

People with Disabilities WA
Individual, self & systemic advocacy



Submission

Impact of COVID-19 responses on people with disabilities

People with Disabilities (WA) Inc. (PWdWA) would like to thank the Australian Government Senate Committee for the opportunity to provide comment on the impact of COVID-19 responses for people with disabilities.

PWdWA is the peak disability consumer organisation representing the rights, needs and equity of all Western Australians with disabilities via individual, self and systemic advocacy.

PWdWA is run BY and FOR people with disabilities and, as such, strives to be the voice for all people with disabilities in Western Australia.

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About People with disabilities WA (PWdWA)

Since 1981 PWdWA has been the peak disability consumer organisation representing the rights, needs, and equity of all Western Australians with a physical, intellectual, neurological, psychosocial, or sensory disability via individual, self and systemic advocacy. We provide access to information, and independent individual and systemic advocacy with a focus on those who are most vulnerable.

PWdWA is run by and for people with disabilities and aims to empower the voices of all people with disabilities in Western Australia.

Introduction

PWdWA acknowledges the work of the Federal and State governments in managing the COVID#19 Pandemic and keeping the level of community transition to a minimum. While we acknowledge the “flattening of the curve” has been successful it is imperative that we remain vigilant with the possibility of a second wave of COVID#19.

People living with disabilities are at higher risk of contracting COVID#19 and experiencing complications associated with the infection. Case Study examples have been included in this submission to further illustrate how people living with disabilities have been impacted during this crisis.

It is vital that all governments take note of the key issues experienced by people living with disabilities as outlined in this submission.

A set of Recommendations has been included in this submission to assist the Federal and State governments to be better prepared, should a second wave of COVID#19 infections occur.

Summary

The structure of this submission is as follows:

Section 1: Key Recommendations

Section 2: Highlighted issues

Section 3: Case Studies

Section 1 – Key Recommendations

Ethics

Recommendation 1

Include people with disabilities and their carers in conversations around the building of an ethical framework for decision making in times of a pandemic.

Recommendation 2

Health and disability professionals to be reminded that biased conversations are not acceptable from a human rights perspective. All end of life conversations should be based within an ethical framework with a clear structure for all information, support, and time that is needed.

Recommendation 3

Government to clarify what supports are being provided for people with disability to participate in conversations about end of life care choices during this pandemic.

Recommendation 4

Provide information on any work being undertaken on the development of ethical frameworks and planning for high risk populations.

Infection Control

Recommendation 5

COVID#19 testing for people at high risk of mortality and those that support them to be prioritised.

Recommendation 6

COVID#19 testing and flu vaccinations for people at high risk of mortality and those that support them to have access to these at home.

Recommendation 7

Access to PPE for support staff in service settings as well as the many people who directly employ or self-manage their support to be a priority. Maintaining a stock of PPE dedicated for the disability sector should be considered.

Recommendation 8

Development of a more targeted and planned approach to accessing PPE for the disability sector is required, including access for those who directly employ support rather than use a service.

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Recommendation 9

Clearer guidelines to the disability support sector in the use of PPE in relation to the control of COVID#19 is required.

Access to Essentials

Recommendation 10

Stricter measures implemented by governments to prevent the wider community from stockpiling food and grocery items.

Recommendation 11

Business to continue working with disability organisations to ensure priority access for people with disability and those in isolation to food, household goods, and medicines. This includes people with disability who work and do not have a Centrelink card.

Recommendation 12

State and/or local governments to coordinate information about what to do in event that someone can't attend the shops due to disability and/or isolation and does not have informal support to help.

Recommendation 13

State and local government to support Foodbank, meals on wheels, and volunteer services to have enough supplies and safe protocols to assist those in need.

Recommendation 14

Local government agencies or large NGOs such as the Red Cross supported to coordinate volunteers to take shopping and essentials to those in need.

Recommendation 15

Governments provide resources to Advocacy agencies to instigate regular phone check ins with people with disabilities known to be isolated.

