

DANA Snapshot of COVID-19 Advocacy Demand

# Insufficient capacity for increased demand

17<sup>th</sup> June 2020

Survey conducted by:

Disability Advocacy Network Australia (DANA)

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

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## Disability Advocacy Network Australia (DANA)

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 have set up a national secretariat in Canberra and maintain strong links with the Australian state and territory advocacy networks and with the peak organisations for people with disabilities.

More information can be found on our website: <https://www.dana.org.au/>

### Executive summary

DANA conducted a 'snapshot survey' of disability advocacy organisations in April 2020, in order to gain a quick understanding of the shifting demands for advocacy services during the COVID-19 shutdown period. The survey received responses from 35 advocacy organisations. The results indicate that:

1. Demand for advocacy services has increased significantly and in a short period of time.
2. Overall, capacity has not increased. In fact, for some, capacity has decreased.
3. Demand is 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. As a result of isolation from informal and unfunded support (family, friends, community)
  - e. The additional time it takes to provide suitable advocacy services that are not face-to-face.

These findings also confirm the critical importance of advocacy for people with disability and their carers. Many of the detailed comments provide strong evidence of how close many have been to being disconnected from essential income and support, especially during this period.

The findings from this survey are also consistent with the findings from other reports into the impact of COVID-19 on people with disability, for example the most recent report produced by People with Disability Australia (2020), *People with Disability and COVID-19*.

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## Introduction and context

This is a report on a brief snapshot taken of demand for disability advocacy services during the period of COVID-19 risk. The survey of advocacy organisations was conducted in late April to early May, and received responses from 35 organisations in total, almost all of which are members of DANA. This was a response rate of approximately 42% of disability advocacy organisations which is high considering the fast turnaround time requested of respondents and the demand on advocacy organisations already.

The results of this snapshot survey draw attention to some worrying emerging issues. In some key areas demand has increased significantly and many organisations have not been able to meet this increased demand, in-part due to the sector already being at or over capacity.

The key contributors to this increased demand are a combination of:

- Needing new advice and support around serious COVID-19 health risks;
- Needing advice or support around the law and advice surrounding shutdowns and social distancing measures;
- Needing new support to continue to access already-agreed services due to COVID-19 shutdowns;
- Needing new and additional supports to replace informal supports that can no longer be accessed due to COVID-19 shutdowns;
- As well as the fact that advocacy services take longer to provide advocacy when they cannot be face-to-face.

These findings also confirm the critical importance of advocacy for people with disability and their carers. Many of the detailed comments provide strong evidence of how close many have been to being disconnected from essential income and support, especially during this period.

This report begins with a discussion of the increased demand alongside little or no increased capacity to meet that demand. The report then discusses the specific areas of increased demand

and includes some descriptive examples of the impact of COVID-19 shutdowns on people with disability, particularly on those with complex and intersecting needs. The report finishes with some recommendations for increasing future capacity to meet this new demand.

The results of this snapshot survey also echo a recent report into the impacts of this COVID-19 period on people with disability. This report states that expenses have dramatically increased while supports have decreased:

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

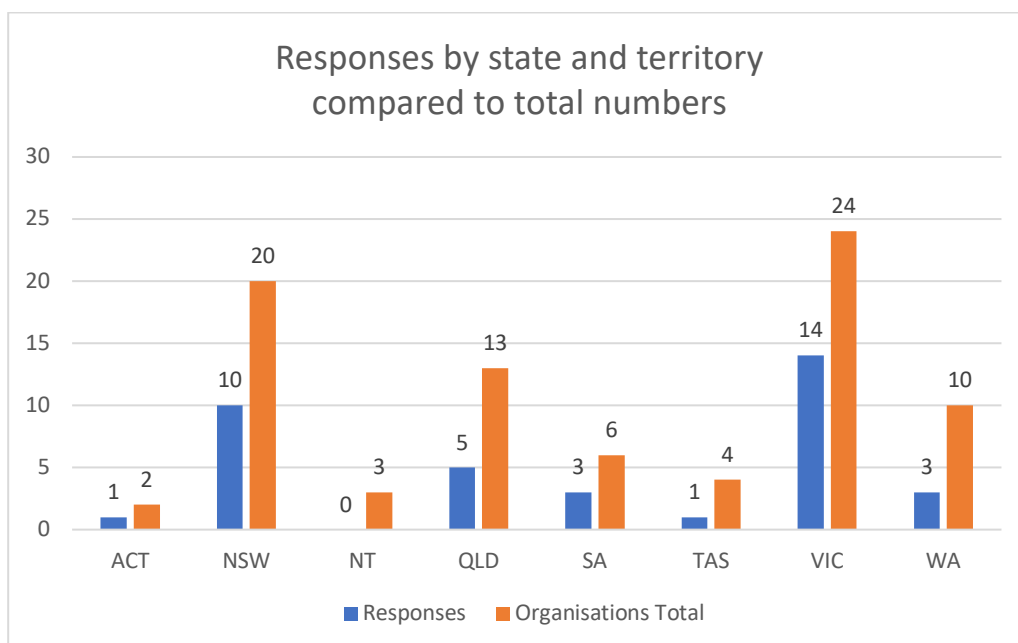
(People with Disability Australia 2020, p.5)

