

COVID-19 and Disability

A Systemic Impact Report

12 05 2020

Authors

Maggie Rutjens – Program Manager

Kendall Field – Chief Executive Officer

Key words: COVID-19, experiences, disability, lived experience, supports, mixed methods, Australia, pandemic, safeguarding, disability royal commission

This report was collated and is offered to the Royal Commission into Abuse, Neglect, Violence and Exploitation of People with Disability ('DRC') in response to their issues paper titled: *Emergency Planning and Response Issues Paper*.

This report discusses the gaps in systems responses that have contributed to exacerbating disadvantage of people with disability amidst humanitarian emergencies such as COVID-19.



Contents

Table of Figures.....	4
Acknowledgement.....	4
Key Terms.....	5
Active clients	5
Intersectionality.....	5
Participants	5
UNCRPD	5
DRC.....	5
COVID-19	5
NDIS	5
Psychosocial.....	5
Statement	6
Background	8
Relevance	9
Design & Participant Group	10
Method of Research and Participant Recruitment	11
Demographic Results Discussions.....	15
Results.....	15
Question 1 "Regarding COVID-19, I as a person with disability feel..."	16
Question 2 "I'm more isolated than I was before COVID-19..."	16
Question 3 "Regarding my mental health and feelings of wellness I feel COVID-19 has..."	17
Question 4 "The thing that most concerns me about COVID-19 is..."	18
Question 5 "Since COVID-19 my disability support needs have..."	19
Question 6 "My disability support needs include..."	20
Question 7 "Since COVID-19 I feel I can still fully access the supports I need..."	21
Question 8 "During emergencies such as COVID-19 I could be better supported if..."	22
Conclusion.....	23
Relevant Literature, Documents & Policy	23



Table of Figures

Figure 1 - Lived Experience Diagram.....	7
Figure 2 - Age of participants.....	13
Figure 3 - Gender of participants.....	13
Figure 4 - Disability of participants per Department Social Services Data Exchange Reporting Protocol	14
Figure 5 - Intersectionality of participants	14
Figure 6 - Involvement of NDIS in participant's lives	15
Figure 8 - Feelings of participants.....	16
Figure 7 - Participants' feeling of isolation since COVID-19	16
Figure 9 - Mental health and wellness of participants	17
Figure 10 - Primary concerns	18
Figure 11 - Status of support needs.....	19
Figure 12 - Types of support needs	20
Figure 13 – Access to required supports.....	21
Figure 14 - Opportunities for systems reform to safeguard people with disability	22

Acknowledgement

Disability Advocacy and Complaints Service of South Australia Inc. ('DACSSA') acknowledges the traditional owners of the country throughout Australia. We pay our respects to Aboriginal and Torres Strait Islander Peoples and to elders past, present and emerging.

We recognise that the people we work with everyday face significant disadvantage and historical oppression. This is even more true for First Nations people living with disability and those from culturally and linguistically diverse backgrounds who experience disadvantage relating to disability, race and other diversity.

This report serves to demonstrate the commitment to improve outcomes and experiences for those we support. We will continue demonstrating our commitment by building meaningful relationships, advocating for disability rights and sharing stories of lived experience in order break down barriers affecting those living with disability, their families and carers in South Australia.



Key Terms

Active clients

Clients who have a disability advocacy matter currently open with DACSSA. Clients may have multiple active matters with DACSSA at any given time. An active client may be a person with disability or a parent of a child with disability.

Intersectionality

The connectedness of social factors like race, class, gender etc. and how this may overlap and intersect to make disadvantage worse.

Participants

Those who participated in the survey.

UNCRPD

United Nations Convention on the Rights of Persons with Disabilities.

DRC

Disability Royal Commission.

COVID-19

The Novel Coronavirus.

NDIS

National Disability Insurance Scheme.

Psychosocial

Referring to mental illness categorised as disability.



Statement

People with disability who are currently receiving support from DACSSA have experienced profound disadvantage subsequent of COVID-19 and must be supported by a targeted approach that facilitates equitable access to critical services.

