

Women with Disabilities ACT

Submission to the

Disability Royal Commission

on the

Issues Paper on Emergency Planning and Response

July 16th 2020

C Moore

CEO WWDACT

Women with Disabilities ACT acknowledges and pays respect to the Ngunnawal and Ngambri peoples, the traditional custodians of the ACT Region, on whose land our office is located. We pay our respects their Elders past, present and emerging. We acknowledge their spiritual, social, historical, and ongoing connection to these lands and the contribution they make to the

Winner 2012 International Women's Day Award, Community Category

Winner 2015 ACT Chief Minister's Inclusion Awards, Excellence in Championing Human Rights

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About WWDACT

Women with Disabilities ACT (WWDACT) is a systemic advocacy and peer support organisation for women, girls, non-binary and feminine identifying people with disabilities in the ACT. WWDACT follows a human rights philosophy, based on the Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Elimination of (all forms of) Discrimination Against Women (CEDAW). WWDACT is a Disabled People's Organisation, governed by women* with disabilities, and its proposals and recommendations to government are consistent with Article 4 (3), and Article 29 of CRPD which outline the imperative for consultation with disabled peoples.

WWDACT, through its membership, has strong links to relevant ACT advocacy organisations such as Advocacy for Inclusion (AFI), People with Disabilities ACT (PWDACT) and the Health Care Consumers Association of the ACT (HCCA). WWDACT also has a close association with the Women's Centre for Health Matters and Women with Disabilities Australia (WWDA), the peak organisation for women with all types of disabilities in Australia.

Background

Under Article 11 of the Convention on the Rights of Persons with Disabilities, Australia is obligated to *"take, in accordance with their obligations under international law [...] all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including [...] the occurrence of natural disasters."*¹ During the Black Summer bushfires and COVID-19 crisis, women with disabilities in the ACT have felt neglected, unsafe and ill-informed. Improvements must be made to both protect people with disabilities from disasters themselves through evacuation protocols, personal protective equipment and other disaster mitigation activities; and also to protect people with disabilities from the increased incidence of violence, abuse, neglect and exploitation that occurs due to isolation and loss of oversight during disasters.

As stated on the Disability Royal Commission website, *"Neglect can be [...] a systemic issue that involves depriving a person with disability of the basic necessities of life such as food, drink, shelter, access, mobility, clothing, education, medical care and treatment."* Based on this definition, it is possible to consider the systemic failings of government to support people with disabilities to maintain access to basic essential services during disasters has been neglectful. As the COVID-19 crisis has gone on, improvements have been made, however the timeliness and appropriateness of these responses has still left women with disabilities feeling that the *"responsibility has fallen on us"*². In order to fully understand the scope of the impact of COVID-19 on women with disabilities in the ACT, WWDACT brought on a project officer to carry out a survey and interviews of women and non-binary people with disabilities in order to understand their experience of the crisis.

¹ <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-11-situations-of-risk-and-humanitarian-emergencies.html>

² [Appendix A] Shanmukhasundaram, S. (2020) *The Responsibility Has Fallen On Us: Perspectives on the impact of COVID-19 on Women* and Girls with Disabilities in the ACT and Region*, Women with Disabilities ACT. Available at <https://www.wwdact.org.au/publications/>

Questions

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

Governments need to have disabled people considered well ahead of time in their emergency planning so that they are not caught off-guard by crises. During COVID-19, it took until May 18th for the first part of the ACT Disability Strategy to be released, well into the pandemic³. As of writing this submission, the implementation plan has still not been released. This plan contains critical initiatives to provide equitable access to healthcare, PPE, safeguards against violence and targeted communications. While welcome, this strategy comes after people have already been experiencing acute distress as a result of the pandemic, which could have been avoided by disability conscious emergency planning, as advocated in the Sendai Disaster Risk Reduction Framework⁴.

