

Lessons for Disaster Preparedness:

Report on the impact of COVID-19 disaster management for people with disability and the advocacy sector, with preliminary advice for future disaster management.

March 2021

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Produced by the Disability Advocacy Network Australia (DANA) with funding support from the Australian Government (Department of Social Services).

Report produced on the lands of the Boon Wurrung, Wurundjeri and Ngunnawal people. We pay our respects to Elders past, present and emerging.

ABOUT DANA

Disability Advocacy Network Australia (DANA) is the national representative body for a network of advocacy organisations throughout Australia.

Our members are independent Australian community-based organisations that advocate for and with people with disability. We are governed by a Board of Directors, who are employees and office holders of member organisations. We maintain strong links with the Australian state and territory advocacy networks and with the peak organisations for people with disabilities.

DANA supports and strengthens independent disability advocacy organisations in their work of advocating for and with people with disability so that they are valued and included members of the community, their fundamental needs are met, and their human rights respected.

Some of the guiding principles for DANA's work, especially during the period of COVID 19, are that people with disability are able to:

1. Exercise **choice** and **decision making**;
2. **Participate** in decisions that affect them;
3. Maintain **relationships** with family and friends.

More information about DANA can be found on our website:

<https://www.dana.org.au/>

DANA's Key Recommendations for Future Disaster Planning

The World Health Organisation has noted that *Covid-19 presents a unique opportunity to design and implement disability-inclusive responses and recovery, and to build more inclusive and accessible societies, in consultation with persons with disabilities.*¹

Covid-19 has also highlighted the essential requirement to ensure that the needs of people with disability are central to disaster preparedness.

This requires that all government agencies and government funded service providers must recognise and act on the fact that people with disability have distinct and particular needs that require additional support and that must be considered in all government disaster preparedness plans and responses.

DANA calls on Federal, State and Territory governments to work collaboratively with each other, and in partnership with disability advocacy agencies, including DANA, to ensure disaster preparedness needs of people with disability are identified and addressed in timely, effective, co-ordinated and consistent ways.

DANA also calls on all Australian governments to ensure the voice of people with disability along with the advocacy organisations who support them are central to any disaster preparedness planning processes.

DANA notes that there is significant economic evidence, including from the Productivity Commission, that highlights the range of economic benefits to government and others of working with advocacy agencies to support the provision of targeted policies, planning and services. DANA sees that these benefits would be amplified in the development of disaster preparedness plans and responses.

DANA advises the following priorities for future disaster preparedness planning:

Priority One: Accessible Government Communication

Priority Two: Consistent Access to Disability Services

Priority Three: Monitoring of Supported Accommodation

Priority Four: Consistently Applied Income Support

Priority Five: Improved Support for Advocacy

Priority Six: Greater Access to Technology

Priority Seven: Maintaining Community Connections

Lastly DANA calls on the Federal government to guarantee funding for any gaps that emerge in securing the safety of people with disability and the disability support workforce, including disability advocates, during any future disasters or emergency situations.

¹ <https://www.un.org/en/coronavirus/we-have-unique-opportunity-design-and-implement-more-inclusive-and-accessible-societies>

EXECUTIVE SUMMARY

In November 2020 the Disability Advocacy Network Australia (DANA) conducted a survey of disability advocacy organisations across the country. This report provides an analysis of the findings.

Survey Response

Thirty organisations responded to the survey, which is 39% of the DANA membership. Of those who responded, 90% completed the 29-question survey. It is not surprising that most responses were from Victoria and NSW as these were also the states most affected by disaster in 2019 and 2020:

- eleven respondents based in Victoria (just over one third);
- eight respondents based in NSW (just under one third); and
- followed by almost equal responses from Queensland, Western Australia and South Australia (altogether, one third).

There was significant overlap in service areas across metropolitan, regional, rural and remote areas. Most organisations serviced metropolitan cities (populations of over 100,000), although there was a significant proportion that service remote areas as well, at a third of respondents. This demonstrates the reach of advocacy organisations, even while under-resourced.

Isolation and Disconnection

People with disability are already comparatively isolated, and this was severely exacerbated for many in 2020. This was particularly felt in Victoria with its extended periods of lockdown, for those living in supported accommodation, and for those for whom technology does not assist with communication.

Even outside of periods of disaster management, restricted or blocked access to services and support can severely impact the physical and mental health of people with disability and lead to social exclusion and increased risk of human rights abuses. Lack of access during disasters is life-threatening (as also documented by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (Royal Commission 2020b and 2020c)).

The following comments are indicative of the levels of isolation experienced by some people with disability:

Groups closed down, people with intellectual disability in group homes locked down for months, not able to go out; psychosocial disability – lockdown exacerbated isolation and mental health issues.

Some clients... experienced more severe restrictions, for a longer period of time than aged care facility residents.

Urgent Issues for People with Disability

Nearly two thirds (61.5%) of comments in the survey detailed access issues for people with disability. The most often mentioned access issues were the following, starting with most mentioned:

1. difficulty accessing advocacy services (due to waitlists for example);
2. lack of access to support services;
3. lack of access to technology;
4. difficulty accessing the NDIS or changes to plans;
5. inaccessible government communication; and
6. difficulty accessing basics such as food.

This finding is matched by the most common additional issues requiring advocacy because of COVID-19 and associated lockdown measures. They were, in order:

1. ensuring continuation of support services;
2. interpreting and helping implement government guidelines and laws;
3. ensuring increased support services;
4. supporting people through isolation and living alone;
5. ensuring safe housing; and
6. adjustments to NDIS plans.

In Victoria, the number of advocates assisting with adjustments to NDIS plans was significantly higher than for other states.

Intensified Marginalisation

Where multiple forms of marginalisation already exist, the impact of COVID-19 has been especially significant. Well over one third of respondents specifically noted additional difficulties for women, for culturally and linguistically diverse (CALD) people, for Aboriginal and Torres Strait Islander People, for the elderly, and for those

with intellectual disability and with psychosocial disability. The following comment is indicative of the complex intersection of forms of marginalisation for people with disability.

Many of the issues people with disability faced were not the result of any one thing that could be ‘fixed’ in isolation, but an exacerbation of pre-existing issues, by emergency response programs that presumed a baseline that was mismatched with the lived experience of our clients.

The Critical Role of Advocacy

The critical role of advocacy for keeping people connected to support and services, for accessing new or expanded support and services and for assisting with understanding and following government health advice was demonstrated throughout the survey.

For disability advocacy organisations, workloads and resource demand have increased considerably in six months. COVID-19 has increased the complexity of cases requiring advocacy and exposed already underlying structural issues in the disability sector in general. The report also highlights the significantly unmet demand for advocacy services. Ninety percent of respondents in Victoria described unmet demand as significant.

Respondents described the following measures as required to assist advocacy organisations in meeting both current and future demand, especially during disaster management:

First Priority: Increased Funding and Resources

Second Priority: Greater Support for Use of Technology

Third Priority: Right of Access into Supported Accommodation.

Fourth Priority: Specific Funding for Particular Cohorts.

Fifth Priority: More Funding for the NDIS and Support Services.

Priorities for Future Disaster Planning

Of the 194 comments received in the survey, 182 contained a recommendation component. This was partly due to the survey design and partly due to the nature of

advocacy work: to find longer term solutions to systemic issues. There was also an 80% response rate to the questions asking for recommendations. This is very high.

The comments indicate a wealth of knowledge held within advocacy organisations. They advise the following priorities for future disaster planning:

Priority One: Accessible Government Communication

Priority Two: Consistent Access to Disability Services

Priority Three: Monitoring of Supported Accommodation

Priority Four: Consistently Applied Income Support

Priority Five: Improved Support for Advocacy

Priority Six: Greater Access to Technology

Priority Seven: Maintaining Community Connections

These are detailed in the final section of this report.

Inclusive Disaster Planning

The final recommendation of this report is that further consultation with disability advocates and people with disability occurs. There is a need to deepen the understanding of people's experiences of 2020 so that future disaster management can be more inclusive and therefore better planned.

That governments/government departments in each jurisdiction should have consulted advocates in each jurisdiction – not just through 'disability departments'.

Having people with lived experience involved in the preparation and planning for disasters (is essential).

Structure of this Report

What follows is a discussion of the findings from this survey. It is broken up into four broad areas: the risks associated with social isolation and disconnection; the impacts on people with disability; the critical and under resourced role of advocacy; and advice for future disaster planning and management.

ACKNOWLEDGEMENTS

Acknowledgement of Country

DANA acknowledges the traditional custodians of the land upon which this report was developed and written. We acknowledge the Ngunnawal people where DANA's head office is based, and the Wurundjeri and Boon Wurrung people of the Kulin Nation where the report was written.

We pay our respects to ancestors and Elders, past, present and emerging. DANA is committed to honouring the rich cultural and knowledge-creating traditions of Aboriginal and Torres Strait Islander People. We also acknowledge their more than 60,000 years of connection to this land.

Acknowledgement of Contributions

DANA and the authors of this report would like to acknowledge advocates across the sector in their contribution to the design of the survey and the completion of this report. We are immensely grateful for their support piloting the survey, completing the survey and through their regular formal and informal reports to DANA on urgent issues for people with disability.

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INTRODUCTION AND CONTEXT

In 2020, as a devastating bushfire season was coming to a close, the country faced a new health emergency: the fast spread of a new coronavirus, now known as COVID-19.

Public Health Response

Over the weeks of March and April, many public health measures were introduced across the country. Some of these measures included: expansion of hospital capacities; telehealth arrangements; work from home arrangements; wider lockdown measures; sourcing and distribution of personal protective equipment (PPE) to priority healthcare workers; a rise in income for those on JobSeeker, and the JobKeeper payments for those working for organisations unable to continue operations.

People with Disability Left Behind

It was quickly evident though that people with disability were being neglected in public health measures. In some areas this was so significant as to put lives at risk.

These gaps were documented very clearly by both the call for immediate actions from over 70 organisations in the *Open Letter to National Cabinet* (March 2020), and the 26th March *Statement of Concern* by the *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (the Royal Commission).

Not long after these statements, the 15th April *Emergency Planning and Response Issues Paper* from the Royal Commission (2020), reported the ‘lack of specific and targeted measures from Australian Government to proactively protect and support people with disability’ in the responses to this pandemic. Following this, advocates reported that *some* improvements were made to:

- ability to amend NDIS plans;
- ability to access technology to connect with community and into telehealth;
- and
- reconnection of disrupted or lost support services.

The Federal Health Department took some steps to improve the situation for people with disability through setting up a Disability and Health roundtable to hear from Disability Representative Organisations and other stakeholders and resolve the

issues for people with disability. The Department of Social Services and Department of Health have been working closely together since then.