## Survey method and responses

The survey was conducted online and was sent to disability advocacy organisations through email. Respondents were given a fortnight to respond. Just over 42% of organisations responded.

The survey asked a mixture of multiple-choice questions and short-answer questions, providing primarily descriptive quantitative data. There was a total of 15 questions and all respondents completed the whole survey. Most questions allowed room for comments, with three questions asking for descriptive answers.

The proportion of responses by states approximately matches the breakdown of organisations per state and territory.



Source of total numbers: DANA 2020

## Insufficient capacity for increased demand

Overall, demand has increased for over half of respondents (53%).

Meanwhile capacity within the sector has stayed the same or even decreased for approximately three quarters of respondents (74%).

A worrying 42% of respondents have been unable to meet this increase in demand. This is with the backdrop of an already under resourced sector.

Of respondents who keep waitlists, almost half (48%) have seen an increase in waitlists due to COVID-19 and related shutdowns. Waitlists indicate a significant risk for future issues, so this is a concern.

Many respondents discussed where capacity was not meeting demand. The comments included:

*(The) Funding model does not fit the work we are currently doing.*

*For us to be able to meet the current demand we would need to receive at least twice the amount of funding we are now for individual advocacy.*

*We are not seeing clients face to face therefore the whole process of gaining consent, making a plan and getting the ball rolling is slower and therefore we can't get to as many people in a week as previously. Many clients don't have technology at home so Australia Post is used for document exchange and that can take a very long time. Sometimes people can't even get to a post office.*

*... the complexity of our work has increased. This is particularly for clients who do not have access to internet/devices.*

*Current staff numbers are working at a high threshold that will require recovery in the next quarter. In other words, staff will require leave soon, to maintain sustainable operations in the COVID-19 recovery phase (assessed as an extremely busy period). More staff will also ease the increase waiting list.*

*Stretched to the limit!*

## Specific areas of demand

Advocacy organisations were asked to select the four main advocacy issues for their clients, during this COVID-19 period, and in-line with the Department of Social Services (DSS) reporting categories for people with disability and carers (Department of Social Services 2020).

*Government payments* here may include any of the government payments available to people, including the Disability Support Pension and Carers' Payment, but also: JobSeeker Allowance, JobKeeper Allowance, Austudy, Sickness Allowance, Aged Pension and any other combination of government payments (for a full list see: Services Australia 2020).

For survey respondents the main issues requiring advocacy included:

