCN staff across our membership during the pandemic indicate that whilst the majority of our members are 'getting by' day to day, there are gaps in the State and Federal Governments' response to Covid19 as it relates to the safety and protection of people with physical disability. These gaps are indicative of a failure to appreciate the real risks to a proportion of people with physical disability, to recognise the hardship many people with disability have experienced as a result of the pandemic, and to understand the diverse access needs across this community.

²⁸ Lung Foundation Australia, *Covid 19 – a guide for people living with lung disease and lung cancer*, https://lungfoundation.com.au/wp-content/uploads/2020/03/COVID-19_Factsheet.pdf, accessed 15 April 2020

²⁹ Queensland Government, Queensland Department of Health, *Covid19 for people with spinal cord injury* <https://www.health.qld.gov.au/qscis/covid-19-for-people-with-spinal-cord-injury>, accessed 14 April 2020

³⁰ Kluge, Hans, Dr., World Health Organisation, 'Older people are at highest risk from COVID-19, but all must act to prevent community spread', 2 April 2020, <http://www.euro.who.int/en/healthtopics/health-emergencies/coronavirus-covid-19/statements/statement-older-people-are-at-highest-risk-from-covid-19-but-all-must-act-to-prevent-community-spread>, accessed 14 April 2020

³¹ Vally, Hassan, *Why are older people more at risk of coronavirus?*, The Conversation, March 17, 2020, <http://theconversation.com/why-are-older-people-more-at-risk-of-coronavirus-133770>, accessed 15 April 2020

Pandemic preparedness pre Covid19

*The wisdom of taking precautions depends not just on the probability of a risk, but also on its magnitude. When a risk is awful enough, precautions make sense, even though the risk may be unlikely and the precautions may be wasted. We don't buy fire insurance because we're confident our house will catch fire; we buy it because a fire could be devastating.*³²

Influenza-type pandemics are not unknown within Australia. No two pandemics are identical – there are always variables that cannot be planned for, however, to the extent that there are similarities across pandemic events, experts agree that it is important to learn from experience and build this knowledge into future precautionary planning. This was something Australia has previously done well; across the 2000's, Australia was seen as a world leader in pandemic preparation, with significant investment in major national pandemic training exercises, for example, under Tony Abbott as Health Minister in 2006 and 2008.³³

The most recent pandemic prior to Covid19 was the H1N1 influenza virus, more commonly referred to as Swine Flu, in 2009.³⁴ There were 37,537 confirmed cases of Swine Flu and 191 deaths reported in Australia.³⁵ Since the Swine Flu pandemic, it has been claimed that the combination of the Global Financial Crisis, the relatively 'benign' nature of Swine Flu and '*pandemic fatigue*' has resulted in pandemic preparedness going on the political 'backburner'.

*"I think one of the dynamics which arose at the end of the 2009 H1N1 influenza pandemic was a phenomenon that we saw across the international community and it's been described as pandemic fatigue, which is shorthand for saying that whenever you mentioned the word pandemic, people's eyes started to glaze over,"*³⁶

There have been no national pandemic training exercises since 2008. It has been argued that pandemic planning exercises would have allowed a quicker response to Covid19, particularly in relation to high level decision making. Conducting training exercises may have identified weaknesses and shortfalls in Federal and State level planning and facilitated innovative technological developments in areas of virus tracking and public messaging.³⁷

*"I think the technology and the changes in Australian society — if we were exercising more regularly, we would have seen perhaps a much better, more efficient response."*³⁸

There were a series of reports and recommendations stemming from the Swine Flu pandemic. A summary of recommendations made by the Department of Health and Aging in 2011,³⁹ and the NSW

³² Sandman, P., *A Severe Pandemic is not overdue, it's not when but if*, University of Minnesota, Centre for Infectious Disease Research and Policy, 2007, <https://www.cidrap.umn.edu/news-perspective/2007/02/severe-pandemic-not-overdue-its-not-when-if>, accessed 9 July 2020.

³³ Welch, D., and Bulcher, A., *Australia ran its last national pandemic drill the year the iPhone launched. Did that harm our coronavirus response?* ABC News Online, April 2020, <https://www.abc.net.au/news/2020-04-20/coronavirus-australia-ran-its-last-pandemic-exercise-in-2008/12157916>, accessed 9 July 2020

³⁴ Sandman, P., op cit.

³⁵ Australian Government, Department of Health, *Australian Influenza Report 2009-12-18 December 2019 (#32/09)*, <https://www1.health.gov.au/internet/main/publishing.nsf/Content/cda-ozflu-no32-09.htm>, accessed 9 July 2020

³⁶ Welch, D., and Bulcher, A, op cit.

³⁷ Ibid., It has been suggested that public debate surrounding the privacy issues relating to the CovidApp may have been resolved prior to the pandemic within the scope of a training exercise.

³⁸ Ibid.

³⁹ Australian Government, Department of Health and Aging, *Review of Australia's Health Sector Response to Pandemic (H1N1) 2009 – Lessons Identified*, 2011, [https://www1.health.gov.au/internet/publications/publishing.nsf/Content/review-2011-l/\\$FILE/lessons%20identified-oct11.pdf](https://www1.health.gov.au/internet/publications/publishing.nsf/Content/review-2011-l/$FILE/lessons%20identified-oct11.pdf), accessed 9 July 2020

Health Management Committee ⁴⁰, for instance, focused on better communication for vulnerable groups throughout various stages of a pandemic, reviewing the types and quantities of goods stored in the National Medical Stockpile and reviewing policy, operational protocols and communication of border measures, with specific reference to managing cruise ships as major transmission risks.

These three issues have appeared again as major concerns in the current pandemic and have directly impacted the safety of persons with physical disability. Whilst we have fared extremely well in terms of managing the pandemic to date (As fatalities reach 367 166 worldwide with 5 934 936 known cases of the virus⁴¹, Australia has 103 deaths out of 7195 cases.⁴²) Recurring problems across Swine Flu and now the Covid19 pandemic suggests that, in some areas, Federal and State Governments have failed to adequately address known deficiencies in emergency preparedness planning, unnecessarily increasing the risk to certain groups of people within the Australian population, including those with physical disability.

The Australian response to the Covid19 pandemic

The Covid19 pandemic was considered an issue of national security. Under the Australian Health Management Plan for Pandemic Influenza (AHMPPI) 2019 various protective measures were put in place including securing borders, infection control measures, the mobilisation of the public health sector and social distancing, with responsibilities split across Federal and State Government. These protective measures can be divided into four general categories:

- **border measures:** measures that can be taken at airports and seaports to delay the spread of illness to or from affected countries (or jurisdictions).
- **social distancing:** community level interventions to reduce normal physical and social population mixing, in order to slow the spread of a pandemic throughout society.
- **infection control measures:** measures to promote hand hygiene, cough/sneeze etiquette; the use of personal protective equipment (PPE).⁴³
- **Health sector mobilisation:** measures to increase capacity across the public health sector in anticipation of increased demand, including demand for acute care resources.