It is clear from later reports however, that these measures were not sufficient, not sufficiently resourced, and were not available to all people with disability.

Early Reports

It is in this context that DANA (2020) first conducted a survey of advocacy organisations in April to ‘gain a quick understanding of the shifting demands for advocacy services during the COVID-19 shutdown period’. The initial report found that:

1. Demand for advocacy services had increased significantly and in a short period of time.
2. Overall, capacity had not increased. In fact, for some, capacity had decreased.
3. Demand was particularly increasing in the following areas:
 - a. accessing existing support services in new ways;
 - b. accessing new support services;
 - c. specific advice around the law and shutdowns;
 - d. responding to isolation of people with disability from informal and unfunded support (family, friends, community); and
 - e. time and resources required to provide suitable advocacy services that were not face-to-face.

Later Reports and Royal Commission Hearing 5

Towards the end of July Victoria went into a second and extended lockdown. On 18-21 August, with continuing reports of people with disability being neglected in public health messaging and disaster management, the Royal Commission also held a public hearing (Hearing 5) into ‘experiences of people with disability during the ongoing COVID-19 pandemic’.

On Friday 21st August 2020 Simon Cotterell, Assistant Secretary from the Department of Health, told the Disability Royal Commission that people with disabilities were left out of the Government's COVID-19 emergency response plan and acknowledged that there was no single area in the health department that had responsibility for the health of people with disabilities. (Royal Commission (2020c)). Australia's Deputy Chief Medical Officer, Nick Coatsworth, also told the Royal Commission into Disability

that developing an aged-care response to the COVID-19 pandemic was a higher priority than making a plan for people with disabilities (2020c).

In August, Every Australian Counts (2020) also released their report: *“Left out and locked down”: The experiences of people with disability and their families during COVID19*. Responses to the survey fell into three main categories:

1. “We’ve been forgotten”
2. “We need more help”
3. “We need things to be easier”

Second DANA Survey

It is in this context that DANA conducted a second survey of advocacy organisations across the country. The aims of the second survey were to understand:

1. the lessons to be gained from the experiences of people with disability and their advocates in managing COVID 19 risks, lockdown measures and the 2019-20 bushfire season;
2. how these might shape measures that would better serve and support people with disability during future crises or disasters; and
3. the particular needs for different groups of people with disability, for example, different geographic locations, different impairments, different socio-economic conditions, different health conditions.

The results of this survey follow in this February 2021 report, which is an assessment of disaster preparedness and management in 2020, alongside some recommendations for future planning.

SURVEY DESIGN AND PARTICIPATION

Survey Design

The survey design was overseen by Dr Polly Bennett in consultation with Sara Franzoni and Mary Mallett of DANA. Questions were a mixture of multiple choice, ranking and short answer questions. There was a total of 29 questions and the survey took around 25 minutes to complete. The survey response rate was about 36%, which is high considering the workload in the sector in November 2020.

A copy of the survey questions can be found in the Appendix.

The survey follows on from the previous survey conducted by DANA in 2020, *COVID-19 Advocacy Demand Snapshot*. The focus this time was on better understanding:

- the rise in the need for advocacy, particularly during a crisis;
- where demand for advocacy is beyond current resources; and
- the ways that disaster responses could be better planned and managed for people with disability.

The researcher, Polly Bennett, is also a person with disability who was in a high-risk category for both COVID-19 complications and bushfire air pollution, and lived alone throughout the lockdown period in Melbourne, separated from family. The insights gained from this experience also helped shape the survey design and analysis.

Why Survey Advocates?

Disability advocates and advocacy organisations are in a unique position to provide insight into disaster management. Advocates often provide the connection between people with disability and access to services, while also being the first point of call when there are barriers to accessing services, when there are urgent health risks and when human rights violations occur. Advocates also have a good understanding of the complex and intersecting forms of discrimination and marginalisation faced by people with disability. This was evident in the detailed comments provided in this survey.

We believe this means the advocates have a critical and unique role to play in disaster management and planning, alongside peak disability and representative organisations.

Survey Distribution

The survey was sent to advocacy, information service and disability representative organisations. Thirty organisations responded to the survey and 90% of respondents completed the survey in full. A total of 194 comments was provided in response to 11 questions inviting comments.

The organisations varied significantly in size. The average (mean) number of paid staff for an organisation was 22, although this varied from two staff to 100. Similarly, the mean number of advocates for an organisation was 13, however this varied from one to 100. This shows the diversity of advocacy organisations, especially when also considering the range of advocacy models (legal, self and citizen advocacy for example) and the groups of people specifically represented by some advocacy organisations (First Nations people, people with intellectual disability, Culturally and Linguistically Diverse people, women).

Data Analysis

As the survey sample size is small, the quantitative data analysis is primarily descriptive. Some comparisons were made of responses from disaster affected areas against other areas – whether bushfire affected or under extended lockdown in Victoria. Some differences were found and they have been noted within the report.

There were three rounds of comment analysis, using NVivo software. Thematic analysis was conducted by the researcher and the DANA project officer. Themes were cross-checked and agreed. Higher level analysis was then conducted by comparing intersecting themes in the comments. As the comments were mostly open-ended, there was considerable overlap across themes in each comment.

Altogether there were 194 comments across 11 questions, with the majority containing a recommendation component. This was partly due to the deliberate design of the survey, focussed on disaster preparedness.

In total 172 comments contained a recommendation component (that is, nearly all comments). Across the survey 86 comments related to advocacy specifically, or just under half of the comments. Some of the total counts for themes are not surprising considering the focus of the survey.

Language and Format of Report

In the write-up of the report some comments were corrected for grammar or where necessary for clarity and consistent use of terms. For example, acronyms have been extended and shorthand for some terms was formalised and made consistent.

Mostly, this report uses person-first language. We do acknowledge this is not how all people with disability describe themselves.

Survey comments in this report are written up:

in bold, blue print and are indented.

WHO RESPONDED

Organisation Type

The vast majority of respondents – 90% – were advocacy organisations, and just under one third were also a Disabled People’s Organisation (DPO).

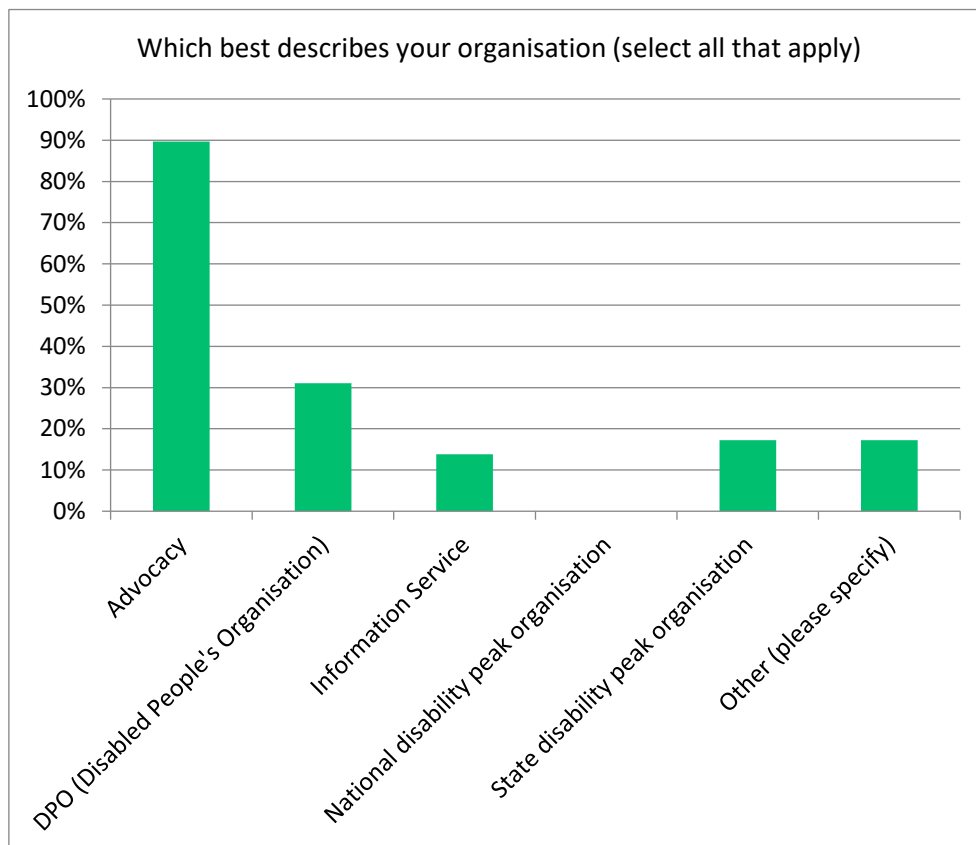


Figure 1: Respondent Organisation Type

State, City, Region

Most respondent organisations were based in NSW or Victoria:

- eleven respondents based in Victoria (just over one third);
- eight respondents based in NSW (just under one third); and
- followed by almost equal responses from Queensland, Western Australia and South Australia (altogether, one third).

It is not surprising that most responses were from Victoria and NSW as these were also the states most affected by disaster in 2019 and 2020. Respondents from

Victoria and NSW also tended to provide more comments and more detail in comments.

There was significant overlap in service areas across metropolitan, regional, rural and remote areas. The majority of organisations serviced metropolitan cities (populations of over 100,000), although there was a significant proportion who service remote areas as well, at a third of respondents. A high proportion of organisations also provide advocacy to people with disability living in remote locations. This demonstrates the reach of advocacy organisations, even while under-resourced.

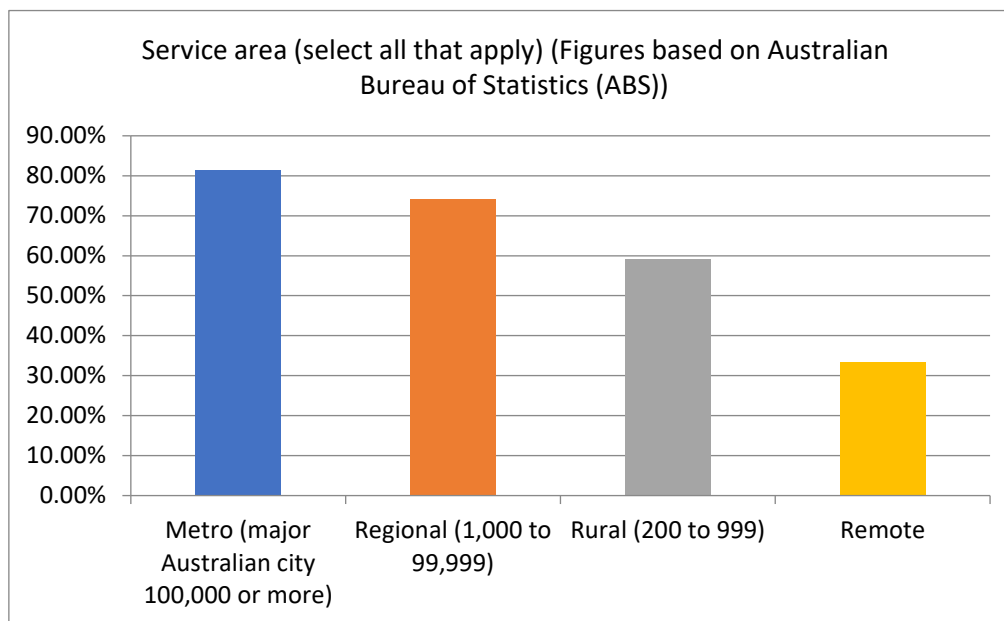


Figure 2: City or regional service area

Under COVID-19 Restrictions

Just over one third of respondents were under either Melbourne or regional Victorian COVID-19 restrictions in the six months prior to the survey. Some of these restrictions covered both Melbourne and regional Victoria.