Aims and Objectives

DACSSA has surveyed and written of the experiences of people with disability who receive support from DACSSA, who may be impacted by the Coronavirus ('COVID-19'). This systemic impact report is published to promote the human rights of people with disability to have appropriate and priority access to disability and health related supports amidst issues of humanitarian emergencies such as a pandemic. This report calls for interprofessional collaboration to safeguard the needs of people with disability and prevent humanitarian emergencies from exacerbating prominent disability related issues such as:

- a) Abuse, neglect, violence and exploitation
- b) Comorbid health
- c) Discrimination on the grounds of disability
- d) Service access





Figure 1 - Lived Experience Diagram



Background

DACSSA provides free, confidential and independent advocacy services to people with disability, their families and carers in South Australia. Advocacy provided by DACSSA consists of individual advocacy to resolve disability related issues and systemic advocacy in order to resolve or inform change for widespread issues affecting people with disability.

With changes in the disability sector evolving day by day as a result of COVID-19, DACSSA noticed and was concerned about an increase in enquiries relating to COVID-19 and its impact on disability needs. Themes of concern included:

- a. Entitlements and eligibility for government assistance
- b. Security of supports including NDIS funded supports
- c. Access to health including critical services & products
- d. Changing disability support needs for example increases in needs attributable to the pandemic
- e. Levels of wellness included mental wellness being exacerbated by the pandemic. This mental wellness consideration is in addition to diagnosed psychosocial disability.

In response to the increase in enquiries received, DACSSA took measures to check in with active clients, to determine their current situation, support requirements and opportunities for safeguarding.

This was achieved by individual phone calls made to participants in order to survey and illicit information.

DACSSA takes a person-centred approach to advocacy practice. We get to know the people we work with and what's important to them. We wanted to check in with clients who had active matters with DACSSA, to ensure their safety and wellness amidst COVID-19.

DACSSA was interested to understand the impact of COVID-19 on clients with regards to:

- a. Their feelings of isolation and vulnerability
- b. Differences in feelings of isolation and vulnerability before and amidst COVID-19
- c. Levels of support requirements and changes to levels of support requirements
- d. Levels of access to necessary supports before and amidst COVID- 19
- e. Key areas of concern for people with disability
- f. Areas of need and opportunity to meet the needs of disability.



Relevance

DACSSA's report gives rise to the lived experience of people with disability during these times and shares their stories. The report provides insight into the experiences of the people DACSSA serves and echoes the issues and recommendations outlined in other literature.

Several letters, statements and recommendations have been made by Australian and international organisations to inform Australian health policy and implore consideration for the needs of people with disability. The information contained in these publications has contributors and signatories with expertise in disability, bioethics, human rights, public policy and natural disasters.

This report is relevant to upholding principles outlined in the United Nations Convention on the Rights of Persons With Disabilities (UNCRPD):

- a. **Article 11: Situations of risk and humanitarian emergencies** that describes how parties shall take all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk like COVID-19.
- b. **Article 25: Health** describes how we need to protect against discrimination on the basis of disability when providing access to health care and health services. In section (b) of this article it discusses how we need to provide health services needed by people with disabilities, specifically because of their disabilities. This relates to the need to safeguard people with disability who are at greater risk of contracting illness such as COVID-19.
- c. **Article 21: Freedom of expression and opinion, and access to information** talks about ensuring people with disability can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice.
- d. **Article 16: Freedom from exploitation, violence and abuse** calls for us to take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.



Design & Participant Group

The participant group consisted of 45 active clients. Active clients may be people with disability or parents of children with disability. Participants were contacted for telephone survey by the advocate supporting them. This was in an effort to maintain a person-centred approach that considered the relationships of trust and integrity between the participant and their advocate.

If a client wasn't able to be contacted to become a participant, they were not pursued further as to avoid compounding issues of overwhelm and obligation. Additionally, if advocates identified risk factors that suggested participation in the survey would potentially bring about harm to the client or DACSSA, the client wasn't contacted. These were two fundamental ethical considerations for safeguarding. While this act could be deemed as exclusionary, DACSSA took the position that it was safer not to include at-risk clients in the recruitment, rather than to include them in the recruitment and risk harm to them.

Participants were supported to understand the function of the survey by way of a consistent disclaimer explained by staff administering the survey. All participants were supported to understand that participation was optional and would not impact the services they receive from DACSSA.