In addition to these protective measures, we have also seen government initiatives aimed at addressing increasing levels of unemployment and decreased economic stability, such as the implementation of the Jobkeeper initiative, and efforts to mobilise and bolster the resources of the public health sector.

⁴⁰ NSW Government, Department of Health, *Key Recommendations on Pandemic (H1N1) 2009 Influenza from the NSW Health Emergency Management Committee*, 2010 <https://www.health.nsw.gov.au/pandemic/Documents/key-recommendations-pandemic-H1N1-NSW-health-2010.pdf>, accessed 9 July 2020.

⁴¹ As of 31 May 2020 – World Health Organisation (WHO), *Coronavirus disease (COVID-19) Situation Report – 132*, 31 May 2020 https://www.who.int/docs/default-source/coronaviruse/situation-reports/20200531-covid-19-sitrep-132.pdf?sfvrsn=d9c2eaeef_2, accessed 9 July 2020

⁴² Australian Government, Department of Health, *Coronavirus (COVID-19) current situation and case numbers*, 31 May 2020 <https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/coronavirus-covid-19-current-situation-and-case-numbers>, accessed 31 May 2020

⁴³ Australian Government, Department of Health, *Australian Health Management Plan for Pandemic Influenza*, 2019, [https://www1.health.gov.au/internet/main/publishing.nsf/Content/519F9392797E2DDCCA257D47001B9948/\\$File/w-AHMPPI-2019.PDF](https://www1.health.gov.au/internet/main/publishing.nsf/Content/519F9392797E2DDCCA257D47001B9948/$File/w-AHMPPI-2019.PDF), accessed 9 July 2020

Border protection measures

The World Health Organisation declared the Covid19 outbreak a pandemic on 12 March 2020.⁴⁴ The rates of transmission of Covid19 within Australia have been well contained in comparison to many other nations. It has been speculated that the main reason that Australia has been able to keep transmission rates relatively low was that Australia rapidly imposed very strict international travel restrictions, closing national borders and requiring returning citizens to quarantine under supervision.⁴⁵

There has been criticism that lives could have been saved had the Federal Government moved more quickly to secure its international borders - Australia's first confirmed case of Covid19 was on 26 Jan, 2020 – a citizen from China. Australia's border closures were announced on 19 March 2020, unfortunately the same day that 2700 passengers, some ill with respiratory symptoms, were permitted to disembark from the Ruby Princess Cruise Liner. The release of these passengers, authorised by the NSW State Government, sparked a massive spike in transmission of the virus.⁴⁶

During the Swine Flu pandemic in 2009, two cruise ships containing infected passengers and staff docked within Australia. In the case of the second cruise ship, 172 passengers disembarked exhibiting symptoms and were directed to self-quarantine at home by NSW Health – drawing criticism when later, States and Territories had to take on the massive organisational exercise of tracing these passengers.⁴⁷ A protocol was quickly developed, with the NSW Department of Health noting in recommendations made in 2011 that:

*The 2009 pandemic experience has shown that, when an international influenza outbreak is occurring, cruise ships pose a risk that needs to be managed. If infection and spread has occurred onboard, there is potential for the introduction of many cases of disease into Australia at one time if disinfection and other controls have not proved effective.*⁴⁸

PDCN is concerned that, despite prior knowledge, cruise ships, such as the Ruby Princess, have featured predominately as a mechanism for community transmission of Covid19 throughout all states and territories - as of 13 May 2020, the Ruby Princess has been linked almost 700 cases⁴⁹. Refinements need to be made to protocols around border protection to ensure that there is a greater level of Government oversight in terms of assessing passengers prior to disembarking, that passengers exhibiting symptoms are appropriately quarantined; and that accurate assessments are made of the risks posed by specific

⁴⁴ World Health Organisation (WHO), Regional Office for Europe, *WHO announces COVID-19 outbreak a pandemic*, 12 March 2020, <http://www.euro.who.int/en/health-topics/health-emergencies/coronavirus-covid-19/news/news/2020/3/who-announces-covid-19-outbreak-a-pandemic>, accessed 9 July 2020

⁴⁵ Klein, A., *Australia seems to be keeping a lid on covid-19 – how is it doing it?* New Scientist Online, 8 April 2020, <https://www.newscientist.com/article/2240226-australia-seems-to-be-keeping-a-lid-on-covid-19-how-is-it-doing-it/#ixzz6Rf6AglLf>, accessed 9 July 2020

⁴⁶ Zhou, N., *Anatomy of a coronavirus disaster: how 2,700 people were let off the Ruby Princess cruise ship by mistake*, Guardian Australia Online, 24 March 2020, <https://www.theguardian.com/world/2020/mar/24/anatomy-of-a-coronavirus-disaster-how-2700-people-were-let-off-the-ruby-princess-cruise-ship-by-mistake>, accessed 9 July 2020

⁴⁷ See for instance – Hall, L., Medew, J & Harvey, E., *Swine flu outbreak on cruise puts authorities on full alert*, Sydney Morning Herald, May 27, 2009, <https://www.smh.com.au/national/swine-flu-outbreak-on-cruise-puts-authorities-on-full-alert-20090526-bm8w.html>, accessed 9 July 2020

⁴⁸ Australian Government, Department of Health and Aging, *Review of Australia's Health Sector Response to Pandemic (H1N1) 2009 – Lessons Identified*, 2011 [https://www1.health.gov.au/internet/publications/publishing.nsf/Content/review-2011-l/\\$File/lessons%20identified-oct11.pdf](https://www1.health.gov.au/internet/publications/publishing.nsf/Content/review-2011-l/$File/lessons%20identified-oct11.pdf), at p. 32, accessed 9 July 2020

⁴⁹ Elsworthy, E., *Australia's coronavirus death toll rises after 81yo Ruby Princess passenger becomes latest fatality*, ABC News Online, 13 May 2020, <https://www.abc.net.au/news/2020-05-13/australia-coronavirus-death-toll-rises-ruby-princess-fatality/12239626>, accessed 9 July 2020

vessels.⁵⁰ It has also been suggested that regular pandemic preparedness exercises may have alleviated some of the confusion in terms of decision making:

*"The fact that there was an element of confusion as to who may have had responsibility for making the final decision, I think sort of points to the lack of preparedness that, in the event we were having these exercises more regularly, some of these errors may not have occurred."*⁵¹

Given our concerns, we welcome the Special Commission of Inquiry that has been established to consider the policies and protocols applied by Princess Cruises and the Commonwealth and State Governments with respect to managing suspected or potential COVID-19 cases.