For these organisations, almost all of the questions about workload increases and changes to work practices showed much higher results. This was expected and is discussed in more detail further in the report. As one organisation wrote:

We have assisted 1,000 families in Vic during past six months of restrictions.²

² All survey comments are written up in this report in bold and blue print, and indented.

Bushfire Affected Areas

Of the organisations who responded, one in four had provided advocacy for people in bushfire affected areas in the previous six months. Most of these were based in NSW.

The priority issues for people with disability in bushfire affected areas covered lack of access to basic life essentials: housing, food, clothing, income and finance. Mental health issues were also a significant factor for those in bushfire affected areas. This was also noted in reports developed by Peter Gartlan for Financial Counselling Australia (2020).

These results are consistent with other sections of this report, which indicate that during disasters and emergencies, access to essential supports for survival for people with disability – food, medicine, housing, essential support services – is often, very quickly restricted. This also emphasises the essential role of disability advocates for quickly responding to these actually or potentially life-threatening situations which include reduced access to essentials.

Only one respondent had supported people both in a fire-affected area and had been under Victorian lockdown measures.

DISCONNECTION IS DANGEROUS

A Recurring Theme: Isolation and Disconnection

One theme deserves special mention. The intensification of social isolation and in some cases active disconnection (from services, from community and from family and friends) had an impact on almost all areas of disaster management in 2020, especially for those with disability.

Of the 194 comments made in the survey of advocacy organisations, 116 noted a variety of access issues. Thirty-one comments specifically referred to issues of social isolation.

It is concerning that so many comments detailed access issues for people with disability. Even outside of periods of disaster management, restricted or blocked access to services and support can severely impact the physical and mental health of people with disability and lead to social exclusion. Lack of access during disasters is life-threatening (as also documented by Centre of Research Excellence in Disability and Health (2020), Kaleveld et al (2020) and the Royal Commission (2020b and 2020c)).

The most often mentioned issues of access in the comments were the following, starting with the most mentioned:

1. difficulty accessing advocacy services (due to waitlists for example);
2. lack of access to support services;
3. lack of access to technology;
4. difficulty accessing the NDIS or changes to plans;
5. inaccessible government communication; and
6. difficulty accessing basics such as food.

As is discussed in more detail under *Urgent Issues and Risks*, the impact of closures and COVID-19 restrictions on people with intellectual disability and those in supported accommodation was particularly felt. The mental health impacts of long-term social isolation were also felt by advocates themselves.

Some of this disconnection was the result of inaccessible public health responses, such as inaccessible government communication. Other forms of disconnection were the active result of excessive responses to public health measures, such as excessively restrictive practices in some supported accommodation.

As described in the survey comments, social isolation contributes to a host of other risks, especially during disasters, including:

- extension of disconnection from services;
- lack of monitoring of accommodation restrictions and human rights violations;
- exacerbation of mental health issues;
- reduced community engagement in general and increased invisibility; and
- slower lines of government communication as informal networks of translation are lost.

It is the view of many advocacy organisations that while the health risks of a pandemic must be managed, this must not also come at the expense of other health risks, or human rights, for people with disability. This view is supported by the Royal Commission and by the guidelines provided by *Disability Inclusive Disaster Risk Reduction Project* (Villeneuve et al 2019).

Advocates Speak on Isolation

Here is a small sample of the comments referring to isolation, disconnection and the impact of excessive restrictions in some accommodation.

Groups closed down, people with intellectual disability in group homes locked down for months, not able to go out; psychosocial disability – lockdown exacerbated isolation and mental health issues.

Victoria has achieved elimination, yet (people in group homes) they are still not allowed to attend groups. It is a human rights abuse!

With many of the NDIS providers not undertaking group events this is causing serious isolation and linkage issues.

Some clients were in complete lockdown as initiated by service providers. This included clients who are unable to communicate by phone. They experienced more severe restrictions, for a longer period of time than aged care facility residents.

On the need to maintain connections, especially during a disaster, one advocacy organisation based in a bushfire affected area talked about the compounding impacts of disaster and then isolation on people's mental health:

(We) have seen some clients undertake activities and behaviours that are putting them at great risk (some of these behaviours did not occur prior to COVID-19).

Alternatives: Community and Connection

Comments did provide suggestions for how to better connect people with disability with community and support during a disaster.

Provide appropriate linkage for people living alone to ensure their welfare and wellbeing were optimised. Planning options for if they needed to attend hospital, self-isolate or quarantine.

Communication Partners available for people with complex communication needs.

Greater contact for those socially and physically isolated e.g. friendly call once a day. Some clients received little or no outside contact.

Critical Role of Advocacy

In a survey of advocates, it is possibly not surprising that access to advocacy was a key issue raised. However this does highlight the critical role of well-resourced advocacy in connecting people with disability.

People within supported accommodation have found it difficult to access advocacy as they have been in lockdown and some are not aware of their rights or how to contact an advocate. Staff in supported accommodation don't assist people to contact advocacy.

This is discussed in further detail under '*Advocacy: Critical and Under-Resourced*'.

This report confirms findings and recommendations from other reports that maintaining access to essential services during disasters and emergencies continues to be a problem faced by people with disability. Further, that where services are

disrupted, advocacy is often required to rectify this. As the Royal Commission (2020, para 133) also stated:

Witnesses from disability representative organisations who gave evidence at Public hearing 5 stressed that independent advocacy organisations are indispensable in safeguarding the rights and interests of people with disability, especially during emergencies such as the COVID-19 pandemic.

INTENSIFIED MARGINALISATION

COVID-19 times (have) clearly identified and further heightened the barriers people with disabilities encounter, and we are in constant communication with many in the community who are impacted.

Those Most Impacted

Organisations were asked who within the disability sector was most affected by the pandemic. While some comments indicated that the impact was across-the-board, the multiple-choice responses indicated that two clear groups were most affected: those with psychosocial disability, and those with intellectual disability.

The questions were broken into two, asking separately:

- Of the clients you work with, are there particular people with disability who have been more affected by COVID-19 restrictions? Select up to 3 that apply.
- Of the clients you work with, are there particular people with disability more affected by the pandemic? Select the top 3, with 1 being most affected.

These categories obviously intersect as well, as is also demonstrated in the comments.

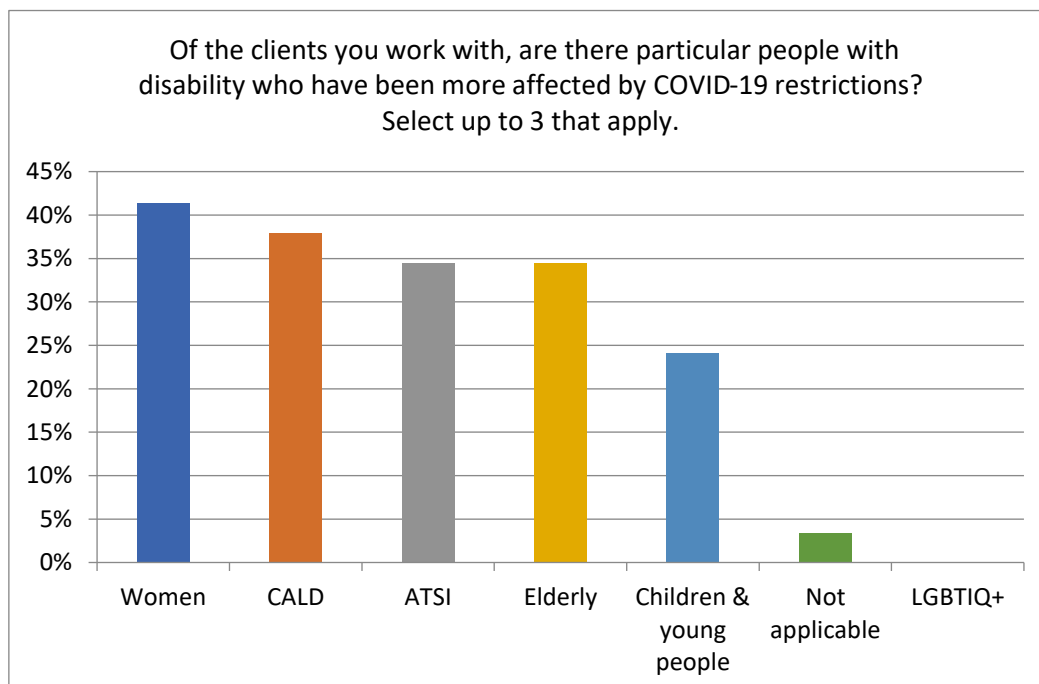


Figure 2: Socio-Cultural Group Most Impacted by COVID-19 Restrictions

The following comments give an indication of the complex intersections between different forms of marginalisation:

Women with disability also bore the carer burden e.g. home schooling, caring for other household members with disability when service providers withdrew carers from service due to OH&S concerns; children couldn't go to school or respite.

Aboriginal and Torres Strait Islander Elders couldn't attend normal groups affecting mental health.

The impact of COVID-19 and lockdown measures on women with disability has been reported elsewhere as well (for example, by Gender Equity Victoria (2020); Women with Disabilities Australia (2020); and Women with Disabilities ACT (2020)). Comments in this survey also indicated that government public health information was particularly inaccessible for people with disability for whom English was not their first language.

The next question asked about the impact on different cohorts of people with disability. Around two thirds of respondents felt that those with psychosocial disability were amongst those most affected and over half felt they were the **most** affected. This result is echoed in many other reports on periods of disaster and recovery, with mental health issues known to result. However, during the pandemic very many people with disability were under even heavier restrictions, which exacerbated isolation from friends, family, support services and advocacy.

People with intellectual disability were considered the second most affected group of people with disability. Around three quarters of respondents felt they were *amongst* the most affected and nearly a third thought they were the most affected.