"We're dedicated to checking in on our clients to see how they're going during COVID-19. As advocates we want to feed information back to government and the Disability Royal Commission to make sure people with disability have the supports they need. I'm wondering if you're willing to participate in a 5 minute survey. Your information will be anonymous".



Method of Research and Participant Recruitment

Social enquiry methods used to undertake the research included both quantitative and qualitative techniques. Per article 21 of the UNCRPD, DACSSA wanted to champion the stories and lived experiences of people with disability which is why semi-structured interviewing methods were used in combination with directive questions. This allowed promotion of qualitative data that was rich and facilitated greater insight into the experiences of participants (Creswell 2016). This emulates an interpretative phenomenological approach aimed at gaining insight into personal lived experience, the ecology of a person and their social reality.

Method of research were chosen with consideration for:

- a. Dignity and Empowerment
 - i. Methods chosen underwent scrutiny for their ability champion lived experience;
 - ii. Promote empowerment and self-determination;
 - iii. Allow for recourse and intervention if required;
 - iv. Consider experiences of diverse groups e.g. First Nations people and those from culturally and linguistically diverse backgrounds.
- b. Accessibility
 - i. The methods allowed for participation that did not compromise DACSSA's ability to safeguard with respect to national distancing requirements.
 - ii. The opportunity to participate and provide feedback was required to be accessible for clients.
 - iii. Supported decision making principles were available if it facilitated equitable access to participation per Article 21 of the UNCRPD.
 - iv. Participation needed to be facilitated in a way that considered re-traumatisation and ethical considerations for the use of free provisions of expertise of disability through lived experience. For this reason, the methods were chosen as they were able to be exercised in a short timeframe as to avoid burden, oppressive practice or harm to the participant.
 - v. The methods allowed for helpful services such as Translating and Interpreting Services, counselling support, decision making support and peer support if required or chosen by the participant.
 - vi. Staff administered the survey to their own case load where possible to promote person-centredness and continuity for the participant.
- c. Safeguarding Responsiveness

- i. DACSSA's policies and procedures allowed for safeguarding measures to be taken where participation would bring about risk to the person or to DACSSA. This meant that some active clients may not have been reached or pursued.
 - ii. Participants were offered referral information if their participation gave rise to issues beyond the scope of DACSSA, or within the scope of already established services relating to COVID-19 or other matters.
 - iii. Participants were supported to explore disability related issues born from COVID-19 and offered advocacy assistance from DACSSA if the disability related issue was within scope. DACSSA has comprehensive assessment and triaging mechanisms that assisted to safeguard those should their disability related issue denote an urgent response.
- d. Responsiveness and Intervention
- i. DACSSA balanced the value of eliciting insight in a timely manner, with the need to exercise great caution for the wellness of people with disability who;
 - Experience higher levels of mental illness
 - Experience higher levels of health and comorbid issues
 - ii. For this reason, DACSSA prioritised wellness and willingness, over efforts to gain as much data as possible.

There were 5 questions directed by the advocate that pertained to demographic information of the participant such as age, gender, disability type, intersectionality considerations and eligibility for NDIS. This information was sourced from DACSSA's client management system and deidentified to protect the anonymity of the participant.

8 questions relating to participants' experiences and the impact of COVID-19 on their lives were administered. All participants were contacted between the 21st April 2020 and the 23rd April 2020. All questions were optional and were able to accommodate communication preferences or support needs. For example, each question had capability for translation into another language, easy English or visual questioning if required.



Demographics

Demographic data of participants are illustrated in figures 2 to 5.