Recommendation 16

Earlier establishment of a Telephone Helpline for referral to services that can support access to essential grocery and medical items.

Recommendation 17

Clear information and guidelines to be provided to the disability sector and people with disability on accessing emergency services and supplies.

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NDIS Policy

Recommendation 18

The NDIA allow much greater flexibility in NDIS policy implementation during a pandemic to prevent financial disadvantage for service providers and clients.

Recommendation 19

The NDIA develop appropriate emergency and crisis response policies and procedures in preparation for a second wave of COVID-19 and future pandemics.

Access to Services

Recommendation 20

Collaboration in the pooling of support staff from providers from other areas including provision of telephone numbers for accessing staff for those self-managing.

Recommendation 21

A plan must be in place specifically for people with disability that ensures continuation of essential health services during a pandemic such as having flu vaccinations at home.

Recommendation 22

Ongoing planning of services for people with disability through co-design to continue to occur on a regular basis in preparation for a second wave of COVID#19.

Mental Health

Recommendation 23

State and federal government to boost support for mental well-being and counselling both online and via telephone services to support people at high risk of suicide and mental illness throughout the crisis.

Recommendation 24

Support disability service providers to continue to implement innovative ways of engaging with people with disability through their community access funding such as online games, video call catch ups, and individual walks in natural areas/parks where social distance can be maintained.

Recommendation 25

Support the implementation of strategies for keeping up social contact with people living with disabilities who have limited phone and internet access.

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Financial Disadvantage

Recommendation 26

Ensure that people with disabilities and their carers are not financially disadvantaged by providing additional support payments in a more equitable manner.

Information Dissemination

Recommendation 27

Guarantee from the Federal Government that no NDIS Client will be disadvantaged from the underutilisation of services within their support plans due to COVID#19.

Recommendation 28

Provision of clearer definitions of 'essential services', as they pertain to people living with disabilities.

Recommendation 29

Development of specific and targeted messages and information to people with disabilities that consider their specific circumstances.

Recommendation 30

The NDIA to provide further clarification regarding the cancellation of services at short notice and how would this would financially impact NDIS clients and service providers.

Digital Disadvantage

Recommendation 31

Greater flexibility in the use of NDIS Plan funding, to reduce digital disadvantage and facilitate access to online services, supports and resources.

Advocacy Services

Recommendation 32

Support and resources from government to all disability advocacy agencies so they can adequately provide services for those most in need during this crisis.

Section 2 – Highlighted Issues

Human rights, disability and ethical decision-making

The COVID-19 pandemic has put a spotlight on the undeniable ableism in our health care system. Access to health care, including emergency and critical health care, should be provided on the basis of equality with others and based on objective and non-discriminatory clinical criteria.

Federal and state governments have done a fantastic job in putting measures in place to curtail the spread of the virus. This means that there is now the time and opportunity to put in place an ethical framework to support members in the community who are at high risk of fatal complications from COVID-19. It is not clear what discussions are occurring in relation to ethical decision-making frameworks in WA and how they will impact people with disabilities.

In recent informal discussions with community members, concerns have been raised about regular review appointments for people with disabilities who are in high risk categories now including discussions about resuscitation decisions. These are conversations which people are not necessarily adequately equipped for when little warning has been given, and require time to think through before decisions are made. These conversations could conceivably lead to an unconscious coercion from health professionals to encourage consumers to opt for “do not resuscitate” orders and similar strategies which can lead to rationed care for vulnerable people should they need medical assistance, particularly with the pressure of a pandemic.

Recommendation 1

Include people with disabilities and their carers in conversations around the building of an ethical framework for decision making in times of a pandemic.

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Recommendation 3

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Recommendation 4

Provide information on any work being undertaken on the development of ethical frameworks and planning for high risk populations.

Infection Control and Personal Protective Equipment (PPE)

Governments, community services, business, and the community in general must take measures collectively and individually to protect people with disability who are vulnerable. We must all limit physical social interaction to stop the spread of the virus and we expect government to act decisively in this area. Many people with disability are vulnerable to serious illness and death from COVID-19.