It is important to note here that very many people will be covered by multiple categories of disability as well. There are not clearly separated cohorts.

Of the clients you work with, are there particular people with disability more affected by the pandemic? Select the top 3, with 1 being most affected.

[Categories based on Survey of Disability, Ageing and Carers]

Group	Total Count ³	Ranking Score
Psychosocial disability	18	5.39
Intellectual disability	22	4.73
Physical disability	17	4.35
Communication and speech	10	4.2

Figure 3: Clients Most Affected by COVID-19 Measures

The following comments provide further insight.

Groups closed down, people with intellectual disability in group homes were locked down for months, not able to go out. Psychosocial disability – lockdown exacerbated isolation and mental health issues. Mask wearing interfered with communication and people were further ostracised or victimised for not wearing a mask.

Many clients lacked access to technologies proposed as solution to lockdown. Some clients were in complete lockdown as initiated by service providers. This included clients who are unable to communicate by phone. They experienced more severe restrictions, for a longer period of time than aged care facility residents.

Systemic Marginalisation Exacerbated

Where multiple forms of marginalisation already exist, the impact of COVID-19 has been especially significant. Well over one third of respondents specifically noted additional difficulties for women, for culturally and linguistically diverse (CALD)

³ Total count is the total number of respondents who selected this cohort as amongst their 3 most affected. The ranking score is calculated by Survey Monkey on the basis of count plus ranking (most affected, 2nd most, 3rd most).

people, for Aboriginal and Torres Strait Islander People, for the elderly and for those with intellectual disability and with psycho-social disability.

Many of the issues people with disability faced were not the result of any one thing that could be 'fixed' in isolation, but an exacerbation of pre-existing issues, by emergency response programs that presumed a baseline that was mismatched with the lived experience of our clients. Many clients had funding for (emergencies) in their NDIS plans, but the supports they needed ceased to be available either due to program closure or staffing shortages.

URGENT ISSUES AND RISKS

The most common additional issues requiring advocacy as a result of COVID-19 and lockdown measures were, in order:

1. ensuring continuation of support services;
2. interpreting and helping implement government guidelines and laws;
3. ensuring increased support services;
4. supporting people through isolation and living alone;
5. ensuring safe housing;
6. adjustments to NDIS plans.

The comments describe a series of complex issues that are interconnected. There were already underlying structural issues which mean that some people with disability are already at risk of housing instability, social isolation and the mental health issues this entails, discontinuity of support services and even violence and abuse. The period of COVID-19 restrictions significantly increased these risks.

Again, the comments provide a detailed picture of the complex cases that required advocacy and resolution:

An Aboriginal and Torres Strait Islander woman with psychosocial disability presented as homeless and needed emergency housing; added difficulties connecting to homeless services due to pandemic.

(There were) increased accounts of abuse, restrictive practice and sometimes family tensions.

Increased demand for NDIS plan reviews.

Reduction in NDIS funding due to all funds not being used due to COVID. Participants penalised due to this with the next plan they get. This has significant flow on effects for the participants.

A lady with disability was evicted from her home (supported accommodation) without notice as she was unable to independently wash her hands and practice social distancing.

Unavailable Essentials

In survey comments the most common issues with access (after difficulty accessing advocacy) were barriers to accessing very basic essentials for survival. This is consistent with other reports from the disability sector.

As noted in multiple reports already (including Royal Commission 2020b; Every Australian Counts 2020; Down Syndrome Australia 2020) and public letters (Open Letter to National Cabinet 2020; Royal Commission 2020a), many essential services were interrupted or even halted, sometimes with no notice. This was especially the case in the March-April 2020 period. These statements detailed the following services and items as difficult to access:

- regular disability support services;
- urgent changes to NDIS plans;
- PPE and other safety measures;
- Government health communication;
- food, especially in some city areas and bushfire-affected regions; and
- medical care.

It is important to note that while improvements were made – partly in response to the public letters and advocacy on behalf of advocacy and disabled people’s organisations – these services are essential to maintain during any emergency. This demonstrates, again, that involving people with disability at the local level, with the support of advocates, is critical to any disaster planning and disaster management (Villeneuve 2020; Villeneuve et al 2019).

According to survey respondents, even in the period June-November 2020, the following (see Figure 4) were in their top 3 most common issues requiring advocacy. Issues are listed in order of ranking, from most common.

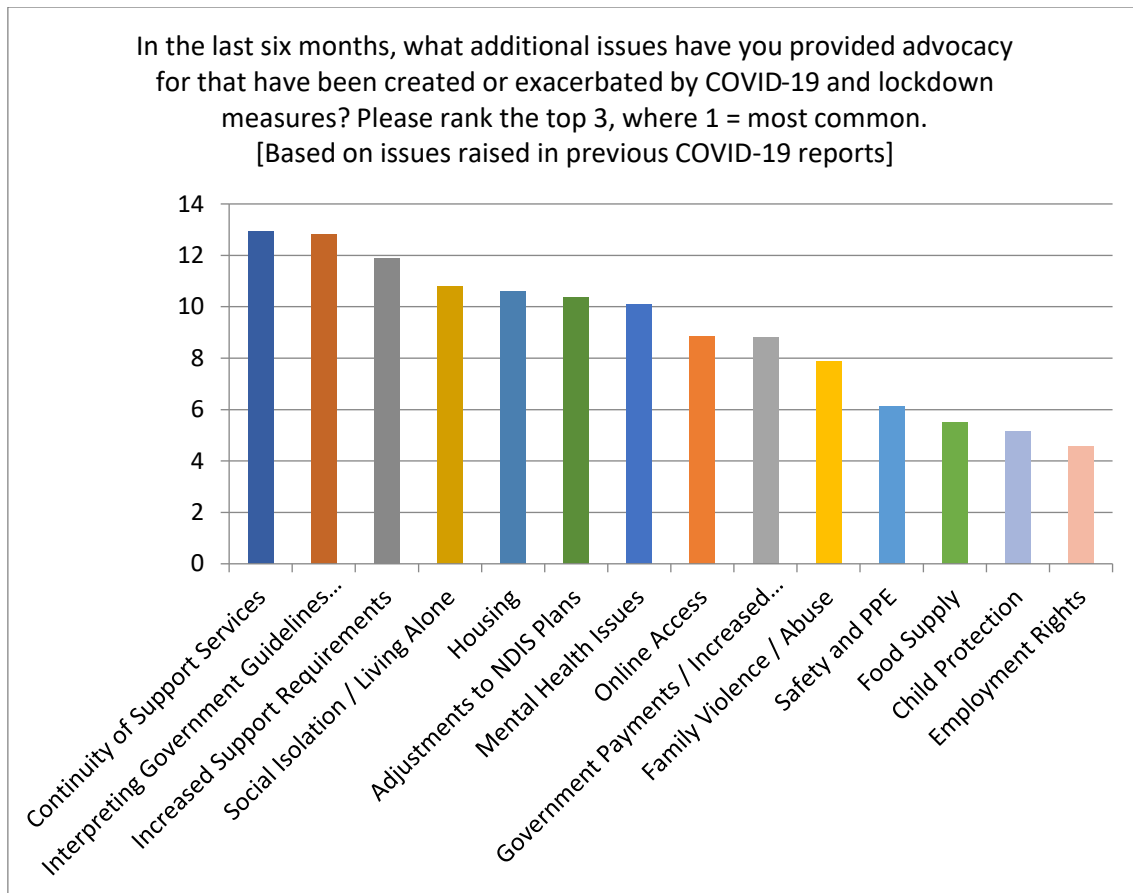


Figure 4: Additional Issues Requiring Advocacy (by ranking)

People with intellectual disability required assistance negotiating the different forms of government income assistance as well, as detailed here:

Clients needing help navigating Centrelink but unable to access online services due to cognitive disabilities. Many would normally go into Centrelink but were afraid of increasing their infection risk as Centrelink offices were extremely busy. We helped many people set up MyGov by coming into our office and using the computer with a projector so that we maintained safe social distancing.

The stimulus package... did not include increases to the Disability Support Pension!

Issues in Victorian Lockdown

While the results were very similar in Victoria to the rest of the country, Victorian respondents ranked the following more highly than elsewhere:

- intervention around family violence and abuse; and
- making changes to NDIS plans.

This is not a surprising finding considering the extended period of restrictions and isolation, requiring both changes to NDIS plans to better suit new working and living conditions, and meaning an increased risk of abuse both at home and within institutions. The latter has been documented in multiple places, including by Women with Disability Australia (2020), Gender Equity Victoria (2020) and the Royal Commission (2020c).

Dealing with extreme cases of trauma with clients. Frustration of not being able to access clients.

Increased accounts of abuse, restrictive practice and sometimes family tensions.

Bushfire Affected Areas

The priority issues for people with disability in bushfire affected areas covered lack of access to basic life essentials and both physical and mental health issues:

- access to housing including homelessness;
- access to essentials such as food or clothing;
- access to government payments;
- access to employment or business income;
- physical health issues (as a result of the bushfires);
- mental health issues (as a result of the bushfires); and
- financial issues such as debt, insurance or banking issues.

Supported Accommodation

As the Royal Commission (2020c, para 119) noted:

In our view, it was unsatisfactory to leave providers of disability accommodation services in the position of having to ‘review’ and adapt

the Residential Care Facilities Guidelines in the urgent circumstances of the COVID-19 pandemic (and potentially in the even more urgent circumstances of a suspected or confirmed COVID-19 local infection or outbreak). More was needed to provide adequate assistance to providers of disability accommodation services, particularly in circumstances where these accommodation settings often do not have the 'facilities' identified in the Residential Care Facilities Guidelines. The lack of more specific information had clear implications for the consistency of infection control and outbreak management within disability accommodation settings.

Advocacy organisations who responded to the survey also provided many detailed examples of the issues faced by residents of supported accommodation. Respondents also described the difficulties of fully understanding the level of restricted practices within accommodation facilities, especially in Victoria (even after the state began to re-open).

One of the key recommendations of this report (detailed under Recommendations and Future Planning) is for greater access of advocates and monitors to supported accommodation settings to assist residents in maintaining some freedom of movement (within prevailing public health guidelines) and maintenance of human rights. The following comments are indicative of the nearly one quarter of comments that made reference to accommodation issues and rights violations.

A lady with disability was evicted from her home (supported accommodation) without notice as she was unable to independently wash her hands and practice social distancing.

Providers that led to unnecessary and unlawful restrictions on people (trying) to access external supports, advocates, and rights to liberty, privacy, and freedom of movement.

People within Specialist Disability Accommodation have found it difficult to access advocacy as they have been in lockdown and some are not aware of their rights or how to contact an advocate. Staff in Supported Disability Accommodation don't assist people to contact advocacy.