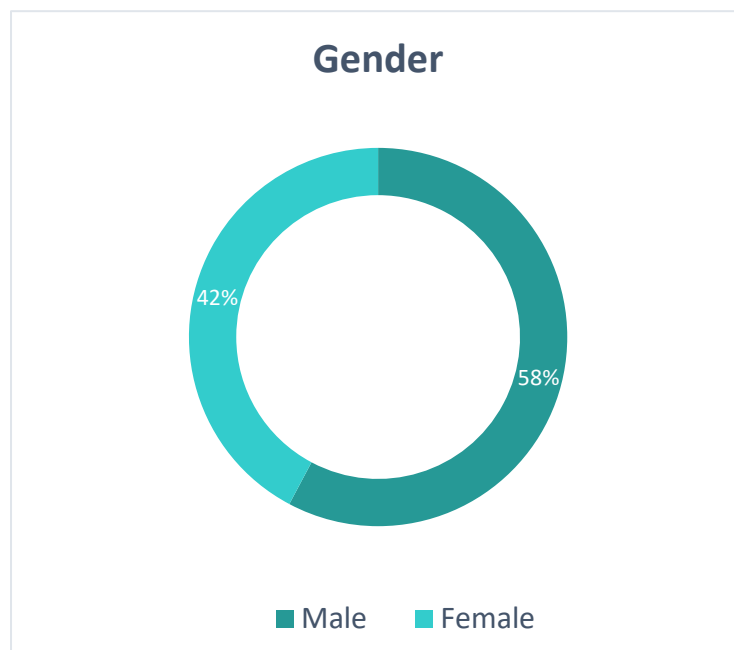


Figure 2 - Gender of participants

Of participants, 26 were male and 19 were female. No participants identified with other genders.

