The Pandemic Project

A review of the literature on the impacts of the COVID-19 pandemic and lockdowns on women with disability in Australia

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## About PWDA

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

PWDA’s primary membership is made up of people with disability and organisations constituted of people with disability. We have a vision of a socially just, accessible and inclusive community in which the human rights, contribution and diversity of all people with disability are recognised, respected and celebrated. PWDA was founded in 1981, the International Year of Disabled Persons, to provide people with disability with a voice of our own.

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

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## Abstract

The outbreak of SARS Cov 2 (COVID-19) in late December 2019 and early January 2020 caused worldwide concern because of the severity of this new coronavirus and its rapid spread. Disabled people were at the forefront of the pandemic, sharing information and alerting governments to the potentially grave consequences of the disease. In Australia, the pandemic arrived on the back of what has become known as the Black Summer, during which devastating bushfires raged across the country’s east coast. These fires impacted air quality and access to services and supports and caused high anxiety across the population, including people with disability. People with disability utilised mutual aid networks during the bushfires but were less able to do so with the emergence of the pandemic. The ‘double whammy’ of the bush fires followed by the pandemic had a cumulative affect for people with disability, especially women with disability.

This literature review examines primary and secondary sources from predominantly grey literature on women with disability and their experiences of the pandemic. Notably, very little has been written on this subject from a peer-reviewed perspective. The review is time limited from December 2019–November 2021. Material was sourced from Google Scholar, reliable media sources, such as the ABC, SBS, The Conversation and the Guardian, parliamentary submissions, peak body websites and community surveys. The review also references reports from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability.

Overall, the literature suggests significant impacts on the wellbeing and mental health of women with disability, including increased risks of intimate partner violence, difficulty in accessing mental health services and sexual health services and increased marginalisation, especially for CALD and First Nation’s women with disability.

As noted previously, most of the literature available on the impact of the pandemic on women with disability is from grey sources due to its contemporaneous nature. However, these sources provide a rich narrative as to the daily impacts and experiences of COVID-19 on women with disability.

**Key words:** COVID, pandemic, wellbeing, mental health, impacts, violence, trauma, disaster.

## Introduction

Many people with disability faced the onslaught of the pandemic immediately after experiencing the impacts of the Black Summer bushfires of 2019/20. This was particularly the case for disabled people living in remote and rural locations. It should also be noted that First Nations people with disability have been disproportionately impacted by the pandemic and this is noted by the First People’s Disability Network (FPDN) and the Disability Royal Commission.

Therefore, many women with disability were already exhausted and struggling as the pandemic started to emerge in Australia. The ‘double whammy’ effect of these successive natural disasters must be recognised when examining the impacts of the pandemic on disabled women’s mental health and wellbeing. Disabled people were marginalised in response to each of them and this is reflected in the literature we were able to locate.

While the available literature on the impact of the pandemic on women with disability is limited, we did identify a range of themes from the available sources including:

* intimate partner violence and DFV
* financial distress and lack of access to food
* isolation, home schooling and the burden of care
* the pressure of living with COVID-19
* access to telehealth and access to information.

These themes are outlined below:

### Intimate partner violence and DFV and access to services

A significant theme arising from the literature is violence, in particular intimate partner violence. Lockdowns and enforced isolation have seen many women with disability ‘locked in’ with perpetrators. The disproportionately high rates of violence experienced by women with disability are already well-established. However, a recent ANROWS study (Boxall and Morgan, 2021) cites that many women with disability experienced intimate partner violence for the first time during the pandemic. Many women were unable to continue with counselling and support services (even digitally) because perpetrators were now constantly present. The lack of access to services is an overarching theme in the literature. When the vaccine became available, reports began to emerge of women disclosing instances of domestic and family violence at vaccination centres (Baker, 2021).

A joint 2021 UNFPA and Women Enabled International report noted that disabled women had difficulties in accessing mental health support and sexual health services during the pandemic. This experience was also reflected in Australia with many women in the Deaf community saying they had immense difficulty accessing mental health services during the pandemic. Women with disability often had to resort to seeking assistance from perpetrators or poorly skilled care workers and this may well prove to have been an increased risk factor contributing to violence.

A UK report on the impact of COVID–19 on people with disability (Lund, 2020), found that the pandemic amplified existing issues for disabled women. Women with disability already face considerable barriers in accessing services, and the requirement of isolation made overcoming these barriers more difficult.

Newman, Fisher and Trollor (2021) emphasise that access to mental health services for people with intellectual disability has been especially problematic during the pandemic. Newman et al., note that whilst people with intellectual disability are nominally included in state mental health policies regarding their right to information, the communication and access needs of people with intellectual disability are not recognised.

### Financial distress and access to food

In a report to the Senate Select Committee on COVID–19, WWDA (Frohmader, 2020) notes that women with disability faced especially oppressive circumstances during the pandemic because they were denied the COVID supplement payments. It should be noted that women with disability have some of the lowest incomes in the country and that a mere 10% of all disabled people have access to the NDIS. A PWDA survey conducted early in the pandemic found that a major cause of distress was the inability to access fresh food once supermarkets ceased online shopping. In their article for The Conversation, Stears, Teesson and Bower (2021) highlighted the stress of financial insecurity felt by people during the pandemic. PWDA’s COVID survey also identified financial hardship as a serious concern for disabled people. While some disabled people were able to access the JobKeeper payment, for many the criteria was onerous and overwhelming.

Early in 2020, PWDA ran a survey for our members to glean their experiences of the pandemic. Key themes included:

* 91% reported increased expenses, mostly groceries and food, healthcare, internet and phone and hygiene/sanitising equipment
* 41% had less NDIS support
* 47% had less non-NDIS disability support.