Technology: Connection and Disconnection

Survey respondents were asked to ‘provide examples of any positive changes for people with disability’ in the previous six months. Of the 23 comments, nearly all spoke to the increased availability of technology and the greater degree of connection to community, to work-from-home and to services that resulted.

Due to changes in government funding models for both support services and advocacy organisations⁴, many people with disability were able to access much-needed communications technology, which in turn increased connection to community, advocacy, health and support services.

People with intellectual disability, acquired brain injury or complex communication issues who were lucky enough to have access to a self-advocacy group in Victoria, as the Self Advocacy Resource Unit (SARU) were able to provide them with devices to connect them to access the outside world.

(This was funded by the Office for Disability in Victoria as part of the Victorian government COVID response)

Some participants in NDIS funded supports reported improved communication and social participation due to enhanced access to technology.

Widespread use of telehealth has been very beneficial, as allows access to practitioners which may have been problematic before, e.g. due to behavioural or transport difficulties. NDIS willingness to be more flexible regarding use of funds has also been welcome.

However, access to technology provided a mixed result as well. Almost as many comments detailed lack of access to technology as an issue, whether because of inflexible funding plans, or because of the particular communications needs of some people with disability. The following provide examples of this.

Many clients lacked access to technologies proposed as solution to lockdown. Some clients were in complete lockdown as initiated by service providers. This included clients who are unable to communicate by phone. They experienced more severe

⁴ In Victoria the government provided additional funding for advocacy organisations for technology.

restrictions, for a longer period of time than aged care facility residents.

For the cohort we work with no positive changes of any significance – people remained isolated, without access to technology, dependent on support services that placed restrictions on what they would and would not do.

A number of respondents also noted decreased access to health services in some cases due to an over-reliance on telehealth, especially for mental health services.

People's stress levels were increased at the beginning of the pandemic. They were frustrated that many services were not providing face-to-face support, which they often need due to difficulties accessing technology. We continued to see people face to face with PPE and social distancing when they needed this support.

As noted here, in some cases advocates became the reliable form of face-to-face support for people with disability.

Next the report discusses how advocacy changed in 2020 and the implications of this for future disaster preparation.

ADVOCACY: CRITICAL AND UNDER-RESOURCED

Not surprisingly, demand for disability advocacy significantly increased in 2020. This is consistent with increased demand in other countries as well (for example, as reported by Voiceability et al (2020)).

Increased Workload and Case Complexity

For over half of all respondents 'time spent on individual advocacy cases' had 'increased a lot' over the previous six months. In Victoria, the workload increase was even more considerable, with time spent on cases having 'increased a lot' for over three-quarters of respondents.

This appears to be largely because of the increased complexity of cases. For about two-thirds of respondents, 'complexity of issues requiring advocacy' had 'increased a lot' over the previous six months.

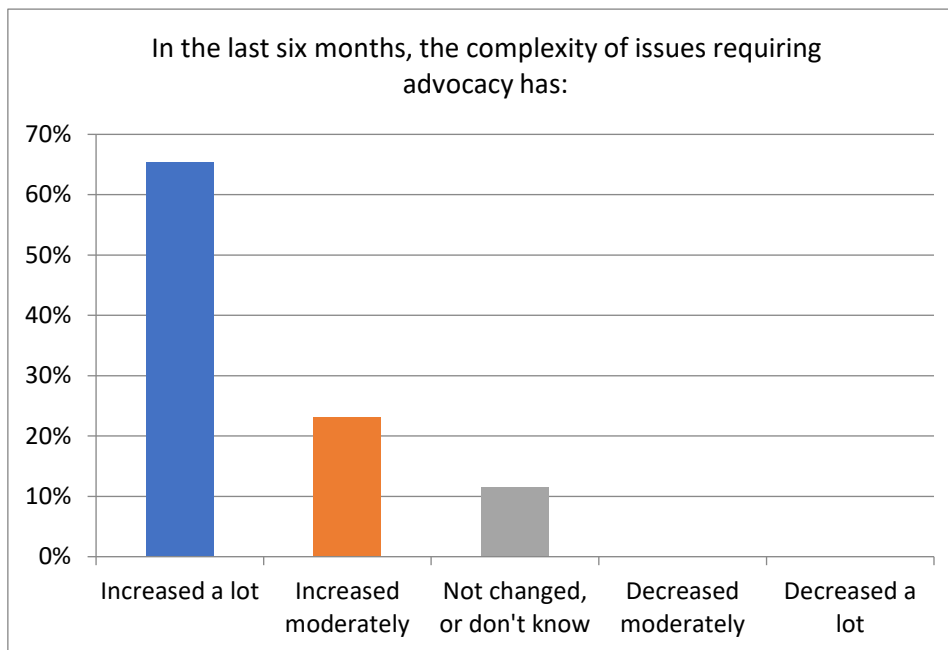


Figure 5: Increase in Complexity of Issues Requiring Advocacy

No organisation said that complexity had decreased.

This change in workload can also be seen in overall work hours and leave accrual. For over half of respondents, there had also been a significant increase here.

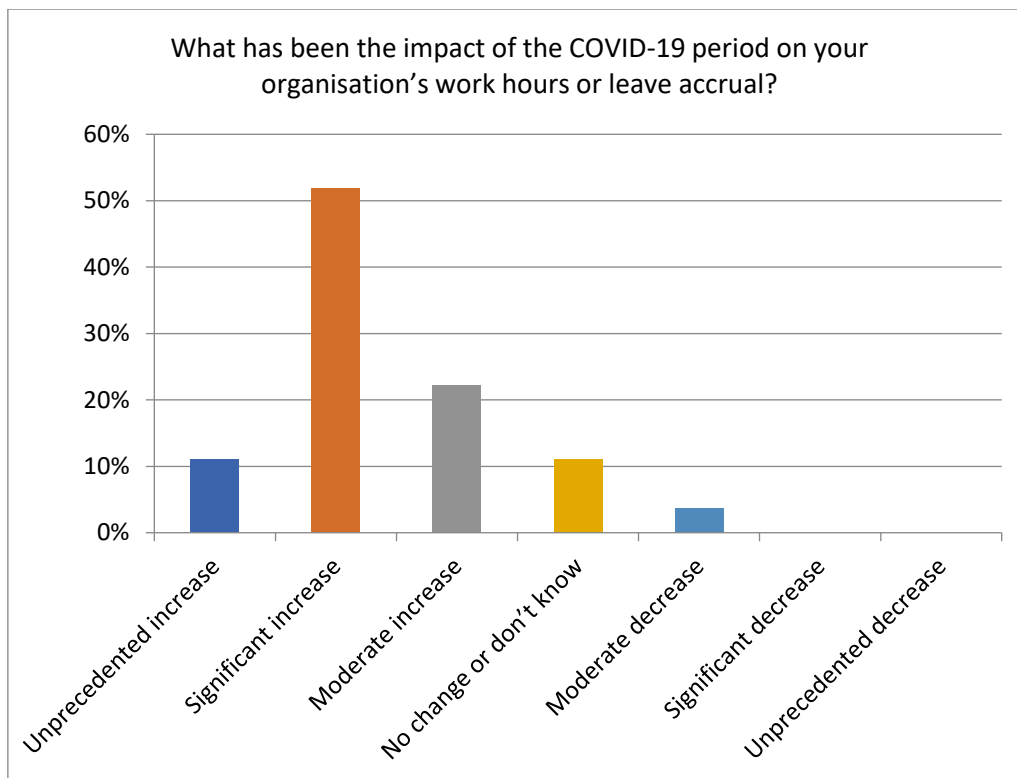


Figure 6: Increase in Work Hours and Leave Accrual

Advocacy organisations described the impact of work changes on workload and complexity of work:

Significant increase in requests for advocacy. We cannot meet the demand. It is 3 times the rate it was a year ago, and the issues are greater and the level of anxiety and stress in those that contact us is greater. It has been frustrating not being able to have meetings within Specialist Disability Accommodation.

Advocacy around the pandemic has significantly driven our work outside responding to calls for submissions. The pandemic has compounded many pre-existing inequities for people with disability and also led to new emerging inequities, such as access to basic essentials and PPE.

More out of business hours work and answering messages from distressed people. People were left vulnerable because advocates do not have right of access and many disability service providers inflicted disproportionately restrictive arrangements (and continue to do so). Pressure on advocates and impact on their well-being due to managing their own reaction/needs during

COVID while responding to people with disability and their advocacy needs

Workload increased as a result of the shift to online, the difficulty in maintaining communication with many clients and the general change to the nature of advocacy work alongside the significantly increased demand.

Changes to Advocacy

While increased workloads are a concern, it is evident in the comments provided that advocacy organisations are more concerned with the changed nature of advocacy during the pandemic. One key concern was the difficulty of maintaining contact with some client cohorts.

The survey asked what the biggest challenges for advocacy organisations during this period were. For 62% of respondents, communication with clients was the biggest challenge. This is significant and is a reminder that, while the use of technology assisted in the running of advocacy and services while under COVID-19 restrictions, this introduced its own difficulties, some of which have led to clients becoming further isolated from much-needed support.

A number of clients are non-verbal and engaging by video is not always satisfactory.