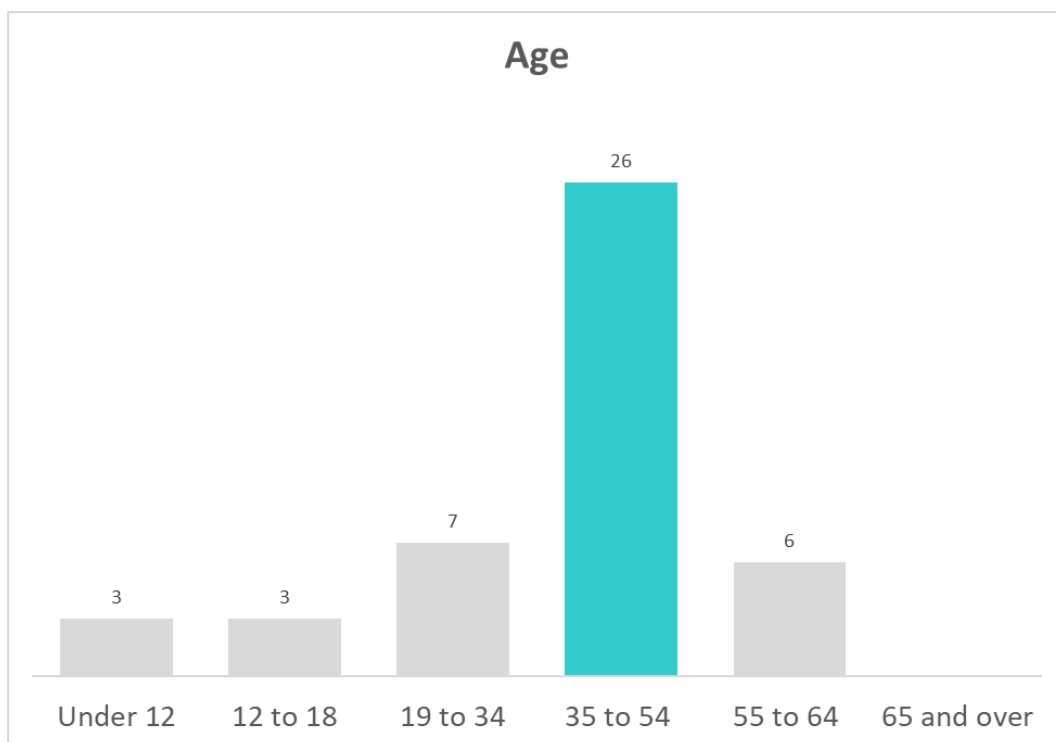


Figure 3 - Age of participants

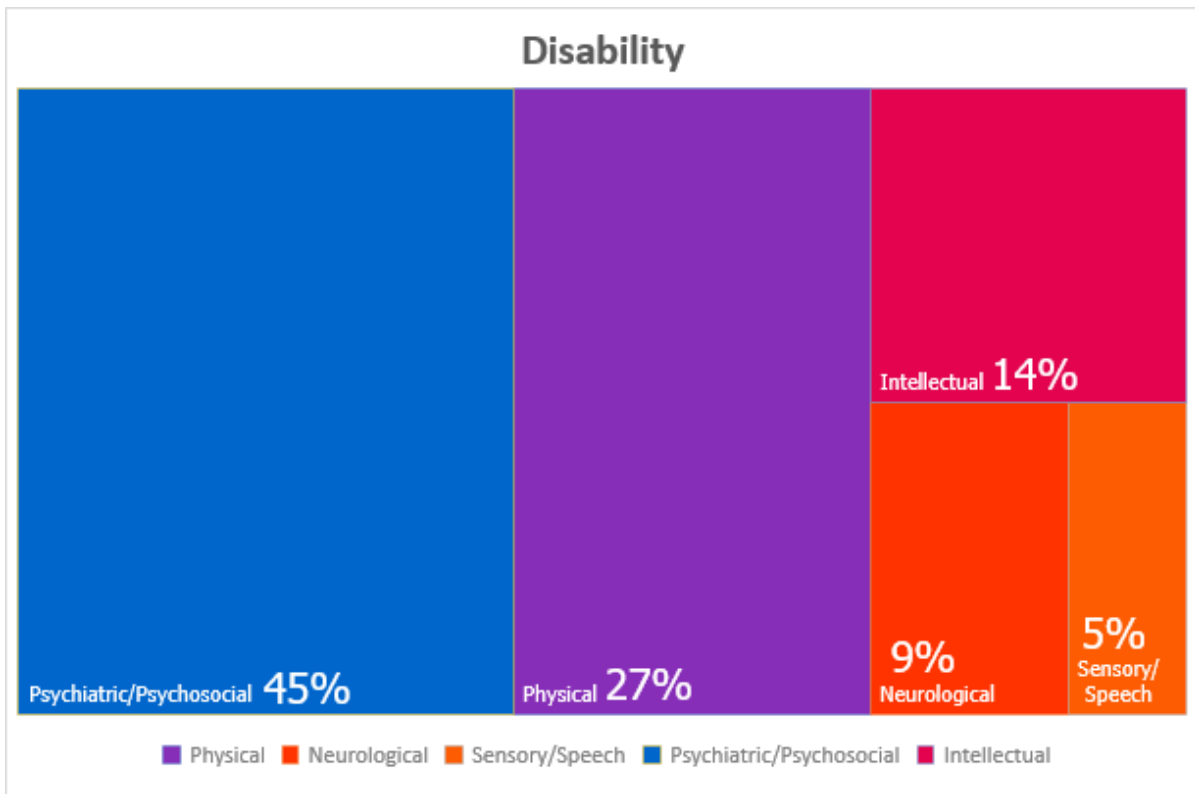


Figure 4 - Disability of participants per Department Social Services Data Exchange Reporting Protocol