Recommendation 13:

That the protocols regarding the management of cruise ships during pandemic incidents be reviewed in relation to:

- a) Responsibilities for identifying on-ship illnesses,
- b) The risk ratings for liners; and
- c) Processes around quarantining passengers exhibiting flu-like illness until diagnosis
- d) Quarantining and treating passengers who are diagnosed as having pandemic illnesses

Recommendation 14:

That State and Federal Governments commit to ongoing pandemic preparedness exercises with a focus on working through various scenarios relating to transmission via international sea and air travel.

The public health strategy – prevention, preparedness, response, and recovery

Another element of the national response to the pandemic has been the development of a national public health strategy - the *Australian Health Sector Emergency Response Plan for Novel Coronavirus (Covid19)*⁵². The strategy operates across 4 key areas – prevention, preparedness, response, and recovery with responsibilities at both State and Federal levels.

The Australian Government is, for example, responsible for ensuring that the resources and systems necessary for an effective national response are in place, such as national public health messaging, management of the National Medical Stockpile (NMS), and vaccine research, whereas the States and Territories have responsibility across the operational aspects of the strategy, including implementing social distancing recommendations, infection control guidelines and health care safety and quality standards, as well as managing tracing, echoing federal health messaging at a local level, supporting federal border protection measures and managing jurisdictional distribution of resources from the NMS. The Australian Government has responsibility for residential aged care facilities including working with other healthcare providers to develop guidelines and set standards to ensure the safety and security of residents.

This submission will focus on aspects of the public health strategy with direct impact on our membership, including public health messaging, the utilisation of the National Medical Stockpile, the development of protocols for management of ICU resources and social distancing. We also describe

⁵⁰ Zhou, N., *Sydney harbour master tells Ruby Princess inquiry he 'did not understand' email*, Guardian Australia Online, 8 May 2020, <https://www.theguardian.com/australia-news/2020/may/08/sydney-harbour-master-tells-ruby-princess-inquiry-he-did-not-understand-nsw-health-email>, accessed 9 July 2020

⁵¹ Welch, D., & Bulcher, A., op cit.

⁵² Australian Government, Department of Health, *Australian Health Sector Emergency Response Plan for Novel Coronavirus (Covid 19)*, 2020, https://www.health.gov.au/sites/default/files/documents/2020/02/australian-health-sector-emergency-response-plan-for-novel-coronavirus-covid-19_2.pdf, accessed 9 July 2020

how people with physical disability and their carers have been impacted by the economic flow on effects from social distancing in terms of both household income and employment.

Access to information regarding the national health response

Providing people with physical disability information to be able to make informed decisions around their health during a national health crisis is a vital responsibility of both State and Federal government. It is also a right accorded to people with disability under both Australian anti-discrimination legislation and the UNCRPD.

*Information accessibility is a right under that UN Convention on the Rights of Persons with Disabilities (Article 21) and is an area protected by the Disability Discrimination Act in Australia. Yet in the face of the COVID-19 crisis, the immediate reality and implications of this right have never been more apparent for people with disability: having access to good quality, up-to-date information in accessible formats is quite literally a matter of life and death.*⁵³

Our members have reported issues in both the method and content of public health messaging during the pandemic.

Methods of public health communication

One of the major issues experienced by people with physical disability, has been a lack of disability accessible public health information. Many of our members, especially those with hearing or vision impairments, are unable to read text or hear spoken information. They may use a variety of communication forms including captioning, AUSLAN, plain English, braille, or pictures. They may require deaf-blind or AUSLAN interpreters to translate spoken information.⁵⁴

We are concerned that accessible modes of communication have not been prioritised by either the Australian or NSW Governments across public health messaging during the pandemic, and that where accessible information is available, it appears to have been provided as an afterthought or has been poorly executed.⁵⁵ PDCN notes accessible public health information has been rolled out more slowly than standard information⁵⁶ and that NGOs have had to invest scarce resources to develop accessible resources so that their members can access vital information in a timely manner.⁵⁷

"In February and early March we were talking to each other in the deaf community trying to piece together what was happening. We were worried we weren't getting the right information. "There was a bit of a sense of 'Oh if the interpreters aren't there, how serious could it really be?'... We were like 'Do we really have to stay home?' You get the main message, but you lose the intricacies."

Physical disability is a spectrum and the accessibility requirements of persons with physical disability are diverse. State and Federal Government have a responsibility to achieve universal accessibility across all public health messaging and to the extent that a Government cannot provide public health information

⁵³ Meltzer, A., Dr., *Information accessibility during the COVID-19 crisis*, The Power to Persuade, 1 April 2020, <https://www.powertopersuade.org.au/blog/information-accessibility-covid>, accessed 9 July 2020

⁵⁴ Calgaro, E., & Dominey-Howes, D., *Increasing the resilience of the Deaf Community in NSW to natural hazards The Needs of Deaf People – Summary of Issues*, October 2013, https://deafsociety.org.au/documents/Summary_The_needs_of_deaf_people.pdf, accessed 9 July 2020

⁵⁵ We note here observations by Deaf Australia regarding broadcasters cutting AUSLAN Interpreters out of footage on TV screens, social media and the internet, <https://deafaustalia.org.au/open-letter-interpreter-on-broadcast-networks/>, accessed 9 July 2020

⁵⁶ This includes information in AUSLAN and Easy Read – see Meltzer, A., Dr., op cit.

⁵⁷ Ibid.

in a specific accessible format, internally, resources should be provided to appropriately qualified external organisations to do so. At the same time, it is critical that additional resourcing be provided to bolster existing services such as the National Relay Service (NRS) to operate more effectively during emergency situations to prevent extensive wait times for service.⁵⁸

National and State Government also has an important role to play in ensuring that national health messages are reported in an accessible format via private broadcast services. It would seem obvious that a broadcast network should ensure that an AUSLAN interpreter is filmed during a public health announcement, however we understand that basic principle can be neglected in practice.

Lack of specific content

In addition to access issues, people with physical disability have reported that the public health information has been too generic - specifically, there is limited ability for those with physical disabilities who have particular needs to obtain further and more detailed information, for example, people at heightened risk from Covid19 and those who have difficulty using standard PPE.

In relation to those at greater risk, PDCN considers that there was scope to provide clearer information about specific risk factors and expand on the information protective measures to reduce risk of infection - for example, Health NSW has consistently only recognised broad groups as being at risk, including older persons and people who are immunocompromised or have chronic health conditions.

Whilst we appreciate that there is a delicate balance in public messaging, we note that more detailed information in terms of risk factors has come to light since a pandemic was declared - we consider that updating information relating to risk factors should be a priority in order to allow people to accurately assess their level of risk - for example, we know that people over 65 years of age but otherwise completely healthy have considered themselves at high risk, whereas we understand that being 65 years or older *and having pre-existing health issues* increases risk, but that age is not itself a key determinate of risk.⁵⁹ At the same time, categories such as '*chronic health conditions*' are of limited practical use – whereas more prescription in terms of categories the general types of health conditions, such as respiratory conditions and heart disease, would assist people to know what level of precautions to take.