The NDIS Quality and Safeguarding Commission advised of a national stockpile for PPE, however providers reported not hearing back from the email address and without access to PPE they were unable to effectively implement business continuity and infection control plans. Of 10 polled organisations that submitted requests from the PPE stockpile, none were responded to. There was also a lack of clear guidance on what PPE should be used in community settings during the COVID#19 crisis, and how decisions were being made regarding its access.

The disability and community sector in WA relied on the Department of Health Infection Control training which was publicly provided, however it was suggested by the sector that this was not necessarily appropriate for disability services as it didn't consider the nature and specific situations that could arise from COVID#19 in the disability context.

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COVID#19 testing for people at high risk of mortality and those that support them to be prioritised.

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Development of a more targeted and planned approach to accessing PPE for the disability sector is required, including access for those who directly employ support rather than use a service.

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Emergency Support and Access to food, medicines and supplies

Many people with disability have chosen to stay isolated for their own health and protection. Many people due to their disability and issues with access, have always used online shopping and services.

During this crisis, especially in the beginning there were issues with accessing online delivery from supermarkets and also with accessing a number of essential grocery items, medicines and supplies such as toilet paper, gloves and hand sanitiser.

Major supermarkets responded by introducing dedicated shopping hours for vulnerable people, however these hours were very early in the morning, and it was not always possible for a person with disability to attend in those timeslots. Even when they were able to attend, many essential supplies were still unavailable. Major supermarkets offered priority delivery to people with disability, however due to infection control policies deliveries had to be left outside. Many people with disability are unable to bring their groceries inside themselves.

In WA 'Cahoots Connect' was funded by stakeholders including the Department of Communities to assist vulnerable people with obtaining essential supplies, however the service did not commence until 16th April. A state of emergency was only declared in WA on the 15th of March, which meant for an entire month people with disability experienced significant issues in accessing food and other essential supplies.

In WA, it was verbally recognised that the Department of Communities would be the 'provider of last resort' for people with disability. However, no written advice was issued to this effect, and no clear guidance was provided regarding the circumstances in which they would act and what type of support would be provided. Disability service providers reported concern about the financial risk of supporting participants in urgent changed circumstances where currently funded supports were insufficient.

Recommendation 10

Stricter measures implemented by governments to prevent the wider community from stockpiling food and grocery items.

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Business to continue working with disability organisations to ensure priority access for people with disability and those in isolation to food, household goods, and medicines. This includes people with disability who work and do not have a Centrelink card.

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Recommendation 17

Clear information and guidelines to be provided to the disability sector and people with disability on accessing emergency services and supplies.

Ineffective NDIS Policy

The National Disability Insurance Agency (NDIA) announced some policies such as:

- A 10% loading for some supports, to help providers cover the additional costs of service delivery in the COVID#19 environment
- Change to short notice cancellation policy allowing providers to charge participants in full for cancellation of services made inside 10 business days. (The policy previously allowed providers to charge a 90% fee for cancellations inside 2 business days).

These changes all required agreements and consent from the participant, therefore placing a significant administrative burden on a disability service organisation's ability to respond in an agile manner. It is important to note the NDIA made these allowed to providers without any respective increase in funding to participants plans, therefore many providers experienced pushback from clients when trying to implement these changes. Many providers decided the risk of upsetting their client base made the short-term gain in NDIS COVID#19 services/ supports not viable, therefore ineffective.

The 10% loading also did not apply to Supported Independent Living services, which provides supports to participants to live independently in their homes. Identity WA reported providing an additional 1000 hours of services per fortnight to support their clients who were no longer accessing community-based supports with other providers. They are currently struggling to recoup this cost as not all participants

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have available funds for extra services, and those who do generally have their funds tied up in Service Bookings with other providers, creating significant administrative impost.