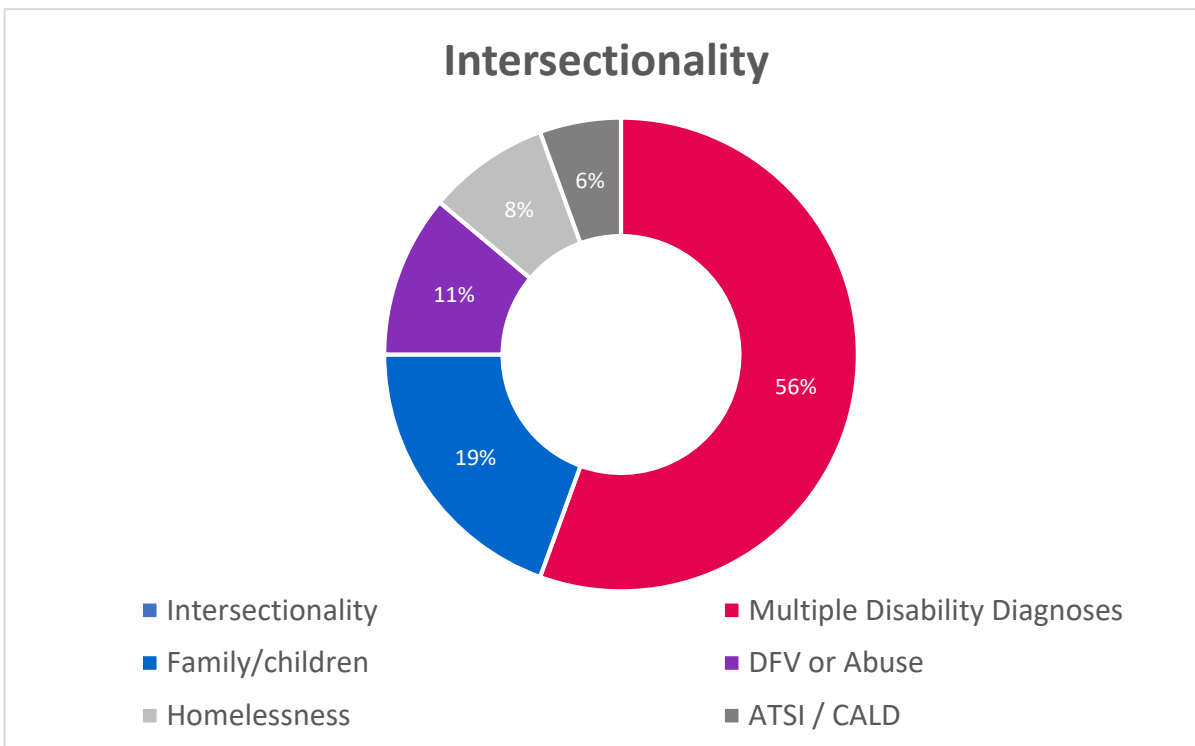


Figure 5 - Intersectionality of participants



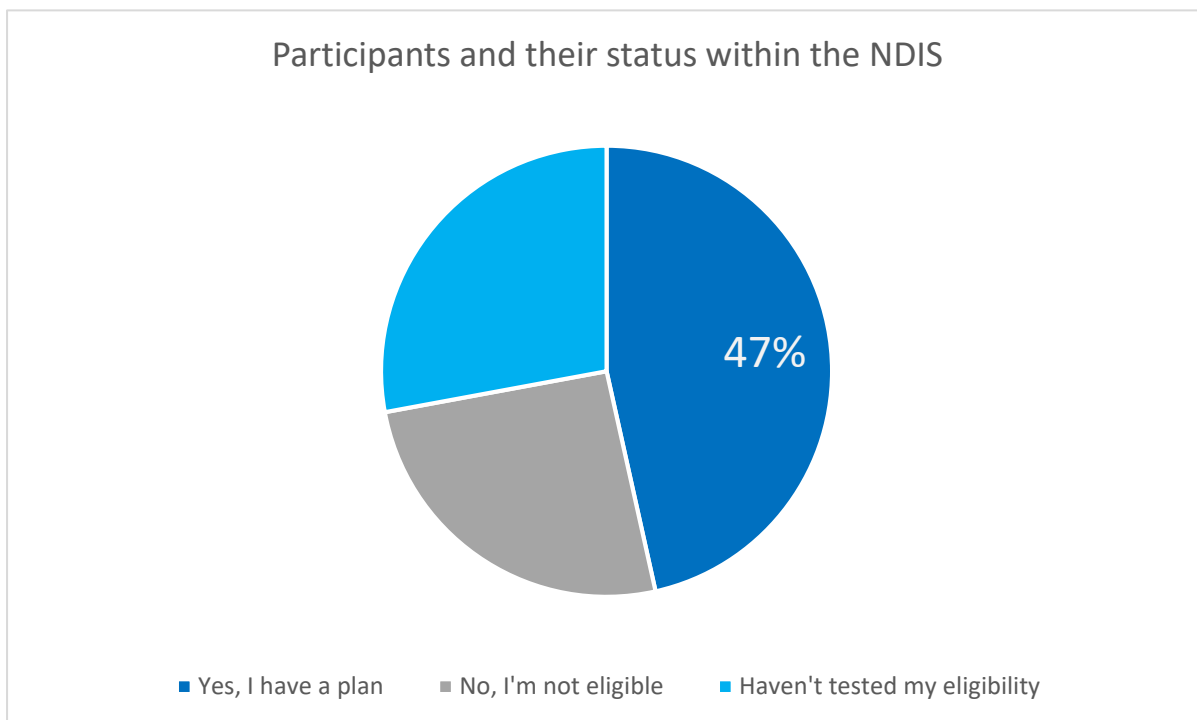


Figure 6 - Involvement of NDIS in participant's lives

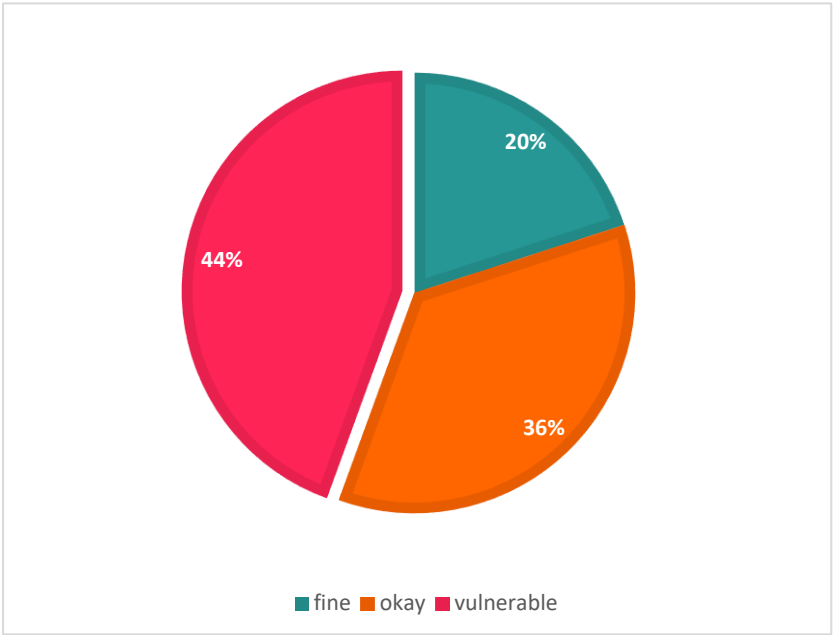
Demographic Results Discussions

1. Demographic data is not representative of the average yearly client base of DACSSA. The data is representative of the demographic details of *active* clients of DACSSA namely, the participants.
2. Over 56% of participants identified with intersectionality, with multiple disability diagnoses and family and children, being the most prominent intersecting factors denoted.
3. DACSSA notes a common relationship within multiple disability diagnoses is the co-occurrence of physical disability and psychosocial disability.

Results

Survey results as below per figures 8 to 14.





Question 1
 "Regarding COVID-19, I as a person with disability feel..."

Majority of those whom DACSSA contacted felt more vulnerable since COVID-19 than they did before.

"Being stuck at home is bad enough, isolated without adequate NDIS support is pushing us to breaking point"

Figure 8 - Feelings of participants

Participants noticed increased feelings of isolation due to interference or discontinuation of services during COVID-19 restrictions.

Most commonly, this was noted to be because of social distancing that prohibited interaction with service providers.

While social distancing can have a toll on the wellness of the general population, people with disability who are more likely to rely on others for their support needs and facilitation of community access are more disadvantaged amidst COVID-19.

"I am feeling isolated can't get to see my friends".