On that point, there has been also been a lack of information for those at heightened risk beyond the generic information around handwashing, sanitising, avoiding close contact with anyone with cold or flu like symptoms, avoiding unnecessary travel, having groceries delivered and covering your mouth and nose when you cough or sneeze.⁶⁰

"There has been a lack of information and guidelines for people at the highest risk from the virus. Government restrictions have been for healthy people. However, high riskers need to be in more restricted isolation and take greater infection control measures than the general public to stay safe. High riskers have been given no

⁵⁸ Australian Government, Department of Infrastructure, Transport, Regional Development and Communications, *COVID-19 will affect NRS Video Relay service wait times*, <https://www.communications.gov.au/departmental-news/covid-19-will-affect-nrs-video-relay-service-wait-times>, accessed 9 July 2020.

⁵⁹ We note here that the Management and Operational Plan for People with Disability provides more useful information in terms of those at increased risk including persons with respiratory disease, persons with conditions that impair breathing, those with chronic renal failure, chronic lung conditions, poorly controlled diabetes and poorly controlled hypertension, persons with compromised immune systems, people aged 65 years and over with chronic medical conditions and those with heart conditions.

⁶⁰ NSW Government, Service NSW, *COVID-19 and vulnerable people*, <https://www.nsw.gov.au/covid-19/how-to-protect-yourself-and-others/covid-19-and-vulnerable-people>, accessed 9 July 2020

information or support in how to do this. Many of us have been forced to devise our own restrictions and measures, while others have given up because it's been too hard to take extra precautions."⁶¹

"I feel that the message I'm getting is that if I get the virus, I will die! (I'm on the risk list) ... so stay indoors...FOR months if not YEARS. !!! until we get a vaccine. STAY away from everyone... but I need support?"⁶²

There has been no information on how to isolate people within households if they are suspected of having Covid19 and no guidance on how to practically manage situations where informal care providers either work or live elsewhere but still need to provide care for someone at increased risk.

Susan* is at increased risk of Covid due to a chronic health condition. Susan's partner, Jerry* works at a high school. Susan and Jerry live in a small one bedroom flat. There is no practical way for Jerry to isolate and he is not able to work remotely. They are concerned because they have heard that people can be asymptomatic. Jerry fears that he might get Covid19 from children who are not exhibiting symptoms and pass it on to Susan. He also understands that people can get Covid19 and be infectious before they exhibit symptoms.

The lack of clear information in terms of risk management for people at high risk has led, in some cases, to people adopting strict isolation for both themselves and their immediate family, a commitment that some may maintain for some time yet. Strict social isolation is itself psychologically damaging as a long-term strategy and can come with its own risks, such as poor mental health outcomes, domestic violence, elder abuse and neglect. It is essential to minimise how many people adopt such extreme measures – clear, instructive messaging, both around risk and how to prevent infection if there is increased susceptibility, are critical in allowing people to realistically assess risk and act proportionately.

Lack of advice for those who cannot use standard PPE or practice social distancing

A final concern relating to public health information is that there has been no advice for people who cannot use standard PPE, practice social distancing or be tested for Covid19 via nasal swab test. We have encountered many examples of situations where people with physical disability have struggled to follow public health directives, for example, persons with vision impairment who require carers to physically assist them to navigate public spaces or cannot see visual social distancing markers or people with physical disabilities which inhibit their ability to put on PPE unaided.

"I struggle to put masks on because of my physical mobility issues. So, I have two masks in my bag. I have to ask someone to come, get the masks, put on one themselves and then help me put one on. "

"I have severe hearing difficulties. If someone is wearing a mask it doesn't work for me. I can't hear them. There's no information on what to do. My support group is talking a lot about this".

"I need a carer to communicate for me, but the hospital is only letting limited people in."

The *Management and Operational Plan for People with Disability* developed during the pandemic, sets out the need for tailored and targeted information for people with disabilities, carers, health care workers and family members as part of the preparedness and stand-down and evaluation phases of any pandemic.⁶³ We already have mechanisms for identifying the specific needs of persons with physical disability – for example, the Disability Community of Practice Group convened by NSW Health. The issue lies in utilising the guiding principles of the operational plan, coupled with the understanding of the needs of people with physical disability, to provide relevant, targeted information.

⁶¹ People with Disability Australia, *People with Disability and Covid-19*, 2020, p.8

https://pwd.org.au/wp-content/uploads/2020/06/PWD_and_COVID_report-final.pdf , accessed 9 July 2020

⁶² Ibid.

⁶³ Australian Government, Department of Health, *Management and Operational Plan for People with Disability*, op cit.

Recommendation 15:⁶⁴

That Federal and State Government commit to an evaluation of the effectiveness of public health messaging specific to both the accessibility and content needs of persons with physical disability through consultation with people with disability, carers, the disability sector and the health sector.

Recommendation 16:

Subject to the outcome of such an evaluation, Federal and State Government commit to investing in the development of clear and mandated processes around the provision of accessible information as an essential component of any national crisis communication strategy, and implement legislation to ensure that broadcasters comply with these requirements.

Recommendation 17:

That Federal and State governments provide sufficient additional resourcing to suitably qualified NGO services in times of national emergencies to mobilise and produce targeted, accurate, high quality information for specific accessibility needs.

Recommendation 18:

That the Federal government invest in increasing the capacity of the National Relay Service (NRS) and provide additional funding for AUSLAN interpreters in times of national emergency.

Recommendation 19:

That State and Federal Health Departments ensure that any public health messaging in relation to risk factors and vulnerabilities, continues to be updated throughout pandemic events in response to increases in knowledge of a pandemic virus AND as different stages of a pandemic response are enacted.

Utilisation of the National Medical Stockpile (NMS)

A lack of access to personal protective equipment has been a major issue for people with physical disability, carers, and contracted health care providers throughout the pandemic. A survey conducted by People with Disability Australia showed that spending on sanitising and hygiene equipment represented 19.6% of the additional costs for people with disability and carers over the past few months.

Products like disposable gloves and face masks sold out of mainstream stores within the early weeks of a pandemic being declared. As demand exceeded supply prices skyrocketed and members of the public started to look to specialist medical supply stores. People with physical disability reported that, in some cases at least, this meant that they were “bumped” down specialist supply store lists to access hygiene products that they rely on day to day.

To counter the lack of supply in the private market, the Federal Government opened the National Medical Stockpile (NMS) firstly to the Aged Care Sector. This was later expanded to cover shortfalls across medical providers and persons who self-manage within the NDIS- however it is clear that the National Medical Stockpile has struggled to accommodate the needs of the public health sector – let alone accommodate the private sector or individuals. We are particularly concerned for those who self-manage outside the NDIS, as we know that these people have, and will continue to struggle to access the PPE they need via the private market.

⁶⁴ NB: Recommendations 15 -18 are the same as recommendations 4 -7 as we believe they apply equally to bushfire emergency and pandemic planning.