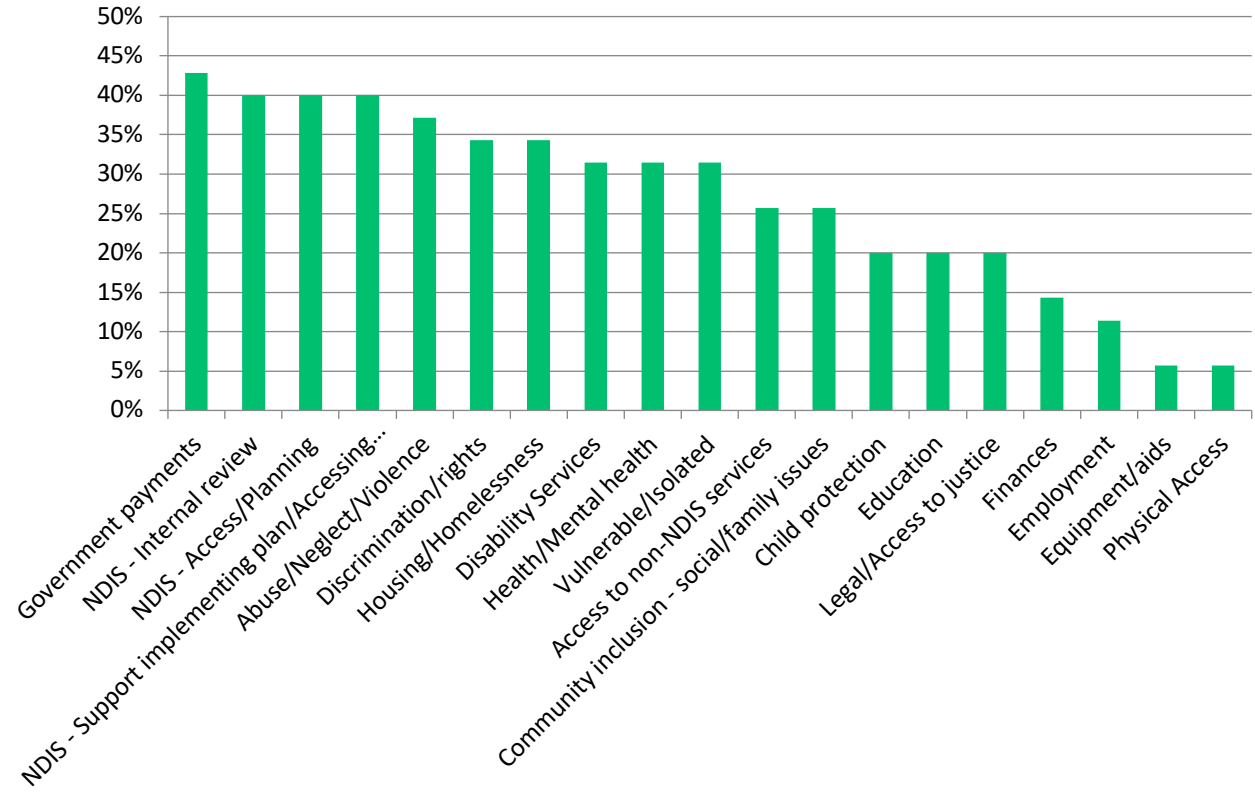
- Government payments
- NDIS – Internal review
- NDIS – Access/Planning
- NDIS – Support implementing plan/Accessing services
- Abuse/Neglect/Violence
- Discrimination/rights
- Housing/Homelessness

After this, access to disability services in general, physical and mental health, and being vulnerable and isolated were the main reasons advocacy was required.

Government payments are very often a substantial or even only source of income for people with disability and their carers. This means that helping people with disability to maintain and seek new sources of income was a substantial part of advocacy work for 43% of advocacy organisations. Not only is this a very serious concern, it emphasises the critical role of advocacy organisations in ensuring basic living standards are met for people with disability.

The second most common issue that required advocacy support was gaining or maintaining access to the National Disability Insurance Scheme. Those requiring NDIS support should be able to rely on these services during a period of shutdown like COVID-19. In this case again, advocacy was required in order to ensure access to essential services.