Service providers were advised to work with participants to flexibly deliver services to participants as needed, however this itself has a significant administrative impost. This is due to the following:

- Any changes in provision of services need to be agreed to by participants in order for providers to claim.
- The expectation was that organisations had a duty of care to check in on their vulnerable participants, however needed to seek consent to claim for this time.
- Providers needed to assess risk of service delivery to both participants and staff on a case-by-case basis, and set up appropriate policy and procedure in response. Lack of clarity around what services were allowed to continue as exemptions to health department advice resulted in many providers withdrawing from face to face services all together.
- It is generally not possible to claim payments for time spent on administration or program setup, which resulted in a significant overhead when pivoting services. If the change in service delivery is only going to be in effect for a short term during the pandemic, these costs will not be recouped, which resulted in many cases of providers withdrawing certain services.

The NDIA remained rigid with some policies which resulted in barriers to people with disability being appropriately supported in response to COVID#19. These include:

- Not allowing family members to claim funds to support participants. In many cases the most appropriate response to the pandemic was to self-isolate with family to mitigate risks of infection, however no flexibility was allowed to compensate them for the supports they were providing that would otherwise be delivered by service providers.

Providers were encouraged to deliver services flexibly to participants during the pandemic, however were unable to claim for services over the price limits in the NDIS Support Catalogue. For example, if staff were requested/needed to isolate in home with participants, registered providers were not able to claim for the resultant overtime required to meet payroll obligations. This meant that providing the service was not financially viable – putting the person with disability at risk of being without support.

In addition to the above, the NDIS has no critical/crisis response mechanisms. All enquiries by participants, regardless of nature, are directed to the one phone number and one email address for triage. There is no legislation or policy which mandates response times to enquiry, including in crises. This can result in lengthy delays in participants receiving funding for services that are essential in response to changed need.

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Recommendation 18

The NDIA allow much greater flexibility in NDIS policy implementation during a pandemic to prevent financial disadvantage for service providers and clients.

Recommendation 19

The NDIA develop appropriate emergency and crisis response policies and procedures in preparation for a second wave of COVID-19 and future pandemics.

Continued access to support services and health care

Some people living with disabilities had their support services cancelled by their paid carer or service provider due to the risk of COVID#19. This left some people with absolutely no support at home, some with no access to basic Assistance with Daily Living (ADL) tasks. For this situation to have occurred, is completely unacceptable.

People with disability are more likely to be disproportionately impacted by COVID#19 due to both the risk it poses to health but also because of other conditions which may require hospital beds and health services during the peak crisis. Some people with disabilities were choosing to self-isolate and avoiding public transport to protect themselves. People with disability are valued members of society and should not be disadvantaged from accessing essential health care services such as GP appointments and flu vaccinations.

Apprehension has also been expressed by people with disability and the broader disability sector, about the post COVID#19 future. During the pandemic long-awaited services such as telehealth became more accessible and some people with disabilities have been able to access a broader range of social activities online, however there is concern about whether these services will still be as accessible once the COVID#19 crisis is over.

Recommendation 20

Collaboration in the pooling of support staff from providers from other areas including provision of telephone numbers for accessing staff for those self-managing.

Recommendation 21

A plan must be in place specifically for people with disability that ensures continuation of essential health services during a pandemic such as having flu vaccinations at home.

Recommendation 22

Ongoing planning of services for people with disability through co-design to continue to occur on a regular basis in preparation for a second wave of COVID#19.

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Isolation, mental health and wellbeing

There has been increased anxiety among people with disability, and people self-isolating due to COVID#19. This increased anxiety is connected to the risk of contracting the virus, risk of the health system not adequately supporting people with disability, the risk of being forgotten and support not being provided.

The suspension of non-essential services and social outings has led to increased isolation, boredom, confusion and some behavioural issues. It must be acknowledged that social connection is vital to the health and well-being of people with disabilities and there is a need to see a variety of approaches.

Recommendation 23

State and federal government to boost support for mental well-being and counselling both online and via telephone services to support people at high risk of suicide and mental illness throughout the crisis.

Recommendation 24

Support disability service providers to continue to implement innovative ways of engaging with people with disability through their community access funding such as online games, video call catch ups, and individual walks in natural areas/parks where social distance can be maintained.