We have made numerous representations to Health NSW and the NSW Minister for Disabilities highlighting the need for adequate supplies of PPE for people with a physical disability as a priority group, advocating for access to the NMS store at no cost to the individual. To date, whilst Health NSW has taken this request on notice and accepted that there is a need, there has been no tangible outcome for our members – this is not to be unexpected, given supply issues across the board.

We note that the addressing the scope and capacity of the National Medical Stockpile was one of the recommendations to come out of the Swine Flu pandemic. Relevantly, the Department of Health and Aging noted in its report on the *Health Sector Response to Pandemic (H1N1) 2009*:

It would be prudent to review the range and quality of stockpiled goods for an influenza pandemic. Mechanisms in place for the distribution of NMS supplies to jurisdictional receiving facilities were successful and holding stocks in various Australian Government storage facilities reduced distribution response time. While a clear principle of use of the NMS is that no jurisdiction will be disadvantaged because of its own stockpiling, there was a lack of clarity with respect to the policy and timing of the transition from jurisdictional stockpiles to the national stockpile, and of responsibility for the provision of personal protective equipment (PPE) for use by GPs. There is a need to better communicate the role of stockpiles and to facilitate better understanding of when and how stockpile items are made available.⁶⁵

We understand that about \$900 million has been invested in the NMS since the early 2000's, but that a significant proportion of that investment – 80% - consists of pharmaceutical products.⁶⁶ The Covid19 pandemic has highlighted the vital role of PPE in inhibiting the transmission of influenza type pandemic viruses, both within the public health care sector and the community. At the same time, the pandemic raises real questions both in terms of the existing PPE supply chains and captive markets.

We consider that it is the responsibility of State and Federal Governments to supply PPE to anyone that is vulnerable who cannot otherwise access it so that that person can comply with the relevant public health directives. To facilitate this, we would suggest the following:

- That the Federal Government reprioritise NMS supplies with a view to investing in additional stocks of surgical masks, gloves and other relevant PPE to prevent transmission of influenza like pandemic viruses.
- That the Federal Government investigate the possibility of being granted special powers during pandemic events to appropriate domestic supplies of PPE, as necessary, to be channelled to key priority groups.
- That Australia consider diversifying its supplier base to minimize over reliance on supplies from a particular geographic region.
- That the guidelines around the distribution of supplies via the NMS be expanded to reflect the observations from this pandemic – that is, that supply be expanded to include the private health industry, the aged care industry, service providers under the NDIS as well as persons who are identified as vulnerable, who otherwise cannot access supplies via the private market.

Informally we know that pharmacies and other private suppliers withheld supplies for those who truly needed these products, whilst at the same time, major grocery chains, in operating designated shopping hours for vulnerable people first thing in the morning achieved the same purpose, by giving these people first access to restocked items. These initiatives within the private sector have worked to redress

⁶⁵ Australian Government, Department of Health and Aging, *Review of Australia's Health Sector Response to Pandemic (H1N1) 2009 – Lessons Identified*, op cit., at p xi

⁶⁶ Sax, N., & Wylie, B., *Coronavirus triggers national medical stockpile as COVID-19 threat intensifies*, ABC online, 29 Feb 2020, <https://www.abc.net.au/news/2020-02-29/coronavirus-covid19-causes-national-medical-stockpile-to-open/12003980>, accessed 9 July 2020

some of the inequity seen throughout the pandemic, however the responsibility should always lie with Government in the first instance.

Recommendation 20:

That the Federal Government, as a matter of priority, expand provision of supplies via the NMS to individuals at increased risk of Covid19, who cannot otherwise access PPE via the private market – and change NMS guidelines accordingly.

Recommendation 21:

That an audit of NMS supplies be conducted post pandemic with a view to critically assessing quantities of various supplies held and the spending allocated to each line item with a view to increasing supplies of PPE.

Recommendation 22:

That, as part of the audit into the NMS, the Government critically assess current suppliers and manufacturers with a view to diversifying supply streams.

Recommendation 23:

That the Federal Government investigate the possibility of being granted special powers during pandemic events to appropriate domestic supplies of PPE, as necessary, to be channelled to key priority groups.

Development of an Intensive Care (ICU) Resource Protocol

"I get that Covid-19 means difficult medical decisions have to be made about who gets treatment and who doesn't. But telling the disabled and already sick to sign away their rights in advance is asking them to volunteer for death. In all my 18 years of helping to look after my lovely daughter Elvi, I've never been so scared for her future as I am in this Covid-19 pandemic. Drop one of those balls at this time, and I could be signing my child's death warrant."

Damien Wilson, in the UK, responding to reports that GPs across Britain were sending out pre-emptive 'Do Not Resuscitate' forms to patients with existing health issues in anticipation of Covid19 related healthcare shortages.⁶⁷

Under Article 10 of the UNCRPD, persons with disability are entitled to their inherent right to life on an equal basis with others.⁶⁸ Coupled with this inherent right to life is the right for persons with disability to access the same range, quality and standard of health services as provided other persons and receive whatever services they require in the management of their disabilities.⁶⁹

Despite this, and specific State and Federal anti-discrimination legislation, many people with physical disability in Australia face impediments in receiving the health care they require – for instance, a study in 2015, indicated that 17% of people with physical disability aged between 15-64 experienced discrimination in the provision of health care services from health care staff, including GPs, nurses and

⁶⁷ Wilson, D., *Doctors are sending out 'do-not-resuscitate' forms telling people like my disabled daughter to sign them, I find that chilling*, op. ed. in RT Question More Online, 3 April 2020, <https://www.rt.com/op-ed/484832-disabled-covid-doctors-treatment/>, accessed 9 July 2020. For similar cases, please refer to Booth, Robert, *UK healthcare regulator brands resuscitation strategy unacceptable*, Guardian Australia Online, 2 April 2020, <https://www.theguardian.com/world/2020/apr/01/uk-healthcare-regulator-brands-resuscitation-strategy-unacceptable>, accessed 9 July 2020

⁶⁸ United Nations, *Convention on the Rights of Persons with Disabilities*, <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html>, accessed 9 July 2020

⁶⁹ *Ibid.*, Article 25.

other hospital employees.⁷⁰ A major concern for PDCN, in light of the anticipated strains on the Australia health care sector - and horrifying developments in other signatory nations, such as Britain, was whether people with physical disability would be treated equally - especially in terms of the allocation of acute care services.

Whilst the development of the national *Management and Operational Plan for People with Disability* can be seen as a major step forward in terms of recognising the unique needs of persons with disability and setting up the guiding principles around ensuring equity of medical care, we remain concerned that there is yet to be any practical protocol in place within NSW to ensure that there is a consistent and equitable approach to ICU resource allocation, including the provision of mechanical ventilators and intensive care beds. We consider that it is vital that such a protocol is developed to ensure that the medical practitioners who administer acute care services during pandemic events are not forced to make life and death decisions that are potentially influenced by their own personal biases.