*‘It is well recognised that 50% of people with disability already live in poverty so additional costs at this time are tipping people with disability over the edge. Over 40% of people in receipt of the JobSeeker payment are also people with disability and/or chronic illness.’ (PWDA Pandemic Survey, 2020)*

The Disability Royal Commission issued a statement of concern (2020) regarding the pandemic and people with disability. The statement outlined a number of key areas including financial distress and access to food and nutrition. The PWDA survey also found that getting access to groceries was highly problematic for many disabled people at the beginning of the lockdowns. This caused extreme anxiety, which was exacerbated by the isolation of lockdown.

*‘I have increased costs for groceries, utilities and disability-related items. Some of my medications have been unavailable for over a month. Some of the disability-related items have increased in price or have been unavailable. I have also had to purchase extra disability-related items for my son.’*

*‘The rush on groceries left me unable to get items at their regular prices. The lack of home brand groceries and the dramatically increased prices on essential items increased my grocery bill by at least one third and left me without ANY spare money each fortnight. It has made a significant impact on my budget, which is low at the best of times.’*

**Isolation, home-schooling and the burden of care**

Whilst there has been a recognition of the increased effects of the pandemic upon people’s mental health, the Mental Health Think Tank report (Bower et al., 2021) did not explore in depth the experiences of women with disability. Children and young people with disability’s experiences of the pandemic were examined from the perspective of schooling, however an examination of the impacts of home schooling on women with disability who are also parents was not examined. Our preliminary research found that lockdown and home schooling was a large contributor to stress and overall poor mental health for disabled mothers. Bower et al. (2021) identified that the bulk of caring and home schooling fell to mothers during lockdown. This was echoed in Gender Equity Victoria’s COVID 19 report which stated that women carried the “triple load” of caring, working and worrying. The report did not address disabled women specifically, however our early findings that the experiences of disabled women concur with those of non-disabled women.

*‘I’m completely isolated...no one has rang to see how I’m going. I have no outside family.’ (PWDA survey participant, 2020)*

### Living with COVID and its terrors

In her Canberra Times article (October 2021), Professor Gemma Carey highlights the stark reality for people who are immunocompromised. She also points to the lag in vaccine rollouts to disabled people in group homes. Disabled women living in congregate settings already experience structural, lateral and physical violence. The added danger of COVID-19 is another strain on an already stressful and often frightening reality.

In early 2021, the federal government deprioritised vaccination for disabled people. This specifically meant that people living in group homes and other institutions were unable to access the vaccine despite being previously identified as category 1A and 1B.

Carey, Dickinson and Kavanagh (2020) identified increased risks to COVID-19 due to many disabled people being clinically vulnerable as a result of co-morbidities. The PWDA COVID survey found that getting access to PPE for disabled people and their support workers was problematic. Carey et al (2020), stated that access to PPE for disabled people and support workers needed to be guaranteed and that the disability support workforce needed to be reinforced to ensure that people with disability were not left without supports and services when workers became ill.

Carey (2021) makes a very clear argument that there is no going back to ‘normal’ for many disabled and immunocompromised people. The prospect of ‘freedom’ is actually terrifying for many and there will be a significant portion of the disabled community who will remain in lockdown long after the rest of society has ‘opened up’. This poses an even greater burden of risk on disabled women who are experiencing intimate partner violence and domestic and family violence wherever they reside.

The deprioritisation of people with disability in the vaccine roll out caused immense confusion and concern for an already anxious cohort who felt that their health and lives were not valued. This was reflected in PWDA’s 2020 Pandemic Survey.

*‘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.’*

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

The interface with the NDIS has been contentious. As noted in PWDA’s survey, many of our members lost NDIS supports, leaving people distressed in a time of crisis. PWDA’s individual advocates worked with clients remotely during this period and many reported, anecdotally, that clients in group homes were being locked in at service providers’ discretion. This was also noted by the Disability Royal Commission in its statement of concern (2020).

### Telehealth and access to information

PWDA’s 2020 Pandemic Survey found that access to telehealth during the pandemic has been well received by many people with disability. Many survey respondents had taken up this opportunity. The survey reflects the different services that people with disability accessed via telehealth, including allied and mental health. Getting accurate information has been difficult for many people with disability and our survey highlighted the lack of Auslan interpreters at some major press conferences.

*‘Deaf people need more Auslan interpreters at emergency announcements and broadcasting with newsreaders.’ (PWDA survey participant)*

*‘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 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.’ (PWDA survey participant).*

In its Statement of Concern on the Pandemic (2020), the Disability Royal Commission identified serious concerns regarding access to information for disabled people and called on all governments to ensure accessible information was made available in all formats.

## Conclusion

Documenting the impacts of the pandemic on women with disability is an ongoing process. As we progress thorough this difficult period more evidence will be collected and analysed.

Despite the limited available literature, serious areas of concern in relation to disabled women’s mental health and wellbeing can already be identified. There is clearly scope for further enquiry and for policymakers to take on these concerns to better serve the mental health needs of disabled women in any crisis.

Article 25 of the Convention on the Rights of Persons with Disabilities (CRPD) states:

*States Parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:*

*a) provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programs*

*b) provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons*

*c) provide these health services as close as possible to people’s own communities, including in rural areas*

*d) require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care*

*e) prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner*

*f) prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.*

Therefore, as signatory to the CRPD, and as a nation committed to public health, including mental health, for all citizens, governments, policy makers and other systems are bound to ensure that disabled women receive the same right to healthcare as any other citizen, on a fair and equal basis.

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