Recommendation 25

Support the implementation of strategies for keeping up social contact with people living with disabilities who have limited phone and internet access.

Financial Insecurity and Disadvantage for People with Disability

The World Health Organisation stated in their report '[Disability considerations during the COVID-19 outbreak](https://www.who.int/publications-detail/disability-considerations-during-the-covid-19-outbreak)'¹ that Governments should undertake 'targeted measures for people with disability and their support networks' including financial compensation for families and caregivers supporting loved ones. During the COVID#19 experience many vulnerable people reduced their contact with formal support staff relying more on their natural supports. Both the Carers Payment and Disability Support Pension (DSP) were not increased in line with other social support payments (such as JobSeeker). A stimulus package of two payments of \$750.00 was announced, however overall people with disability and their families were placed in greater financial insecurity than people receiving other government support payments.

NDIS participants were not provided any discretionary funds for urgent changes in circumstances caused by COVID#19. Participant plans were funded as to what was

¹ <https://www.who.int/publications-detail/disability-considerations-during-the-covid-19-outbreak>

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considered reasonable and necessary at time of plan issuance, however in critical circumstances (such as COVID#19) there may not be enough funds available for supports, for example a child with disability being supported in the home with school from home.

Many DSP recipients do not have access to the NDIS, so already need to cover the costs of medications, transport and other support services themselves. Prior to the COVID-19 crisis many of these people were already living in poverty and experiencing extreme financial pressures. Additional costs encountered during the COVID-19 crisis such as delivery costs and availability of essential equipment and supplies has exacerbated this situation.

Many DSP recipients have also lost work during this crisis and have found themselves having to skip meals and stop taking medications to reduce expenses. Relying solely on the current DSP payment, can be extremely difficult for many and it is unfair for them to be further financially disadvantaged during this crisis.

Recommendation 26

Ensure that people with disabilities and their carers are not financially disadvantaged by providing additional support payments in a more equitable manner.

Information dissemination to people with disabilities and service providers

Information dissemination during this crisis has at times been disjointed and unclear leading to confusion among people with disabilities and those that support them.

Some NDIS clients received unclear information regarding their NDIS Plan reviews. Some clients say they were not informed that these would be happening over the telephone and were surprised and unprepared for this to occur.

Many clients expressed concern about the impact of the underutilisation of services within their NDIS plans due to COVID#19 restrictions. Some services were cancelled at short notice by service providers, however some were also cancelled by the client to protect themselves from infection. This issue has been raised by a number of NDIS clients who were concerned about the impact on their allocated budgets.

There has been some confusion within the sector over what is considered an essential service. It needs to be acknowledged that this may be different for certain high-risk groups for example social visits, face to face counselling, exercise, social support services and other allied health services. It appears that some NDIS providers were not following the NDIS codes and policies correctly and some may have also gone further than or misinterpreted the official government health orders.

NDIS clients had received letters regarding disruptions and cancellations to some of their services, however many expressed that they found this confusing and distressing. This was especially the case for people with a cognitive or intellectual

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disability. In a number of cases, NDIS clients claimed that there had been no follow-up after the letters had been sent out.

Key messages relating to the need for social distancing have not been helpful for some people with disabilities and have left many feeling 'left behind' and 'forgotten about'. For example, telling a person with significant mobility issues to stay isolated and socially distant is an unhelpful and impractical message.

PWdWA acknowledges that this has been a very difficult time for everyone to navigate and in particular trying to find a balance between a service provider's duty of care and the human rights of people with disability. All decisions however, regarding access to support and health care must be done within a human rights framework to ensure a breach of human rights does not occur.

Recommendation 27

Guarantee from the Federal Government that no NDIS Client will be disadvantaged from the underutilisation of services within their support plans due to COVID#19.

Recommendation 28

Provision of clearer definitions of 'essential services', as they pertain to people living with disabilities.

Recommendation 29

Development of specific and targeted messages and information to people with disabilities that consider their specific circumstances.