In particular, equitable access to information and tailored advice must be a priority of governments at all levels in future emergency response. As a Disabled Person's Organisation, WWDACT has often struggled to get honest, relevant, and timely advice from governments for people with disabilities during both the bushfire crisis and COVID-19. During the Black Summer bushfires, disabled women in Canberra regularly asked us, "will the evacuation centres be accessible," because that information was not readily available online or in the news. Because all ACT evacuation centres were to be located at Colleges/High Schools, all of which are accessible, it would have been useful to include this information in all emergency press conferences and news bulletins where the possibility of evacuations was discussed. This lack of disability specific information was a characteristic of the response.

Long term, governments also need to consider what can be done to reduce the severity and regularity of disasters such as bushfires, which are directly linked to climate change and funding losses in environmental management agencies. Women with disabilities are a cohort that will experience the consequences of climate change first due to high rates of poverty, poor quality housing and isolation from the community all being affected by more extreme seasons and climate related disasters.

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

Women with disabilities expressed a desire for access to advocates during both the Black Summer bushfires and the COVID-19 pandemic. Several women that WWDACT referred to local advocacy agencies during these crises for assistance with housing, Centrelink

³ <https://www.actcoss.org.au/news-events/media-release/media-release-actcoss-welcomes-release-covid-19-act-disability-strategy>

⁴ https://www.preventionweb.net/files/43291_sendaimrameworkfordrren.pdf

applications, NDIS planning and domestic abuse struggled to get timely help as the agencies were so overloaded. Advocates are often in short supply during normal periods to help women with disabilities navigate complex system such as public housing and welfare, and navigating these systems during a crisis is even more difficult due to the move to online systems, change in income and eligibility, and stress affecting individuals decision making capacity.

WWDACT survey respondents also said that they wished for equitable Centrelink payments to support increased cost of living during COVID-19. These increased costs include increased transport costs to avoid public transport, delivery costs for groceries and increased utilities costs. One respondent said:

“The Government should treat everyone equally! Any extra payment would have helped me with some essential household items and therefore any money would have gone back into the economy.”

Limited financial assistance means that people with disabilities also need priority access to affordable Personal Protective Equipment (PPE). Between November 2019 and January 2020, Canberra was regularly cloaked in smoke so thick that many people with respiratory conditions were required to stay home. PPE was scarce, and when available, was too expensive for many people with disabilities to afford. One WWDACT member saw the need was so great that she shipped masks down from Brisbane and distributed them at personal cost to support other people with disabilities⁵. During the current COVID-19 crisis, it took many weeks for community organisations to negotiate for people with disabilities to be given access to the ACT government’s supply so they could continue to access disability supports in their homes.

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

“As always information is targeted at the general population and as a pwd [person with disabilities] you never quite know how the impacts are for you.”

Respondent – WWDACT COVID-19 Survey

People with disabilities need equal access to information about disasters so that they can understand what is happening and make decisions about their safety. During the bushfire crisis, AUSLAN interpreters were not always available, due to a chronic shortage of interpreters qualified to interpret emergency broadcasts in the ACT. Systemically, this needs

⁵ White, D. 3rd January 2020, 'Shouldn't be up to poor uni students to provide masks': shortage causes concern. The Canberra Times. <https://www.canberratimes.com.au/story/6565066/shouldnt-be-up-to-poor-uni-students-to-provide-masks-shortage-causes-concern/>

to be addressed by reinstating training programs for Auslan interpreters at ACT tertiary institutions and providing incentives for interpreters to train to this level.

Not only does information need to be accessible, it also needs to be appropriately targeted to people with disabilities. At first, women with disabilities did not know if it was possible to leave their homes during COVID-19 to seek help for abuse. WWDACT worked with our local government to help implement advertising to directly dispel this myth on social media and in print⁶. We would like to see similar actions taken proactively in future to make sure that women with disabilities know they can still seek help in times of crisis, especially where they may be reliant on a support worker or family carer for support during an emergency.