### Four main advocacy issues in COVID-19 environment

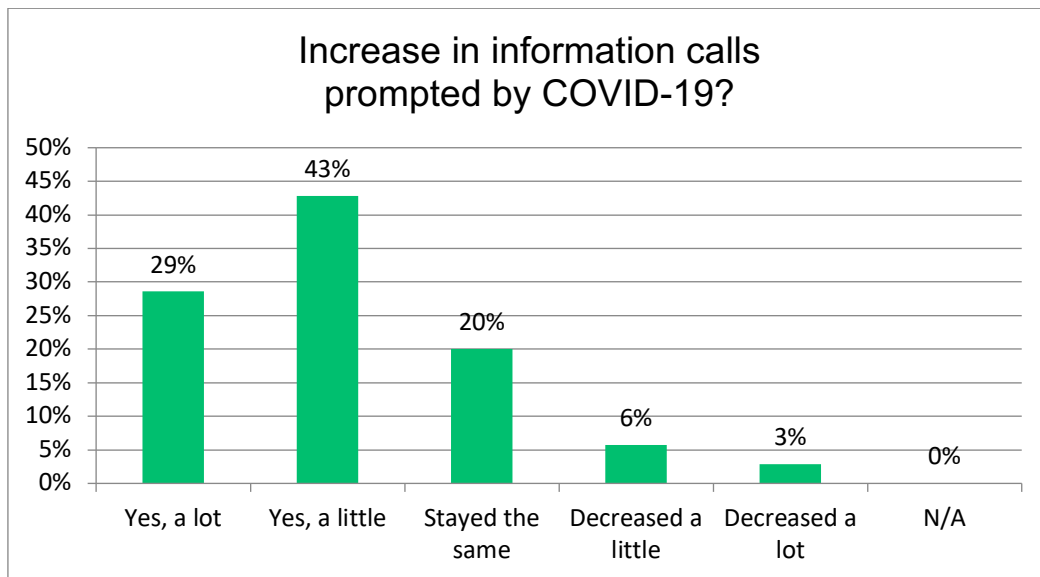


Note: respondents were able to choose up to four options.

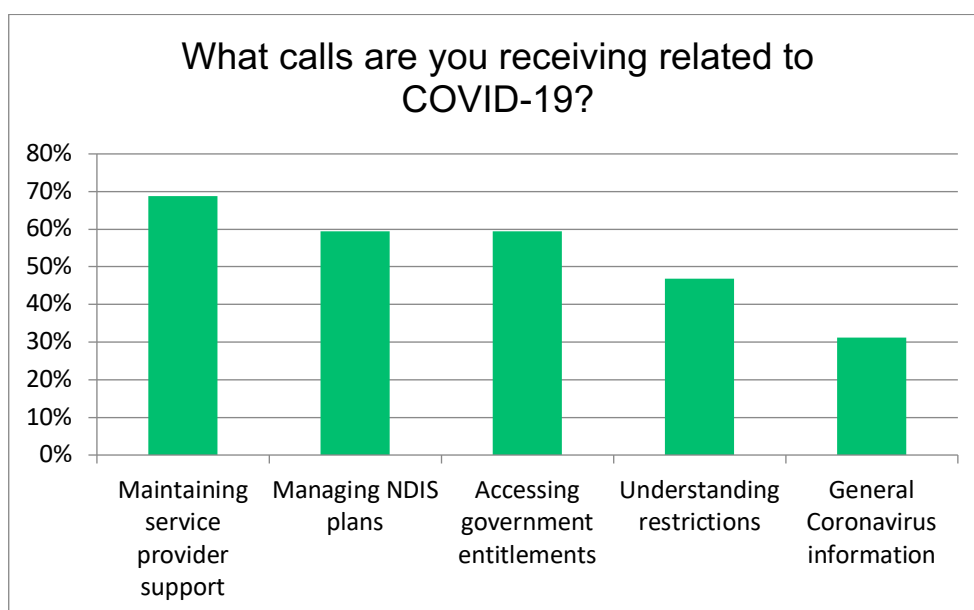
## Information calls

Well over two thirds of respondents, or 71%, have seen an increase in information calls, prompted by COVID. Of these a very high proportion, or 29% of respondents, stated the increase was ‘a lot’. The comments indicate that the increase has been due to both existing and new clients. One respondent described well the issues of concern:

*‘Nearly all of the citizen advocates have been dealing with issues in relation to COVID 19. Specifically, (around) restrictive practices and isolation. We are supporting... with factual information, support, guidance and advice.’*



Of the COVID-19 specific issues, over two thirds of respondents said that issues with maintaining existing services was a key part of phone calls. Not surprisingly, not far behind this, managing NDIS plans and accessing government entitlements were both key issues as well.



Note: respondents were able to choose more than one option.



One respondent provided a good description of the complex mix of issues for people with disability navigating the implications of this COVID-19 period:

*'Support workers unable to visit participants in their home, using NDIS funds to pay family members where support workers are unavailable, family members being unable to visit participants who are in nursing homes or hospital, (plus) evictions, housing inappropriate and not fully accessible'.*

## Mode of outreach

Respondents were asked what modes of outreach they were using to keep in contact with people with disability during this COVID-19 period. The vast majority (over 90%) use either email or phone or both as their current method of contact.

After this, video conferencing, text and post were the methods of contact. Facebook was used by under half of the respondents (43%) although those organisations that have used Facebook are finding it very useful for outreach.

Mode of outreach	Percent
<b>Email</b>	94%
<b>Phone</b>	91%
<b>Video conferencing (e.g. Zoom)</b>	74%
<b>Text</b>	66%
<b>Post</b>	60%
<b>Facebook/ Facebook Live</b>	43%

Note: respondents were able to choose up to four options.