Inherent in the development of a robust, ethical protocol is public engagement and consultation. People with physical disability are significant stakeholders in this issue - PDCN understands that a protocol is being developed and has pushed strongly to be able to review the document as the peak representative body for people with disability across NSW.

Recommendation 24:

That the NSW Department of Health commit to engaging with key stakeholder groups, including the disability sector, in the preparation of a health services protocol to guide the distribution of ICU resources at times where demand exceeds sector capacity.

Social distancing in practice for people with physical disability

"I'm fine, I live in an aged village. I've joined many online groups to stay busy. I go to the shops nearby with my carer and go to medical appointments. There's been strict hygiene processes..." PDCN Member

"I am a single mum. I have disabilities. One of my children has disabilities. Our life is hard, really hard. I live with chronic pain that at times makes me cry just getting out of bed. For over 8 years I have not been able to sleep for more than 2-3 hours at a time. I am always tired, always feeling like I am just hanging in there. Prior to the Corona Virus Pandemic I was very lucky to have carers here 5 days a week (20 hours) to assist my daughter and I. Now because my immune system is compromised I have had to stop them coming. I am trying to do it all on my own, including home schooling." PDCN member

Our members have a diverse range of physical disabilities, and their experiences regarding social distancing have likewise been diverse – many have managed day to day with a relative level of comfort, whereas for others social distancing has proved a massive challenge.

Access to services and supports (both informal and formalised) and sufficient levels of income has been critical to how well people with physical disability have managed during the pandemic. We have seen a great deal of innovation across stakeholder groups which work with people with disability, ranging from health care providers and disabled persons' organisations (NGOs) to pharmacies.

⁷⁰ Australian Government, Australian Institute of Health and Welfare (AIHW), *Access to health services by Australians with disability*, 3 Dec 2017, <https://www.aihw.gov.au/getmedia/2b4b4f65-e0b8-469b-97e2-48c4bf96f182/Access%20to%20health%20services%20by%20Australians%20with%20disability.pdf.aspx?inline=true>, accessed 9 July 2020

Many members have reported that they have been able to negotiate telehealth sessions, arrange to have medications delivered to their homes and to negotiate for carers to take on additional responsibilities like grocery shopping. In relation to social connection and engagement, innovation has provided opportunities for people who may otherwise struggle to attend events, with an increase in online social events, ranging from trivia nights to online work happy hours.

“People are really appreciating the events, they’re making new friends and meeting new people and it’s just really exciting so we will definitely keep them going.” – Emma Bennison, CEO of Blind Citizens Australia⁷¹

“Lots of our events were always in Newcastle and the Lake Macquarie area so this new style and this new world we’re in has definitely increased participation from people further up the Hunter Valley... those people have been able to phone in or meet up online for the first time, so it’s been great to be able to help those people feel connected.” – David Belcher, EO of Community Disability Alliance Hunter⁷²

Likewise, where they can access them, people have seen great value in initiatives from supermarkets such as dedicated supermarket shopping hours, pick up services and home delivery services. The general consensus is that members reported that such initiatives have generally worked well – many carers have utilised the dedicated shopping hours as a precautionary measure and deliveries of groceries have generally been prompt, however we would point out that such services have not been universally accessible across NSW, forcing those who live in towns that do not have close access to the major supermarket retail chains to continue to travel and physically access supermarkets. With store-imposed limits on certain high demand products, like hand sanitizer and toilet paper, this has sometimes meant multiple weekly trips, increasing fuel costs, and risks (through multiple contact) for this group.

In many ways, the transfer to a more mobile mode of service delivery across society has improved accessibility for persons with physical disability. The pandemic has demonstrated that society can operate in a more inclusive way, and we hope that many businesses see the value in continuing these initiatives post-pandemic.

At the same time, having access to a decent income has made a significant difference in terms of peoples’ general comfort during social isolation. Those who can afford PPE (even at inflated prices), afford extra incidental costs such as delivery charges, are able to adequately heat and cool their homes and invest non essentials like entertainment, have fared significantly better than those with less financial resources.

Isolation and decreased physical health and wellbeing

While many of our members have managed to adapt relatively well to increased restrictions, others have struggled significantly. We have identified 3 main concerns across this demographic – decreased service provision, isolation and financial pressures caused by increased costs.

Decreased service provision

A national survey of 204 people with disability conducted by People with Disability Australia (PWDA), indicated that 41% of people with disability on the NDIS had less NDIS support and 47% of people had

⁷¹ Carpanella, N., *People with disabilities find new ways to connect during COVID-19 lockdown*, ABC News Online, 27 April 2020, <https://www.abc.net.au/news/2020-04-27/people-with-visual-impairments-isolated-during-coronavirus/12170312>, accessed 9 July 2020

⁷² Ibid.

less support outside of the NDIS system.⁷³ These supports might include health services, supports given under home care packages or capacity building supports under the NDIS.

As this early stage it is impossible to gauge the long-term effects of a reduction of services on the health and wellbeing of our membership and their families as carers. Anecdotally however, members are already reported negative effects on their physical health stemming from the inability to access health services such as physiotherapy and hydrotherapy. We do not know what this will mean in terms of the long-term health outcomes or future service needs for these individuals:

"I'm not getting my hydrotherapy. I need that for my condition. I know that I've gone downhill. I've had it [hydrotherapy] since the 80's. I don't think I'll ever get back to how I was."

We anticipate that it will be much harder to assess the mental health impacts on people with disability and carers. Whilst many of our members report feeling increasingly optimistic now that restrictions have eased within NSW, feelings of isolation have been felt almost universally as people have been distanced from their friends and family and have lost the community connections that they would otherwise have, be that through catch ups with friends, church, work, exercise or volunteer activities. We are particularly concerned about the health and wellbeing of those who are continuing to isolate, particularly as we move into the stand-down phase of the State Government's response to the pandemic, where the divide between those at risk verses those who are not will become more acute.

The sustained emotional toil of the pandemic for people with physical disability needs to be recognised, and emphasis placed on the provision of subsidised accessible mental health support for those who need it. Support must also be extended to informal carers, who have often had to take on additional care responsibilities and maintain heightened social distancing and hygiene measures within households in order to protect more vulnerable family members, with reduced capacity to utilise respite services.

Lack of access to information technology as an equity issue

We have observed that isolation is most keenly felt by those who are not able to use technology. People may not be able to use technology due to their age, physical limitations they may have around the use of technological devices, inability to afford the necessary technology, poor internet speed/connection or they may simply lack the technological literacy. Given that the internet has been so critical to much of the innovation we have seen during the pandemic across service provision and social interaction there has been a strong divide between the technological 'haves' and 'have nots.' It is important that any pandemic planning, particularly around service delivery must be available across a variety of mediums to counter this inequity.