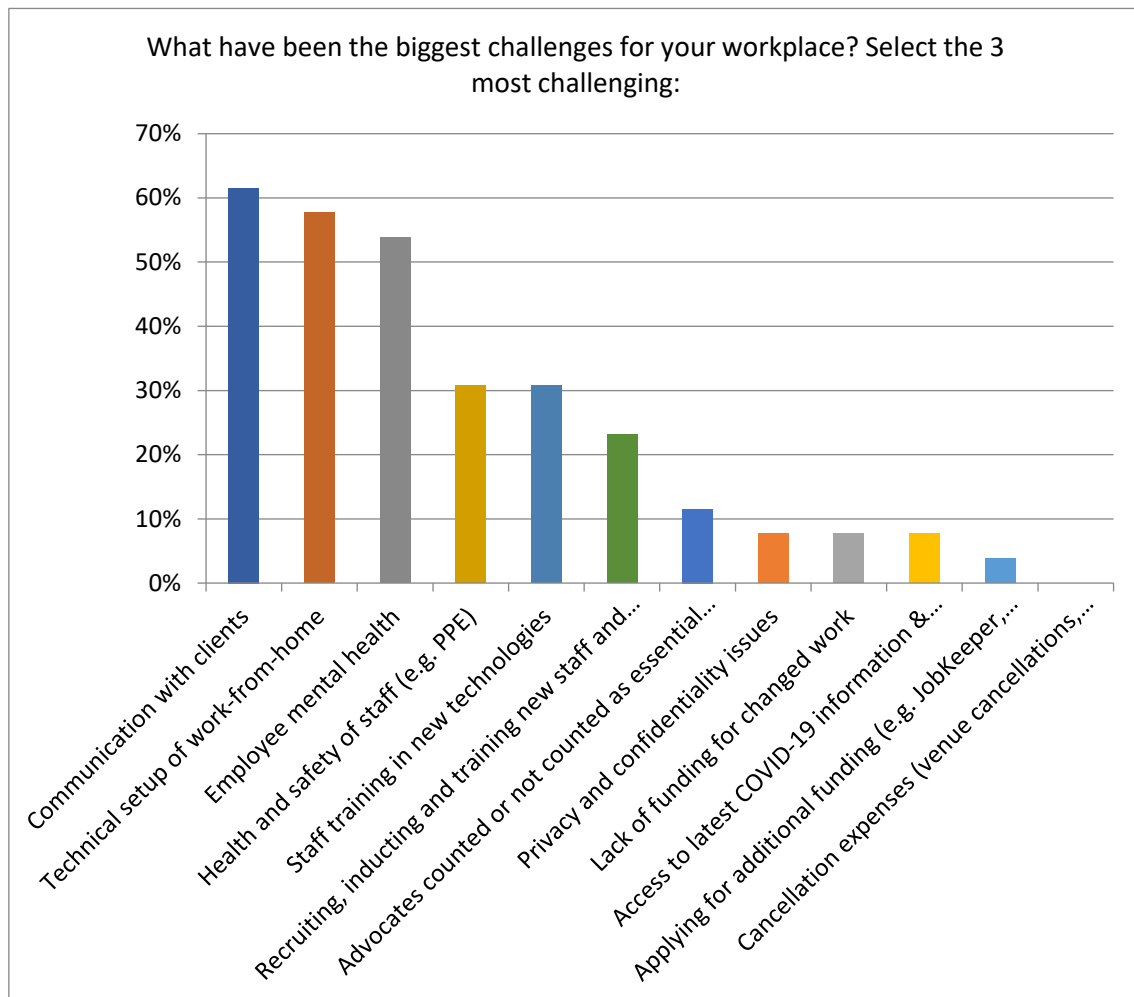
Dealing with extreme cases of trauma with clients. Frustration of not being able to access clients.

Suitability and availability of work from home space (for communicating with clients).

Some organisations were eventually able to adjust and manage safe processes through which advocates could continue to meet some clients face-to-face. This could provide a model for other organisations in the future.

At the height of covid many staff were concerned about balancing the urgent needs of vulnerable clients with health and safety - particularly when it was difficult accessing PPE. Once the supply improved and organisational policies and procedures were implemented staff felt more reassured and confident in our ability to provide a safe face to face service when required.

After communication with clients, respondents described a range of technical difficulties associated with working from home, including home setup and advocate mental health.



For nearly two-thirds of the organisations based in Victoria, employee and volunteer mental health was one of the biggest challenges, a significantly higher rate than for respondents from other states. The comments provide insight into the difficulties of working from home:

The technical set-up to work from home was time consuming and an added expense.

The mental health and wellbeing of staff & volunteers has fluctuated due to the unprecedented restrictions experienced in Melbourne.

Access to COVID funding for enhanced technology for our organisation was greatly appreciated. However, it is insufficient

for the need for addressing organisational cohesion and capacity building. There has been a massive increase (in) demand and huge rapid growth for (us) in only 3 years. It is vital for (our organisation) to have funds and time for organisational capacity.

Disability advocates are facing the same issues as our clients and vicarious trauma has been horrifically exacerbated during the pandemic.

Being aware of signs of mental health impacts on workforce when working remotely for many months and responding appropriately (was challenging).

One organisation detailed how they did adjust to the new conditions over time:

One area of impact is that services moving to a more remote service offering need to have infrastructure and remote data platforms to provide continual services. We continued to provide a service during the pandemic, just in a way that was more creative.... It has allowed us as an organisation to offer more flexible working conditions for staff that we wouldn't have offered before the pandemic.

Overloaded Advocacy and Unmet Demand

Respondents felt strongly that the people they see are only a small proportion of those in need of advocacy, particularly during the pandemic. Three-quarters of respondents (74%) felt that there is a significant number of people with disability 'who need but are not currently accessing advocacy services' (see graph below). In Victoria, 90% of respondents felt this was the case.

Most respondents (73%) also agreed that a significant number of people with disability have 'found accessing advocacy particularly difficult during the COVID-19 period'.

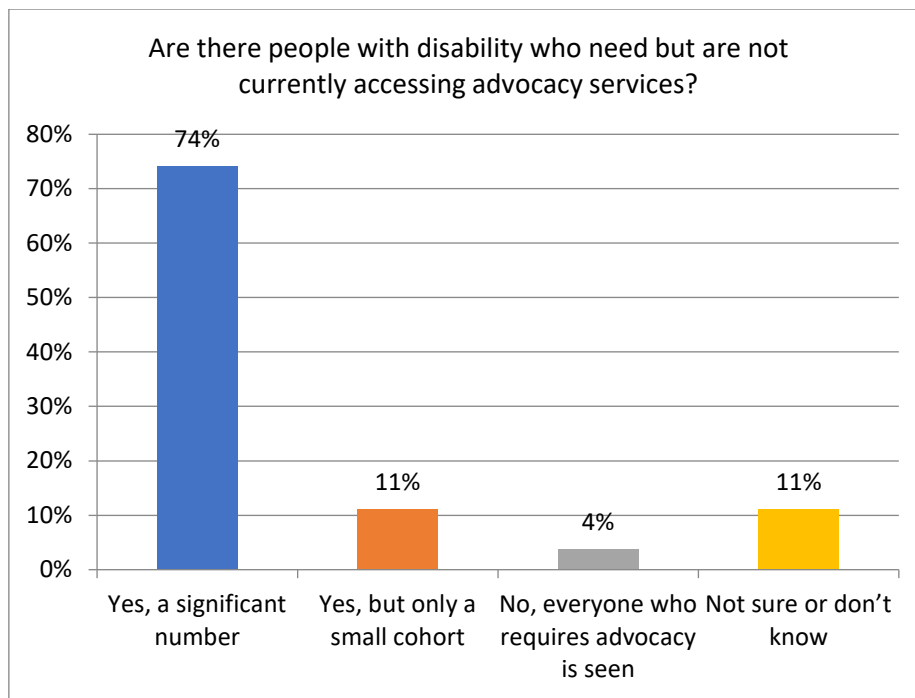


Figure 7: Unmet Advocacy Needs

The survey also asked why advocacy organisations thought this was the case and if there were any particular cohorts who find connecting with advocacy services more difficult. The replies were detailed and complex, with 80% of respondents providing a comment for one of these questions. They can be broadly grouped into the following themes, albeit themes which overlap considerably.

Those most likely to be missing out on much needed advocacy include:

1. people with intellectual disability whose support workers or carers do not support their access to advocacy, or who may not know about their right to advocacy;
2. people in supported accommodation who are closed off from accessing disability advocacy, but who need this;
3. culturally and linguistically diverse people, particularly those for whom English is not a first language;
4. a new cohort of potential clients who are on waitlists to see an advocate; and
5. people with as-yet undiagnosed or unsupported forms of disability, particularly those with psycho-social disability.

The following descriptions were provided:

People with undiagnosed mental health conditions, people with intellectual disability whose families/carers don't talk about advocacy with them or offer it as an option.

People with intellectual disability who are extremely marginalized and reliant upon services for their day-to-day needs, that is, living in Supported Independent Living, group homes and institutions. This cohort is unlikely to be able to self-refer or be supported to self-refer or indeed know about advocacy.

People who live in 'closed environs' such as boarding houses and hostels, hospitals, nursing homes and group homes and those under appointed guardianship. Many appointed guardians do not see advocacy as essential, and consider they are not only the only decision makers (and view advocacy as a service) but also see themselves as the only necessary safeguard.

When asked who else might require advocacy, the comments, again, were detailed and insightful.

Clients who are unaware of either their right to live free from abuse and neglect, or that advocacy exists. Clients dependent on service providers for communication and/or access.

SUPPORTING ADVOCACY'S CRITICAL ROLE

The Critical Role of Advocacy During Disasters

Advocacy is a critically beneficial service, both to those who advocates support and to government. The Australian Productivity Commission has noted the role of independent disability advocacy in delivering significant savings to government by enabling the delivery of targeted services. In 2017 an independent cost benefit analysis found that every dollar spent on disability advocacy returns \$3.50 in benefits, which is considered to be an outstanding return on investment.

Throughout the bushfire season and the pandemic, advocacy organisations have provided a key support for people with disability. They have reconnected people with essential services and supplies, provided translations for government communication, ensured people's rights were not violated under COVID-19 restrictions, assisted with changes to NDIS plans and provided support for people facing violence and abuse under home isolation. Without this support during emergencies and disasters, many people with disability would have been left even further isolated and disconnected.

It is the view of the advocacy organisations that participated in this survey that this work could be better recognised in more consistent funding models and practices.

Building in an assumption with funders that there will and always be a need to safeguard many issues alongside people with disability and we will also need to progress systems improvement. Funding multiple models essential. State and federal funding. Increase things like CA (Citizen Advocacy) model and other models that relied on community to be involved. Services are clear on the need to access an advocacy organisation however this is not always done.

As the Royal Commission also stated (2020c, para 142):

Whatever may be said about the adequacy of the regular funding provided to disability representative organisations, the evidence shows that regular funding is not sufficient in extraordinary times.

Supporting Advocacy During Disasters

Advocacy organisations were also asked how they could be better supported to assist people with disability, especially those who are not currently using advocacy services. Responses can be grouped as follows:

FIRST PRIORITY: INCREASED FUNDING AND RESOURCES

Forty comments described as essential being able to connect with those requiring advocacy, being able to shorten waitlists, and to develop improved outreach programs, particularly into restricted accommodation settings.

More funding and to not have to fight to keep the funding we have. We have had the Appeals funding returned to us this financial year, but it is set to be removed next year. The Fair Pay funding is budgeted for 3 years now but not made ongoing. We waste valuable time fighting to retain what we have. Meanwhile we have had significant increase in requests for advocacy. We cannot meet the demand. It is 3 times the rate it was a year ago. and the issues are greater and the level of anxiety and stress in those that contact us is greater.

Greater resources for advocacy services. An old & tired statement but one that still holds relevance.

SECOND PRIORITY: GREATER SUPPORT FOR USE OF TECHNOLOGY

While the current funding for a shift to online was appreciated, the funding and support is not yet sufficient. Many staff would benefit from further training, computers are often insufficient for their use and clients do not always have access to technology, and nor do they have access to training in its use.

Having resources to enable people to teach clients how to use technologies and interact with resources such as Speak Out Live at Home would have been useful.

THIRD PRIORITY: RIGHT OF ACCESS INTO SUPPORTED ACCOMMODATION.