Recommendation 30

The NDIA to provide further clarification regarding the cancellation of services at short notice and how would this would financially impact NDIS clients and service providers.

Digital Disadvantage for People with Disability

Many disability providers chose to deliver alternate services via virtual methods, and whilst NDIS recently made it possible for devices to be purchased from existing plan funding to support this, NDIS will not fund internet access/data leaving many with digital disadvantage as a result. It should also be noted that the current NDIS policy on purchasing devices to assist people to access online services, has so many caveats about being the most basic models and that you can only purchase items if you absolutely have nothing else, in reality it has not provided a helpful solution.

Other Australians with a disability not eligible for the NDIS also have no government-supported access to the internet during the COVID#19 crisis.

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Consistent with the Royal Commissions Issues Paper, *Emergency Planning and Response* [15 April 2020]², without access to internet services people with disability could not have access to remote therapies, education providers, social network or supports. This reduced social/community connection is placing people with disability at significant disadvantage of further isolation, health and psychosocial co-morbidities and increased exposure to violence, abuse and neglect.

Recommendation 31

Greater flexibility in the use of NDIS Plan funding, to reduce digital disadvantage and facilitate access to online services, supports and resources.

Advocacy services for those at high risk

We were pleased to see announcements from Minister Stuart Roberts of NDIS to provide for outreach to high-risk participants, continuity of service support, flexibility in planning, and financial assistance to maintain a workforce.

We are however advocating for all people with disability and are concerned that those without NDIS packages may experience a higher risk of disadvantage during this crisis.

We are also aware of the risk of people who are experiencing mental health problems, at risk of suicide, homeless, losing work, financially distressed, and at increased risk of family and domestic violence.

Recommendation 32

Support and resources from government to all disability advocacy agencies so they can adequately provide services for those most in need during this crisis.

² <https://disability.royalcommission.gov.au/publications/emergency-planning-and-response>

Section 3 – Case Studies

The case studies below are real-life examples from clients in WA. The names have been changed to protect their identity.

Diane

Diane is a woman with an intellectual disability living on her own and has an NDIS Plan. The COVID#19 Helpline advised support workers not to enter Diane's home until Diane tested negative for COVID#19. Diane's service provider also stated that they had reached out to the national PPE stockpile, but has yet to receive any PPE and as a result, was unable to send staff into homes where there is a risk of contracting COVID#19.

According to the NDIA, service providers are required to continue delivering supports to clients as a condition of their NDIS registration. The advice from the COVID#19 Helpline also led to staff/support workers refusing to enter client's homes due to the risk of COVID#19.

The different messages being given to clients and disability service providers from different sources had directly led to a woman with a disability being left alone without any support services.

Peter

Peter called and wanted to know if there would be any changes to his NDIS plan budget if he was unable to use services due to the COVID#19 restrictions. Peter chose not to allow support services into his home as he has lung problems and is afraid of contracting the virus. Peter stated he called his LAC to seek clarification, however his LAC could not provide him with any information regarding this.

Peter also stated his Woolworths account has not been working for home deliveries and he was unable to get through on the Woolworths customer service line due to increased caller volume.

Peter also stated he feels "left behind" by the government during this time, as his DSP payments have not increased during this crisis, while the Job Seeker payment has doubled.

Conclusion

PWdWA will continue to work with our national and state peak bodies, to raise concerns and work with government and business to ensure the needs of people with disability is in all planning and responses to COVID#19.

PWdWA will continue to provide services via telephone, email, Zoom, Skype, Facetime or in any other way that works for people needing an advocate. PWdWA will also endeavour to keep members and the disability community as updated as possible through our member mail outs and Facebook page.

It has been great to see how the disability sector and a broader community, has collaborated to get things up and running so quickly during this crisis. PWdWA would like to take this opportunity to stress the importance of co-design of any strategies and policies impacting people with disabilities.

Further information about any of the issues or recommendations contained within this submission can be provided along with further advice or support in how these may be implemented.