Financial pressures

Loss of work or reduction in work

In September 2019, 48% of working aged (15-64) people with disability within Australia were employed⁷⁴ Many of those employed have been impacted by the economic slowdown effect of social distancing – people have reported less hours of work, as well as job loss.

⁷³ People with Disability Australia, 2020, op. cit. - *note, this report is based on persons with both physical disabilities and cognitive disabilities.*

⁷⁴ Australian Government, Australian Institute of Health and Welfare, *People with disability in Australia*, Sept 2019, <https://www.aihw.gov.au/reports/disability/people-with-disability-in-australia-in-brief/contents/how-many-are-employed>, accessed 9 July 2020.

The Federal Government's rollout of the Coronavirus Supplement across Jobseeker and the introduction of the Jobkeeper Scheme have been vital to this demographic to allow them to retain a level of job security, or to otherwise continue to meet their ongoing household costs whilst trying to obtain new jobs in a tight market. Persons accessing these payments have identified this support as being critical in preventing severe financial hardship.

Given that these payments are forecast to come to an end soon, our concern is how these people will be able to manage on an ongoing basis financially. We advocate strongly for the Government to hold back on removing these payments until the job market recovers sufficiently for people to be realistically able to find work.

At the same time, it is critical that the Government acknowledge that job seeking will be particularly challenging for those with physical disability at increased risk from Covid19. People who are at heightened risk of Covid19 should not be expected to actively be seeking employment until it is safe to do so.

Impacts across households primarily reliant on income support

Whilst the economic downturn has affected us all to an extent, some households have fare less well than others. PDCN has observed that those on income support payments such as like the Disability Support Pension, Carers Payment and Aged Pension have been hit particularly hard, with members who rely on these payments are now reporting extreme financial hardship. We believe there are a number of factors behind this:

CPI increases resulting from drought, bushfires and Covid19

A culmination of extended drought conditions, the Black Summer Bushfires and the Covid19 Pandemic across late 2019-2020 have resulted in a CPI increase of 0.7% across the Dec 2019 quarter followed by a further increase of 0.3% for the March 2020 quarter.⁷⁵

The most significant price increases seen across basic household essentials such as fruits and vegetables, non-durable household products, tobacco, meat and seafood and pharmaceutical products.⁷⁶

At the same time, households relying on income support were unable to take advantage of decreased costs seen across high end products like domestic and international travel, accommodation or even fuel.⁷⁷ Households on income support were similarly less likely to see savings across entertainment or childcare costs which would otherwise offset increasing prices in other areas.

CPI changes are more strongly felt by lower income households

Whilst tracking the CPI is one way to assess changes in costs to households, Selected Living Cost Indexes (SLCIs) are designed to measure changes in living costs for selected population sub-groups. SLCIs are specifically designed to answer the question:

*'By how much would after tax money incomes need to change to allow households to purchase the same quantity of consumer goods and services that they purchased in the base period?'*⁷⁸

⁷⁵ Australian Bureau of Statistics, *Report 6401.0 - Consumer Price Index*, Australia, March 2020, <<https://www.abs.gov.au/ausstats/abs@.nsf/mf/6401.0>> accessed 7 July 2020.

⁷⁶ Ibid.

⁷⁷ Ibid.

⁷⁸ Australian Bureau of Statistics, *Report 6467.0 - Selected Living Cost Indexes*, Australia, Mar 2020 <<https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/6467.0Main%20Features2Mar%202020?opendocument&tablename=Summary&prodno=6467.0&issue=Mar%202020&num=&view=>>> accessed 7 July 2020.

In the March 2020 quarter, the living costs of pensioner and beneficiary households (including DSP and Carers Payment) and age pension households rose by 0.8%.⁷⁹ At the same time, living costs of employee households only rose 0.1%. This indicates that the disposable incomes of families on income support are falling behind that of employed households.⁸⁰

These households are already paying a cost for disability

These additional costs are compounded by the fact that households where a family member has a disability already face inequality in terms of their standard of living verses households without disability.⁸¹

A report conducted by the National Centre for Social and Economic Modelling (NATSEM) in 2015-2016, found that a household relying on the Disability Support Pension had, on average, a gap in household income of \$183 per week, whereas households with a person on the Aged Pension were out of pocket \$122 per week⁸² - these amounts represent the monetary cost of disability.

Statutory changes to the Pharmaceutical Benefits Scheme and the Medicare Benefits Scheme

Statutory changes to the Pharmaceutical Benefits Scheme (the PBS) and the Medicare Benefits Scheme (the MBS) have resulted in increased out of pocket expenses for pharmaceutical products and medical and hospital services – services that are utilised heavily by households on DSP, Carers Payment and Aged Pension.⁸³

Loss of capacity to supplement income via part-time work

People on DSP, Carers Payment and Aged Pension are all permitted to supplement their income via paid work - and many do. In 2018, 8.9% of recipients of DSP and Carers Payments aged between 18-64⁸⁴ and 4.1% of persons on the Aged Pension reported earnings in addition to their income support payments.⁸⁵ Recipients of either payment can earn up to \$178 per fortnight whilst still receiving the full pension rate. Earnings of more than \$178 per fortnight reduce pension rates by 50c per \$1.00.⁸⁶

Many people within this cohort, who would otherwise supplement their income support have had to make tough decisions and have left paid work to maintain strict social distancing either to protect themselves or those they care for.

People with disability and their carers are more likely to work in positions that are casual or to work reduced hours - as such, they are less likely to meet the threshold for the Jobkeeper Supplement. Persons who receive DSP, Carers Payment and Aged Pension are also excluded from the Coronavirus Supplement.

We also anticipate that the timeframe at which people on DSP and Carers Payments will return to work will be considerably longer than other groups, on account of the heightened risks associated with

⁷⁹ Ibid.

⁸⁰ Ibid.

⁸¹ Li, J., Brown, L., La. H.N., Miranti, R., and Vidyattama, Y. (2019). *Inequalities In Standards of Living: Evidence for Improved Income Support for People with Disability*. NATSEM, Institute for Governance and Policy Analysis, University of Canberra. Report commissioned by the Australia Federation of Disability Organisations. September 2019, <https://www.afdo.org.au/wp-content/uploads/2019/09/02A-NATSEM-Online-Disability-Report.pdf>, accessed 7 July 2020

⁸² Ibid.

⁸³ Ibid.

⁸⁴ Australian Government, Australian Institute for Health and Welfare, Disability Support Pension and Carers Payment Snapshot, Sept 2019, <https://www.aihw.gov.au/reports/australias-welfare/disability-support-pension-and-carer-payment>, accessed 7 July 2020.

⁸⁵ Ibid., Income Support Payments for Older People, <https://www.aihw.gov.au/reports/australias-welfare/income-support-payments-for-older-people>, accessed 7 July 2020.