*Will engage in other platforms dependent on individual and / or organisation i.e. Microsoft Teams. The mode of outreach often needs to also be supported by the care provider and this fluctuates especially in group homes*

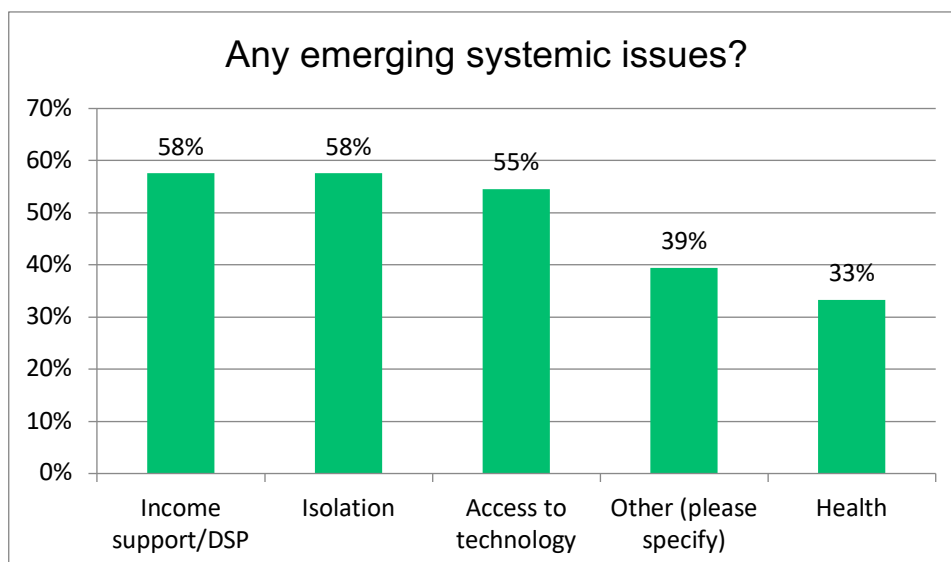
*Our Facebook engagement has increase from around 16,000 people in January to 56,000 already this month. We have done a number of livestreams and video updates.*

*We are still seeing people who do not have access to technology or those that are difficult to engage with without face to face contact.*

*It's challenging to support clients over the phone and lose that honest face-to-face contact.*

## Systemic issues and urgent concerns

A majority of respondents described the emerging systemic issues as connected to COVID-19 shutdowns, rather than health issues. Isolation and (lack of) access to technology were both issues for a majority of respondents. In addition, issues relating to income support / the Disability Support Pension were highlighted.



Note: respondents were able to choose more than one option.

*It's unfair that people of DSP don't have an increase to payments during this time when additional cost will likely be accrued.*

*We have been co-opted onto an additional 5 representative groups specifically related to COVID at this time on top of our usual workload.*

*Huge surge of DRC (Disability Royal Commission) work. Hidden Violence.*

Respondents were also asked to describe where they have particular concerns for people with disability. This was an open-ended question and allowed organisations to provide detail around the intersecting issues faced by some clients.

The issues within these comments were identified, named and counted. Nearly every comment indicated that most or a significant number of their clients have complex and intersecting needs that are of serious concern. Six respondents said that all of their clients, all people with disability, were impacted by the COVID-19 period and a lack of support services.

Only two respondents did not reply to this question, which is a high response rate for an open-ended question in a short survey. It is indicative of the level of concern that advocacy organisations have for many of their clients.

<b>Additional Concerns</b>	<b>Count</b>
Isolated	13
Intellectual Disability	8
Living Alone	8
Family Violence	5
Communication Difficulty	4
COVID-19 Health Risks	4
Psychosocial	3
Group Home	3

Respondents also specifically mentioned Aboriginal and Torres Strait Islander people, Culturally and Linguistically Diverse people, those who are homeless, those who are not on the NDIS, and families with children with complex behavioural needs, as also having higher support and advocacy needs during COVID-19.