Some advocates described the variations in access as well, particularly during the pandemic. Some felt this should be a right that is more clearly established, especially during the pandemic and when managing disasters.

Promotion of advocacy into group home settings, through self-advocacy sessions run by self-advocates.

FOURTH PRIORITY: SPECIFIC FUNDING FOR PARTICULAR COHORTS.

Funding for specialist legal and para legal services is needed, especially for more marginalised people with disability and those experiencing human rights violations.

There should be access to Justice Support type programs in each Court jurisdiction to ensure people with cognitive and intellectual impairment have access to competent legal representation.

CALD specific advocacy funding.

FIFTH PRIORITY: MORE FUNDING FOR THE NDIS AND SUPPORT SERVICES.

More funding is needed for NDIS and support services, so that less advocacy time is bound up with NDIS applications and appeals, or for providing services beyond advocacy.

More resources and recognition and funding needed to meet the need. In excess of 75% of demand evolving from NDIS issues.

We have found too many requests come from service coordinators who are not skilled or have key knowledge. (They) expect us to fill all the gaps.

PRIORITIES FOR FUTURE DISASTER PLANNING

Urgent Needs During Disasters

Survey participants were asked: *for the people you advocate on behalf of, what is most urgently needed during disaster like COVID-19?* Participants were asked to select their top 3, again in order of priority. The options were based, in part, on the results of the *Every Australian Counts* study (2020).

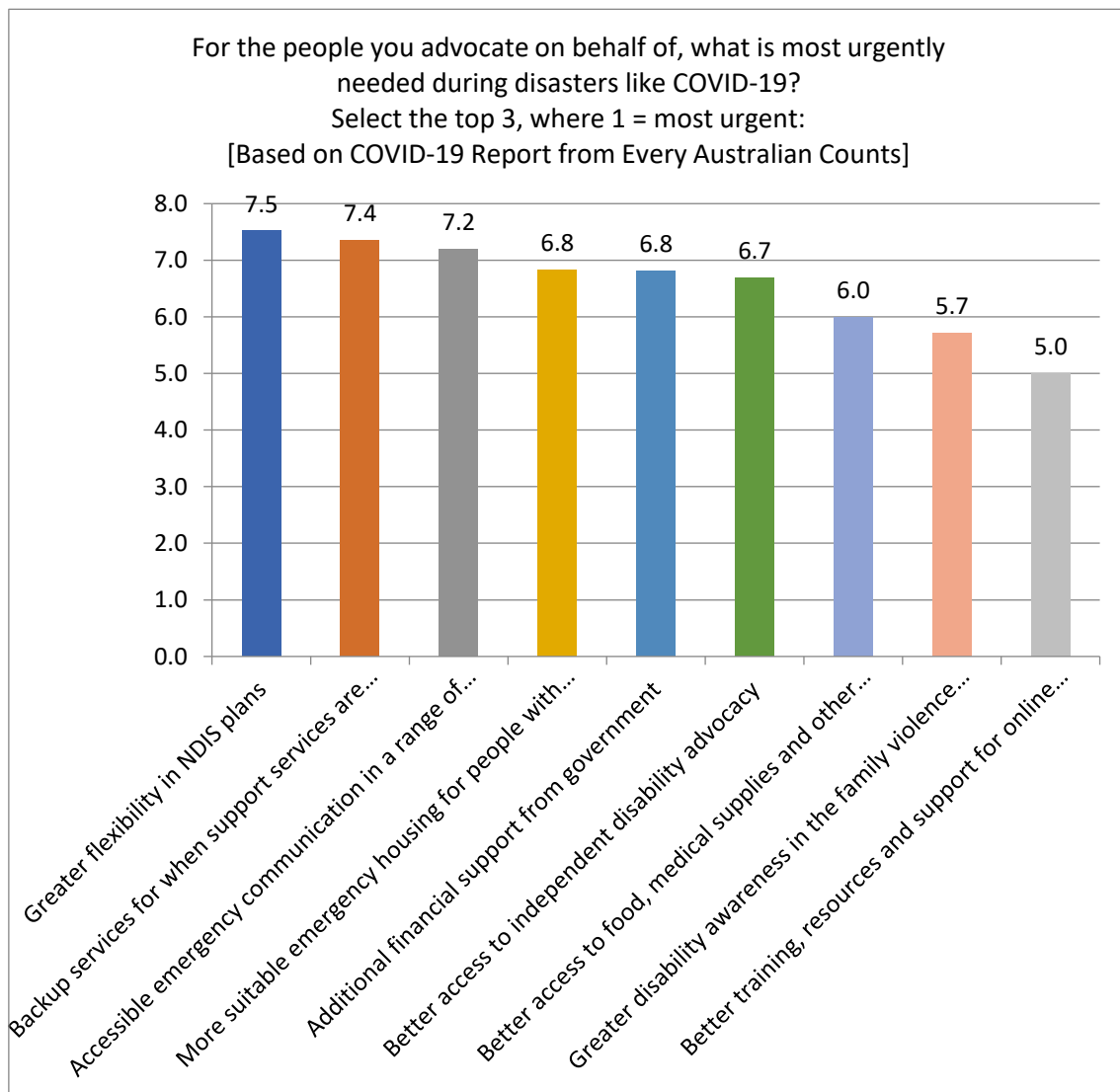


Figure 8: Ranked Priority of Needs for Advocacy Clients

As agreed by a third or more of survey participants, the most urgent needs for clients, in order of priority were:

1. greater flexibility of NDIS plans;
2. backup services for when support services were interrupted;
3. accessible emergency communication in a range of formats and languages;
4. more suitable emergency housing for people with disability;
5. additional financial support from government; and
6. better access to independent disability advocacy.

For those in Victoria the priorities were slightly different:

1. accessible emergency communication in a range of formats and languages;
2. greater flexibility of NDIS plans;
3. backup services for when support services were interrupted; and
4. greater disability awareness in the family violence prevention sector.

The emphasis on family violence awareness in Victoria appears to be a reflection of the different experiences resulting from extended lockdown measures and the social isolation to which this contributed. Confusing government communication was also an issue, especially for people with intellectual disability and for those who communicate in languages other than English. It took some time for government communication to be provided in a range of languages and formats.

Future Disaster Planning

Of the 194 comments received in the survey, 182 contained a recommendation component. This was partly due to the survey design and partly due to the nature of advocacy work: to find longer term solutions to systemic issues. There was also an 80% response rate to the questions asking for recommendations. This is very high.

Many of the comments were very detailed and well considered. They indicate a wealth of knowledge held within advocacy organisations. The following is just one example of a list of recommendations provided:

- 1. Access to support services, including services informing clients that unless they cease all other supports, that service cannot provide support.**
- 2. Access to information that the person with a disability could digest.**

- 3. Access to food – reduction in food supply and increase in costs and sourcing alternative options.**
- 4. Access to medication and PPE – negotiate and organise both.**
- 5. Provide appropriate linkage for people living alone to ensure their welfare and wellbeing were optimised. planning options for if they needed to attend hospital, self-isolate or quarantine.**
- 6. Liaising and negotiating with NDIS providers and NDIA for flexible use of plans and supports that were fit for purpose.**
- 7. Access to justice – either as someone who had charges, someone who had experienced violence, or those going through Mental Health Review Tribunal hearings or Guardianship and Administration hearings.**

The following is a more detailed discussion of the 182 comments containing recommendations for future disaster management. They are prioritised here on the basis of most often mentioned advice.

PRIORITY ONE: ACCESSIBLE GOVERNMENT COMMUNICATION

Communication between government, service organisations and clients was a significant issue. Communication needs to be:

- more accessible and available in a range of formats;
- more detailed for both service and advocacy organisations;
- developed in consultation with those who are already experts in disability communication; and
- produced in a timely manner.

Communication to all people with a disability within all communities and housing. People with disability are isolated and not always able to access the messages regarding disasters. Not all understand the messages on TV or have access to the internet or smart phones.

The COVID hotline was inaccessible and the national relay service was inconsistent to support this. Deaf and hard of hearing Victorians needed direct accessible information.

We would be able to develop animated videos that would assist people with disability who are not literate, with clear accessible accurate and complete information that is useful and specific to them.

Welfare checks, accessible information including access to Interpreters and focus on carer supports.

PRIORITY TWO: CONSISTENT ACCESS TO DISABILITY SERVICES

Disability services are essential and yet in many cases were severely disrupted or even cancelled. This creates very significant health risks for people with disability.

Additional funding is unlikely to have addressed the issues that arose for our client base. Most clients were eligible for COVID stimulus payments and so had much greater discretionary budgets but were often alone and scared. Many of the issues they faced were not the result of any one thing that could be 'fixed' in isolation, but an exacerbation of pre-existing issues by emergency response programs that presumed a baseline that was mismatched with the lived experience of our clients. Many clients had funding in their NDIS plans, but the supports they needed ceased to be available either due to program closure or staffing shortages

There is also a need for someone to oversee continuing entitlements and access to basic rights during periods of disasters. This is particularly necessary for the more marginalised sections of the community.

PRIORITY THREE: MONITORING OF SUPPORTED ACCOMMODATION

A very high proportion of comments described serious concerns about practices within supported accommodation. There was a general call for both greater scrutiny over practices which were seen to be overly restrictive, and potentially abusive. This was alongside the call for greater access for advocates to current and potential clients. 'Right of Access' policies were suggested in some comments:

Resources to go into some of the closed settings and address issues because the impact of rights violations and excessive/inappropriate restrictions during COVID has ongoing negative consequences for people with disability in confidence, rights awareness and futures planning.

Opportunities for people with disability to hear accurate information from trusted people such as advocates is essential.

People dedicated to considering individuals rights during COVID. Although people with disability are more vulnerable, their vulnerability was a rationale for increased restrictions but was this being highly risk averse due also to the changes to the OH&S laws.

A report produced by a coalition of advocacy organisations in the UK – *Valuing voices: Protecting rights through the pandemic and beyond* (Voiceability et al (2020)) – provides a strong case for establishing, maintaining and monitoring rights to social connection and freedom of movement within supported accommodation settings, not only during emergencies and disaster management, but *especially* during these periods. As reported in the section ‘Disconnection is Dangerous’, connection to not only services, but also to community and to advocacy, is essential during disasters.

Proactive check on service providers to ensure inappropriate and excessive restrictions not put in place.

PRIORITY FOUR: CONSISTENTLY APPLIED INCOME SUPPORT

Several comments discussed the discriminatory nature of the lack of increase to the Disability Support Pension, especially when expenses were so high for people with disability. Others have reported on this too (DANA 2020; People with Disability 2020; Every Australian Counts 2020).

The stimulus package... did not include increases to the DSP Pension.