⁸⁶ <https://www.servicesaustralia.gov.au/individuals/services/centrelink/disability-support-pension/who-can-get-it/non-medical-rules/income-and-assets-tests/income-test-pensions>

contracting Covid19 seen across this demographic. We know that many are still practicing strict isolation. Some people have indicated that they will continue to do this into the foreseeable future.

Additional incidental costs

In addition to increased costs across usual purchases, and the potential loss of supplementary income, the Covid19 pandemic has also resulted in additional necessary household expenses which households with restrained budgets have struggled to meet.

The most common types of additional costs we have observed across our membership include costs for personal protective equipment (PPE), hygiene products like hand sanitizer, increased utility costs, delivery costs for groceries, an increase of 10% on NDIS services and increased fuel costs. Low income households have also reported being additionally hit by inflated costs for high demand items like PPE and sanitary products or having to buy more expensive equivalent products in consequence of panic buying behaviours.

"I have to go with no food some days so I can pay for my medications and transport is expensive"⁸⁷

"All of 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..."⁸⁸

How do we redress financial pressures for people with disability??

In order to ensure that people with physical disability are given sufficient financial support we would make the following recommendations:

Recommendation 25:

That the Federal Government reconsider its current plan to cut the Coronavirus Supplement and Jobseeker Payments in September.

Recommendation 26:

That the Federal Government retain Jobkeeper and Jobseeker payments (at the current levels) for persons who are able to work (or their carers) where there increased risk to that individual to resume normal work/mutual obligation requirements for as long as necessary.

Recommendation 27:

That the Federal Government increase the DSP, Carers Payments and Aged Pension as a matter of urgency by an amount that is not less than the income gap identified across these households via the NATSEM report and backdate this increase to 27 April 2020.

Recommendation 28:

That the Federal Government permit persons receiving the Carers Allowance who are otherwise ineligible for the Jobkeeper Payment, to access Jobseeker without the need for mutual obligations.

Moving forward

⁸⁷ Ibid.

⁸⁸ Ibid.

In 2018, there were 4.4 million Australian who identified as having a disability – this represents 17% of the total Australian population.⁸⁹ Of that 4.4 million, three-quarters (76.8%) reported a physical disorder as their main condition.⁹⁰ A proportion of these people will be at increased risk from Covid19.

For this group, the risk of contracting Covid19 remains and will do for some time. These people, and the people who love and care for them will continue to take measures to keep safe even as social distancing measures are downgraded and we move toward the stand-down phase of the National pandemic response. We are concerned that these households will increasingly be 'out of sight, out of mind' as Governments shift towards rebuilding the economy.

It is vitally important that both National and State Governments acknowledge these people as 'the 3%' and ensure that they receive the support they need. At the same time, it is important that Governments do not succumb to the '*pandemic fatigue*' identified during the Swine Flu Pandemic – and continue to follow through on mechanisms to contain and eradicate the virus.

For the remainder of persons with physical disabilities, their experiences during the pandemic to date have been mixed. For some, social distancing has enhanced their capacity to engage in society – as society has become more innovative and creative in terms of social interactions. These new freedoms are bittersweet, aptly summed up in the comment "*It's a shame it took a pandemic to get us here*" - we can only advocate for the continuation of these innovations post pandemic.

A common theme, whether people with physical disability have managed comfortably or otherwise is that they have felt like they had to manage on their own. People with disabilities and their families are protecting themselves, working around supply shortages, researching their specific levels of risk, organising the supports they need through informal channels and reconfiguring their NDIS plans. They are sourcing accessible information from advocacy and disabled persons organisations (DPOs) and developing ways to adapt PPE. This sense of marginalisation is not unwarranted, given that there have been distinct gaps in terms of Federal and State support of the disabled community:

Until very recently I had felt in a very similar situation to other single parents. The Govt has however now made a big divide between parents with disabilities and those without. I feel invisible to people that are making such massive decisions effecting [sic] my life so negatively. These feelings of being ignored, discriminated against and worthless are having a very detrimental effect on my mental health.

⁸⁹Australian Bureau of Statistics, 4430.0 - *Disability, Ageing and Carers, Australia: Summary of Findings* – 2018, 24 Oct 2019 <https://www.abs.gov.au/ausstats/abs@.nsf/Latestproducts/4430.0Main%20Features52018?opendocument&tabname=Summary&prodno=4430.0&issue=2018&num=&view=>, accessed 9 July 2020

⁹⁰ Ibid

Conclusion

Since September 2019, Australia has been hit hard by two different, yet equally devastating, emergencies – the Black Summer bushfires, and the Covid-19 pandemic. Australia, as a signatory to the UN Convention on the Rights of People with Disabilities, has a responsibility to ensure the safety and protection of all its citizens with disability in emergencies. However, the research outlined in this submission has found Australian governments are not fulfilling their responsibilities, and people with disability are at risk of neglect. While the two emergencies are very different, PDCN found a number of common themes in Australia’s planning and response for people with disability to these emergencies. There appears to be a lack of consideration for the needs of people with disability, a lack of relevant information for people with disability, a lack of tools for effective communication with people with disability and a lack of engagement with people with disability.

These are not unique events, similar emergencies have happened before, and yet there doesn’t appear to be any learnings taken away on engaging with, or even considering the needs of, people with disability before, during and after an emergency, despite clear obligations for the government to do so. The intentions are good, but there are no real tangible outcomes. Issues are raised, taken on notice, but nothing comes of it.

This is was the experience of PDCN member Ben*, who lives on the NSW South Coast. Ben, as a member of his local council’s access and inclusion committee, was involved in a post-bushfire focus session at its meetings in February and March 2020. The committee put forward a report to the council with a number of recommendations, including a register of vulnerable people, an inventory of accessible accommodation, and ways to utilise accessible on-demand transport in an evacuation. However, four months later the committee has had no response from the council. It was the committee’s expectation that by now there would be a plan for implementation of the recommendations, but this has not been the case. It demonstrates that despite the information, knowledge and advice being available – and people with disability being more than willing to participate – governments are still not engaging and meeting their obligations.

Governments need to be more innovative, flexible and able to respond quickly to emergencies and not get caught up in bureaucracy or red tape. PDCN recognises that this can be difficult to do, however the obligation to do so is enshrined in legislation and not acting or responding is a form of neglect. It is a neglect of responsibilities when governments don’t act, despite information and advice being available. Governments must put knowledge into practice and ensure nobody gets left behind.

Whilst not specific to the either individual situation discussed in our submission, it should be noted that advocacy plays an essential role in emergency preparedness; from systemic advocacy organisations partnering with emergency organisations, governments and other bodies to provide expertise to continue to address gaps in inclusion and access prior to and post any emergency occurring, to individual advocacy often operating during, and very early post, an incident as people with disability struggle with individual barriers or issues and need support to address these issues, in order to remain safe, independent and included in community.

PDCN would like to thank the Disability Royal Commission for the opportunity to make this submission. We look forward to following the progress of the Commission’s work and make ourselves available to the Commission to discuss the issues raised in our submission.