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

A central point of contact, such as an emergency hotline, which can refer people out to services for assistance in their local area and provide tailored, appropriate advice for people with disability would have been helpful during the Black Summer bushfires and throughout COVID-19. Respondents to WWDACT's COVID-19 Survey said that an emergency hotline would have been helpful. However, one respondent expressed frustration with the national COVID-19 hotline for people with disabilities:

"The disability COVID helpline is a total waste of time and effort. I was asked if my disability was? Mmm why? Would that have had an impact on the information I received? I also rang only yesterday to talk about the safety of my return to work. They actually can't give you any answers and have no information on where to get the answers."

As bushfire management and COVID-19 restrictions were largely managed on a state-by-state basis, it may be more appropriate to create local hotlines developed in collaboration with disabled people's organisations in future crises.

Several respondents to our survey also noted that relying on phone and internet may not be enough during such times:

"I believe persons with a disability and people experiencing high levels of vulnerability were not accommodated for during this time. People who don't have access to phones and internet were essentially cut off from their support services and daily routines. There was a lack of resources for persons living with vision or hearing impairment, particularly in a home context with online meetings. Those [who] are risk of social isolation before COVID-19 have had reduced access to services."

Some of these people may be assisted by timely funding for their internet and up-to-date technology through government support, while others may need information to be mailed out, or communicated directly by a support worker. Television and radio are also used by

⁶ See example image at <https://mcusercontent.com/21d04b548512fef76bf405b16/images/7aeb1a27-e777-4c9d-81f8-7b2772f1d8fb.gif>

many people with disabilities, and public emergency broadcasters such as the ABC and SBS should be properly resourced to provide regular, accessible broadcasts, including audio descriptions, captions, Auslan and translated information for culturally and linguistically diverse communities.

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

During the COVID-19 crisis, WWDACT has been presented with policies for people with disabilities that have not been adequately consulted with DPOs, the Office for Disability and disability sector stakeholders, and has had to ask for these policies to be significantly redrafted to meet community needs and expectations. The outcome of this is that policies written for people with disabilities have been substantially delayed. Such delays have placed women with disabilities at increased risk of neglect and abuse in health care settings and in their homes as they have delayed the implementation of much needed community and health responses, including ethical frameworks for care, access to telehealth and more.

One of the policy development processes that WWDACT has found particularly difficult has been the development of an ethical framework for resource allocation should there be a surge in COVID-19 cases beyond the capacity of hospitals.

“It's something that was concerning me a lot. Once I started reading reports from other countries about the prioritization of disabled people when it came to access to ventilators. I have a history of like a serious lung infections and just respiratory issues. And the idea of potentially being denied a ventilator, because my likelihood of surviving because of that is probably less than somebody else.”

Interviewee, WWDACT COVID-19 Project

Even after consulting with the disability sector in the ACT, many of the concerns documented through the consultation process have not been considered in proposed operational guidelines for triage. We are still concerned that if a surge in cases were to occur, people with disabilities would be at risk of neglect if they presented to a hospital for care due to discriminatory triage processes. WWDACT recommends that a nationwide ethical framework be designed in line with the *Statement of Concern on COVID-19: Human rights, disability, and ethical decision-making*⁷.

In future, it is critical that governments consult disabled person's organisations and the disability sector as early as possible in policy development to prevent these delays. Feedback received on any perceived or actual breaches of human rights within policies must be properly considered. In some cases, additional resourcing for small advocacy organisations may be needed to support the volume of consultation during these crises, and

⁷ Statement of Concern COVID-19: Human rights, disability and ethical decision-making, https://dpoa.org.au/wp-content/uploads/2020/04/Statement-of-Concern-COVID-19-Human-rights-disability-and-ethical-decision-making_Final.pdf

this should be considered in disability-aware emergency planning. Local emergency planning needs to follow the Person-Centred Emergency Preparedness (PCEP) model⁸ for individuals, the Disability Inclusive Disaster Risk Reduction (DIDRR) guidelines⁹, and the UN Sendai Framework¹⁰ to ensure governments and communities are prepared ahead of time.

Question 7: How can people with disability be protected from violence, abuse, neglect and exploitation when oversight and safeguarding practices are affected during emergencies? Should additional practices be in place during emergencies? If so, what should those be?