*People who were already isolated due to other factors – i.e. living in rural & regional areas, being home-schooled, unable to leave home due to health conditions, unable to live with family etc. We are also concerned about people who have barriers in receiving information (i.e. no devices, or accessible information is not easy to find).*

*People living in congregated living environments where there could be increased unapproved restrictive practices implemented under the COVID-19 protection guise. People who do not have other people in their lives and are living without basis necessities. People, because of the nature of their disability are unable to use a telephone or device and therefore at greater risk of abuse, neglect, exploitation or violence. People living in environments where they become 'closed' and only people from one service attend to their needs, again increasing the risk around experiencing abuse, neglect, exploitation or violence. People who do not understand what is happening around them regarding COVID-19 because they have had all communication/media removed.*

*People with intellectual disability, brain injury or complex psychosocial disability who are not understanding the COVID restrictions and messages for staying safe. People are becoming more anxious and depressed due to frustration, isolation, confusion, absent support workers and isolation from social networks. We are concerned in particular about people in rural areas and those living in group homes and boarding houses with little access to advocacy or independent information*

All these comments echo those of the recent report put out by People with Disability Australia (2020), looking into the impacts of COVID-19 measures on people with disability. This report found that lack of access to changing services, as well as little access to proper financial compensation for significantly increased expenses (no increased Disability Support Pension, for example), were contributing to additional physical and mental health risks.

## Conclusion and recommendations

This COVID-19 management period has created significant challenges for people with disability. These challenges range from being socially isolated, struggling with use of technology, withdrawal of or changed access to existing services, and the impact of social distancing measures and physical isolation laws on the support provided by family and community. In addition, income support has not matched this new need for support.

Advocacy service delivery could be significantly improved with a combination of:

1. **Additional research** into the details of the impact of COVID-19 shutdowns on people with disability and their advocacy needs;
2. **Additional funding** to the disability advocacy sector, to provide increased advocacy capacity, especially for the purpose of ensuring critical supports and incomes are maintained for people with disability;
3. **Additional funding** to both the disability advocacy sector and to people with disability, to support technology use and continuing access to both direct services and the protective support of advocacy;
4. Treating **disability advocacy as an essential service**, so that the additional demand for advocacy can be met during any period of significant social and health crisis, like during COVID-19;
5. Treating **disability advocacy as an essential service** so that those who require in-person advocacy support are able to continue to access this, and so that disability advocacy workers can also be supported through the establishment of proper health and safety protections for both workers and clients.

Overall, a worrying 42% of advocacy organisations stated that they were unable to meet the increase in demand for advocacy services during this period. This indicates a significant emerging systemic issue.

Further, respondents have highlighted (particularly in the comments listed in *Systemic issues and urgent concerns*) the complex interaction between access and health issues for people with disability. A sudden lack of access to advocacy services, income and/or NDIS support will often create an immediately higher risk of experiencing violence, health deterioration and/or injury. During this period advocacy organisations have been central to minimising these risks.

In the context of likely future staff leave, growing waitlists for individual advocacy and the potential effects of individual issues compounding, this lack of support for advocacy needs addressing, and urgently.

## References

DANA (2020) *Advocacy organisations*: <https://www.dana.org.au/find-an-advocate/>

Department of Social Services, Australian Government (2020) *Disability and Carers*: <https://www.dss.gov.au/disability-and-carers>

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/>

Services Australia, Australian Government (2020) *Income Support Payment Description*: <https://www.servicesaustralia.gov.au/individuals/topics/income-support-payment-description/34696>

## Appendix: Survey questions

1. Which state and/or territory does your organisation operate in? (Able to select more than one)
2. In the COVID-19 environment, what are the main issues you are providing advocacy for? (The following categories are those used in the DSS Data Exchange, DEX). Please select up to four issues only.
3. Have you had an increase in information calls prompted by COVID-19?
4. If yes, what calls are you receiving related to COVID-19?
5. Any emerging systemic issues?
6. Any specific gaps emerging in your state/territory/local area for people with disability?
7. Has the demand for individual advocacy increased because of COVID-19?
8. If yes, is your organisation able to meet that demand?
9. Has your capacity to take on new advocacy clients changed during the pandemic?
10. Have your waiting list(s) changed because of COVID-19?
11. If you do have waiting lists, how many people do you currently have on these waiting list(s) (We understand that some organisations have limited access to databases at present)
12. What modes of outreach are you using to stay in contact with people with disability who may require support at this time?
13. Which people with disability/clients/groups are you most concerned about?
14. Anything else you would like to tell us?
15. What is the name of your organisation? (This information is optional and kept strictly confidential. You or your organisation will not be identified).