There should have been:

Extra government support payments for people on DSP, Carers Payment and Aged Pension.

Increased financial support for those on DSP, Carers Payment and Aged Pension.

There were also difficulties in accessing rightful entitlements with the move to online and inaccessibility of Services Australia (previously Centrelink) offices:

More telephone support in accessing government services such as Centrelink, MyGov, housing. Our client group struggled to access online services and did not want to access local offices due to concerns about the large numbers of people waiting in line seeking support. This increased our workload and meant we needed to see more people face to face to help them address pressing financial/payment issues.

PRIORITY FIVE: IMPROVED SUPPORT FOR ADVOCACY

As detailed earlier in this report, under *Supporting Advocacy's Critical Role*, there was an overwhelming call throughout the survey for greater recognition of, and support for, the disability advocacy sector. This is perhaps not surprising considering the survey participants. However, the comments received do emphasise the critical, sometimes life-saving, reasons for this call.

This has been a highly challenging year for the sector. We have had to deal with a number of new issues for our membership on top of the Royal Commissions on the back of funding uncertainty. This has taken an emotional toll on many within the workplace with a sense that there has been little to no 'breathing space'.

COVID 19 has been a drain on already overstretched advocacy resources. We simply need more feet on the ground. Government ministers tell everyone to go and access advocacy – great notion but how can we service everyone who needs us and protect human rights without the human capital.

Increased resourcing to meet demand around concerns. Integrating knowledge in mainstream systems how best to service people with disability.

Increase organisational capacity by employing advocates. Facilitating greater collaboration between advocacy agencies.

Many suggested that at the very least there be a process of application for essential worker status for disability advocates. Advocacy is not always essential, but often it is. Lack of access to advocacy can sometimes lead to significantly increased health risks, especially when support work and social contact is also restricted.

Emergency plans specific to people with disability should have occurred much sooner. Opportunities for people with disability to hear accurate information from trusted people such as advocates is essential.

Advocates being classified as essential workers. More proactive Safeguarding Commission.

These comments provide an indication of the level of detailed expertise that disability advocates hold. This is especially useful for future disaster planning.

The following comment from one advocacy organisation echoes other reports calling for more integrated planning and for working with disability advocacy.

There needs to be:

- **A data platform purchased outright that was web based (for use by the advocates)**
- **Discretionary funding to assist people to access emergency relief.**
- **Brokerage so people with a disability who needed to leave their homes due to health concerns, DFV or relocate to another area to be closer to medical/family resources.**
- **(Consistent) information for all disability services across the country.**
- **(Consistent) and clear information in language for all people with disability regardless of where you live.**
- **Key Connector – Using advocacy services that are across all domains in community to link people with a disability with – ensuring that planning, medical, essential services, housing, supports etc are covered for people with a disability using local advocates who know the systems and how to rally resources around people to meet their needs.**

PRIORITY SIX: GREATER ACCESS TO TECHNOLOGY

Access to technology and training in how to use it was seen as essential by many advocacy organisations. This is necessary, not only for general communication and reduce social isolation, but very many government organisations and services also assume access to technology.

Access to technology for people to have devices and internet connection and support to access these. Support workers to assist persons to set up, use and connect with others.

Access to technology to care facilities so we (advocates) can be engaged.

When people are locked down – connection to the outside world. Provision of tech devices and the instruction in how to use them for video calls etc (is essential).

There was a note as well though:

Better recognition that access to technology is uneven and not a solution (or even possible) for all people.

PRIORITY SEVEN: MAINTAINING COMMUNITY CONNECTIONS AND PROGRAMS

Many comments also remarked on the urgent need to not only maintain social connection during disasters. This means making sure that people with disability are connected beforehand.

Communication Partners available for people with complex communication needs.

Greater contact for those socially and physically isolated eg friendly call once a day. Some clients received little or no outside contact.

Local councils should door knock – as that is the only way they can know someone has gotten the message to evacuate or stay at home in an emergency, disaster or pandemic.

Community messages should have encouraged neighbourly concern and assistance rather than driving fear and resentment. The (late) messaging about checking on elderly neighbours and

relatives should have applied to people with disability, including that members of community could take personal responsibility for maintaining social distance from those who perhaps did not understand or always managed to do this themselves.

As the Royal Commission (2020b, 7) stated in their 15th April Issues Paper on Emergency Planning and Response:

People with disability in closed facilities and segregated settings may be at increased risk of violence, abuse, neglect and exploitation during emergencies due to reduced safeguarding and oversight by family, friends, supporters, advocates and community visitors. Closed facilities and segregated settings include group homes, prisons, mental health facilities, Australian Disability Enterprises, and day programs.

Removing informal community-based safeguarding and oversight practices may expose people with disability to higher rates of violence, abuse, neglect and exploitation. We are interested in hearing what measures governments have in place to protect and support people with disability in all closed facilities and segregated settings during emergencies. We are also interested in hearing how these measures can be improved.

Inclusive Disaster Management

Two thirds of respondents also provided contact details for any follow-up consultation DANA may want to conduct.

The final recommendation of this report is that further consultation with disability advocates and people with disability occurs in order to deepen the understanding of people's experiences of 2020 so that future disaster management can be better planned. Future disaster management should be more inclusive.

That governments/government departments in each jurisdiction should have consulted advocates in each jurisdiction – not just through 'disability departments'.

Having people with lived experience involved in the preparation and planning for disasters.

Ultimately it is people with disability who understand their functional needs through the changes that occur in emergencies. They are therefore best placed to guide disaster management, for themselves.

This is also confirmed in multiple reports, including: Australian Institute for Disaster Resilience 2020; Centre of Research Excellence in Disability and Health (2020); People with Disability Australia (2020); Royal Commission (2020c); Michelle Villeneuve (2019 and 2020). As Villeneuve (2015) describes:

People with disability are twice to four times more likely to be killed or injured in natural disasters than the general population...

To reduce their vulnerability during natural disasters, people with disability should be included in the planning and preparation for disaster risk reduction.

REFERENCES

- Australian Institute for Disaster Resilience and Margaret Moreton (2020) *Engagement for Disaster Resilience*, April:
www.knowledge.aidr.org.au/resources/handbook-community-engagement
- Centre of Research Excellence in Disability and Health (2020) Recommendations for a Tailored COVID-19 Response for People with Disability, July:
<https://credh.org.au/covid-19/covid-19-recommendations-for-a-tailored-response-for-people-with-disability/>
- Daly, Anne (Professor Emeritus), G. Barrett and R. Williams (2017) *Cost Benefit Analysis of Australian disability advocacy services*. Disability Advocacy Network Australia, Canberra. <https://www.dana.org.au/wp-content/uploads/documents/Disability-advocacy-CBA-2.pdf>
- Disability Advocacy Network Australia (2020) *Insufficient capacity for increased demand: Snapshot of COVID-19 Advocacy Demand*, June:
<https://disability.royalcommission.gov.au/system/files/exhibit/DRC.2000.0003.0181.pdf>
- Down Syndrome Australia (2020) *Submission to Disability Royal Commission Emergency Planning and Response*, July:
https://disability.royalcommission.gov.au/system/files/submission/ISS.001.00225_1.PDF
- Every Australian Counts (2020) *“Left out and Locked Down”: The experiences of people with disability and their families during COVID19*, August:
<https://disability.royalcommission.gov.au/system/files/exhibit/DRC.9999.0015.0001.pdf>
- Financial Counselling Australia (2020) *Money on Your Mind: Financial Counselling and Mental Health*, September.
<https://www.financialcounsellingaustralia.org.au/docs/money-on-your-mind-financial-counselling-and-mental-health/>
- Gender Equity Victoria (Gen Vic) (2020) *Gender Disaster and Resilience: Towards a Gender Equal Recovery*: <https://www.genvic.org.au/resources/covid-19-resources/>

- Kaleveld, Lisette, Catherine Bock and Rebekah Maycock-Sayce (2020) *COVID-19 and Mental Health: Centre for Social Impact Response*, October:
https://www.csi.edu.au/media/uploads/csi_fact_sheet_covid_and_mental_health.pdf
- Open Letter to the National Cabinet (2020) *Immediate Actions Required for Australians with Disability in Response to Coronavirus (COVID19)*, March:
https://disability.royalcommission.gov.au/system/files/exhibit/Exhibit%205.19.19_0.pdf
- People with Disability Australia (2020) *Experiences of People with Disability During COVID-19: Survey Results*. People with Disability Australia:
<https://pwd.org.au/experiences-of-people-with-disability-during-covid-19-survey-results/>
- Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020a) *Statement of concern: The response to the COVID-19 pandemic for people with disability*, March:
<https://disability.royalcommission.gov.au/publications/statement-concern-response-covid-19-pandemic-people-disability>
- Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020b) 'Issues Paper: Emergency Planning and Response', 15th April: <https://disability.royalcommission.gov.au/publications/emergency-planning-and-response>
- Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020c) *Public hearing 5 – Experiences of people with disability during the ongoing COVID-19 pandemic*, 30th November:
<https://disability.royalcommission.gov.au/publications/report-public-hearing-5-experiences-people-disability-during-ongoing-covid-19-pandemic>
- Villeneuve, M, B Dwine, M Moss, L Abson and P Pertiwi (2019) *Disability Inclusive Disaster Risk Reduction (DIDRR) Framework and Toolkit*. Produced as part of the Disability Inclusive and Disaster Resilient Queensland Project Series. The Centre for Disability Research and Policy, The University of Sydney, NSW 2006: https://collaborating4inclusion.org/wp-content/uploads/2019/11/DIDRR_Framework_document_FINAL.pdf
- Villeneuve, Michelle (2015) *People with disability should be included as equal partners in disaster planning*, The Conversation, 13th March:

<https://theconversation.com/people-with-disability-should-be-included-as-equal-partners-in-disaster-planning-38718>

Villeneuve, Michelle (2020) *3 things we can do now to help people with disability prepare for disaster*, The Conversation, 11th January:

<https://theconversation.com/3-things-we-can-do-now-to-help-people-with-disability-prepare-for-disaster-151843>

Voiceability and National Development Team for Inclusion (2020) *Valuing voices: Protecting rights through the pandemic and beyond*, United Kingdom, 19th

October: <https://www.voiceability.org/news/valuing-voices-protecting-rights-through-the-pandemic-and-beyond>

Women with Disabilities ACT (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 and Girls, Feminine Identifying & Non-binary People with Disabilities in the ACT), June:

<https://disability.royalcommission.gov.au/system/files/exhibit/DRC.2000.0003.0265.pdf>

Women with Disabilities Australia (2020) *Response to Emergency Planning Issues*, Submission to the Disability Royal Commission Emergency Planning and Response, October:

https://disability.royalcommission.gov.au/system/files/submission/ISS.001.00494_0.PDF