Safeguarding practices such as community visitors need to be considered essential services and should be maintained as much as possible during the pandemic, using PPE and physical distancing to minimise risk. Community visitors may have a role to play in also ensuring that appropriate risk management is being followed in congregate living settings to prevent outbreaks, and that people with disabilities are not being excessively isolated.

A member of the WWDACT community suggested that they wanted to be able to call the NDIS Quality and Safeguards Commission 24/7 to report issues with group homes. Another suggestion is that the National Abuse Hotline and the NDIS Quality and Safeguards Commission work more closely together to allow abuse, neglect and exploitation to be reported to one place, at any time of day or night, and reports to reach the appropriate channels for action.

It is important that all organisations that are collecting data about the access to services do so in a manner which enables disaggregation by gender and membership of minority communities such as Aboriginal or Torres Strait Islander or Culturally and Linguistically Diverse background. Aggregation of data from diverse sources present problems with accuracy.

Question 8: What are the particular experiences of children and young people, First Nations people, culturally and linguistically diverse people, women and LGBTQI+ people with disability during emergencies?

Women with disabilities are facing complex, intersecting issues that have a cumulative impact on their wellbeing and resilience during these crises. One respondent to the WWDACT COVID-19 Survey said:

“Vulnerable people are being told to stay home for our own safety, but I can't afford delivery fees. I can't afford a car, so I have to risk public transport. I can't talk on the

⁸Villeneuve, M., Sterman, J., & Llewellyn, G.L. (2018). Person-Centred Emergency Preparedness: A process tool and framework for enabling disaster preparedness with people with chronic health conditions and disability. Centre for Disability, Research and Policy, University of Sydney, NSW 2006. http://sydney.edu.au/health-sciences/cdrp/projects/UOS_PrepareNSW_user_guide_FINAL_v2.pdf

⁹Centre for Disability Research and Policy and Natural Hazards Research Group (2017). Local Emergency Management Guidelines for Disability Inclusive Disaster Risk Reduction in NSW. University of Sydney, NSW 2006. https://www.sydney.edu.au/health-sciences/cdrp/projects/Emergency%20Preparedness_brochure_August2017_WEB_ACCESS.pdf

¹⁰ Ibid

phone, so I can't attend my psychology appointments. My face-to-face therapies have stopped so I'm in significant pain, but my usual pain medication is too dangerous to take if I get COVID-19, so I have been prescribed more expensive (and addictive) medication."

Another said she was concerned about the ongoing impact of COVID-19 on disability discrimination and racism.

"I feel as though people with disabilities (particularly first-nations and people of color) have been systemically excluded from the national conversation around public health. I am concerned as a Chinese-Australian, that I will face heightened racism and systemic discrimination in areas like employment."

Many women with disabilities are also managing the increased strain of caring for children and family members during the crisis, while also juggling changed work, service, and support arrangements. Nearly one-third of respondents to WWDACT's survey indicated that their caring responsibilities had increased due to COVID-19, in addition to all the other pressures placed on them by the crisis. It is unsurprising then that the top concern for women with disability in the ACT was their mental health. Going forward, a drastic increase in mental health support will be needed for our community and it is important that any new mental health services are disability and gender competent.

Women with disabilities have also been particularly vulnerable to isolation from the community during emergencies, and thus may be at increased risk of violence, abuse and neglect. The enforced isolation, lack of access to health services and therapy services has had an effect on mental health for many women such that it is possible to envisage the risk of self-harm in a continuum of increased risk of abuse.

WWDACT has had success working with our main local domestic violence service, the Domestic Violence Crisis Service, to promote different ways of contacting the service during the crisis, acknowledging that phone calls may not be accessible for all, and may not be safe for women if all members of a household are at home for an extended period of time. These methods of contact have included messaging the service on social media, through SMS or by email. However, WWDACT and other disability organisations have observed that many crisis services do not have disability awareness training and may not always be prepared to make reasonable adjustments, such as letting support workers contact them on a client's behalf.

WWDACT also spoke to young people attending university who have experienced discrimination and exploitation during the COVID-19 crisis. These experiences are outlined on pages 53-55 of our COVID-19 Report.

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

In our COVID-19 survey, many women said that community shopping hours were unhelpful as they were early in the morning, so they were unable to get support workers or transport.

Home delivery services were so restrictive in their criteria that many women with disabilities could not access them because they were not on a pension or the NDIS. This left women with the choice to go out and risk their health or go without groceries. In future, supermarkets and their staff need to be aware that not all people with disabilities access government payments or the NDIS and that this should not be an identifier of disability for the purposes of access to community shopping hours and delivery.

The ACT Government set up the Canberra Relief Network with a group of community services organisations to supply those in need with groceries. However, they were not able to meet the dietary requirements of many disabled people who contacted them. Some of the organisations that were members of the scheme made their own supplies of gluten and dairy free product available, but only on an ad-hoc basis that was not made known to the public. Schemes like this need to be properly resourced in future so that those in greatest need are not left without food and people with disability are not neglected by relief schemes.

Many women needed access to pharmacies for medical and hygiene supplies, and to continence pads and items for reproductive health. Although many pharmacies did make home deliveries for women in certain categories and age groups, this was not uniform from suburb to suburb or to different pharmacies within suburbs.

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

Despite the difficulties posed by the Black Summer bushfires and COVID-19 pandemic, there have been some positive experiences that should be carried beyond times of crisis to improve the lives of people with disabilities. Flexible work arrangements have had positive impacts for many women with disabilities and their carers. One of our survey respondents said:

“...my level of support has increased as a result of COVID-19. My partner works for the federal government and the shift to WFH [Working from Home] has allowed him to provide care and support for me in a much greater capacity than before. This has had significant benefits in that it has allowed for greater flexibility in managing our work and study commitments whilst reducing the impact of my illnesses on the structure of our lives.”

However many of our respondents expressed worry that they would not be able to continue accessing these kind of reasonable adjustments by their employer. For example:

“Worry about whether I'll be allowed to continue working from home isn't a worry I needed on top of all the others!”

Continued flexible working arrangements may also allow more women with disabilities to enter the workforce and achieve improved economic security and community connection, a protective factor against abuse, neglect and exploitation.

Similarly, telehealth has improved access to health care for many women with disabilities, and there is a widely-held hope that it will continue beyond the COVID-19 pandemic. Access to telehealth means that people with disabilities with limited transport access or other barriers to seeking health care are able to see their doctors more consistently. One WWDACT member said:

“The medical appointments over the phone or video call are fantastic- meaning if I'm unwell I can inquire about doing my appointment from home to keep up with the therapy required if its [sic] able to be done via call/video [...] If I'm unable to leave the house this gives me a way to still continue through with the appointment without the added stress.”

Many more echoed this sentiment, saying that telehealth for doctors and allied health professionals should be continued into the future.

Recommendations

While there have been major issues with the quality and timeliness of government responses to the Black Summer Bushfires and COVID-19, major lessons have been learned about the need for inclusive planning, accessible communications and flexible access to work and health care. WWDACT's key recommendations regarding emergency planning and response are summarised below:

1. Local, state and federal governments must implement disability conscious disaster planning in line with best practice.
2. Governments must take action on climate change to reduce the frequency and severity of natural disasters.
3. The availability of disability advocates must be increased during times of crisis.
4. Emergency hotlines with locally relevant, accessible, and tailored information should be made available in each state during emergencies.
5. Communications such as mail, television and radio must be supported and made accessible for people with disabilities who cannot access internet.
6. Disabled people and Disabled People's Organisations must be included in future planning and during reactive policy development in times of crisis.
7. All responses to COVID-19 must seek to address the intersectional issues being faced by women with disabilities
8. Domestic violence services need to consider innovative and flexible way of working with people with disabilities and those that support them.
9. Flexible working arrangements, telehealth and other innovations that have improved access to essential services should remain in place after the COVID-19 pandemic ends.