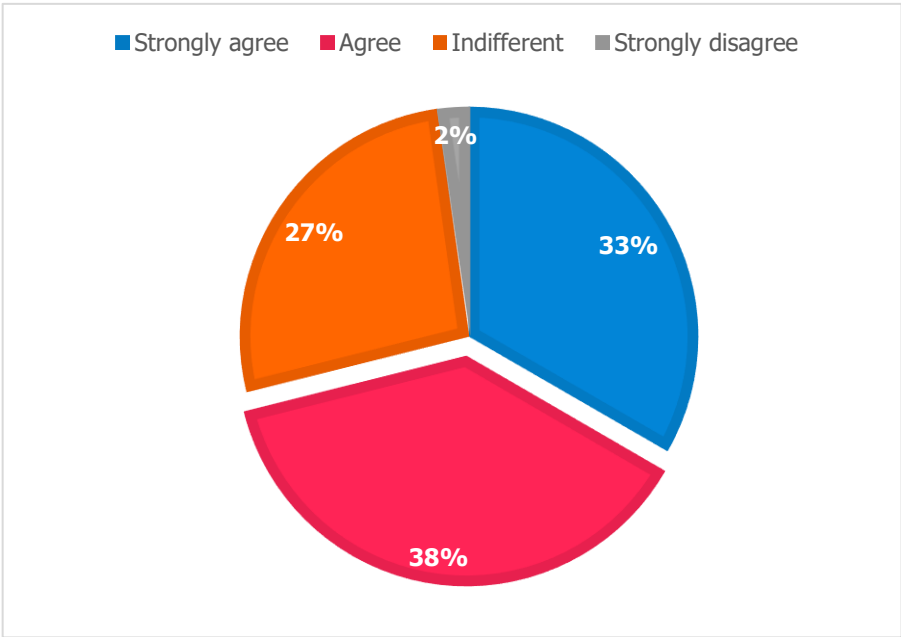


Figure 7 - Participants' feeling of isolation since COVID-19

Question 2
 "I'm more isolated than I was before COVID-19..."



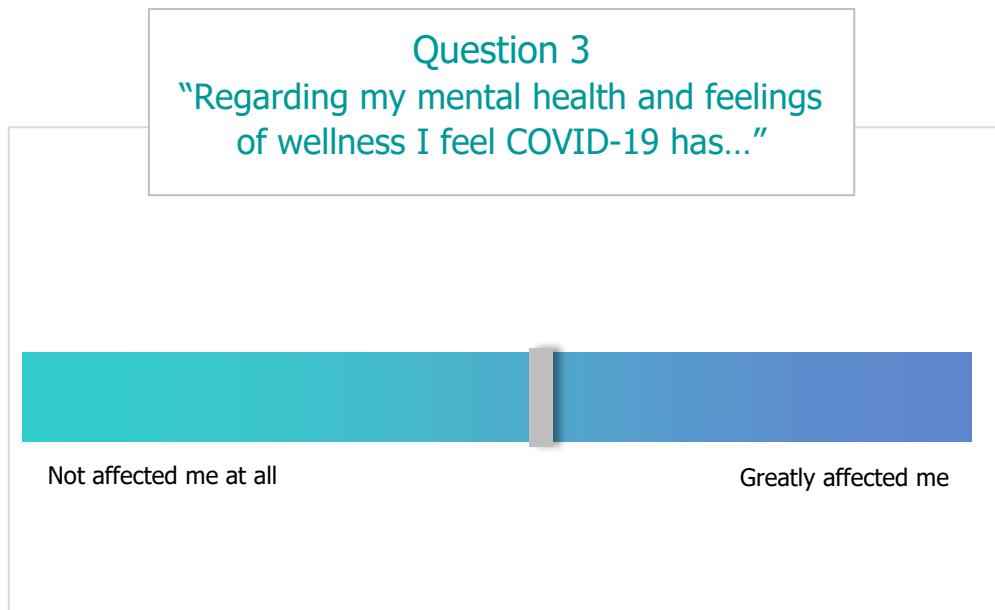


Figure 9 - Mental health and wellness of participants

Participants identified with a diminished sense of mental health and wellness subsequent of the isolation they were experiencing, and other factors depicted in figure 9. Participants discussed with DACSSA how their susceptibility to illness and risk of contracting COVID-19 was their primary concern. This concern was commonly paired with the concern for a lack of PPE available to participants.

DACSSA noted a concerning prevalence of 'risk of abuse' among the primary concerns identified by participants. Through their relationships with DACSSA, these participant's matters were not categorised as abuse related. This means that despite being clients of DACSSA, the issue they were working with an advocate to resolve, wasn't pertaining to abuse. **This evidenced to DACSSA that COVID-19 and its impact brought about fear of abuse for participants for the first time.**

DACSSA raised issues of equitable access to supports and vulnerability to abuse in their ABC radio interview on the 4th May 2020. DACSSA raised that findings from this research indicated people with disability are significantly disadvantaged and experience increased risk of abuse subsequent of COVID-19.

"I hate feeling trapped and I feel more isolated. I worry a lot about my son who is also suffering because of the isolation".

"We're all in same boat so I don't feel any different from anyone else in this".

"I am feeling very confused and do not understand why I can't attend my day options".

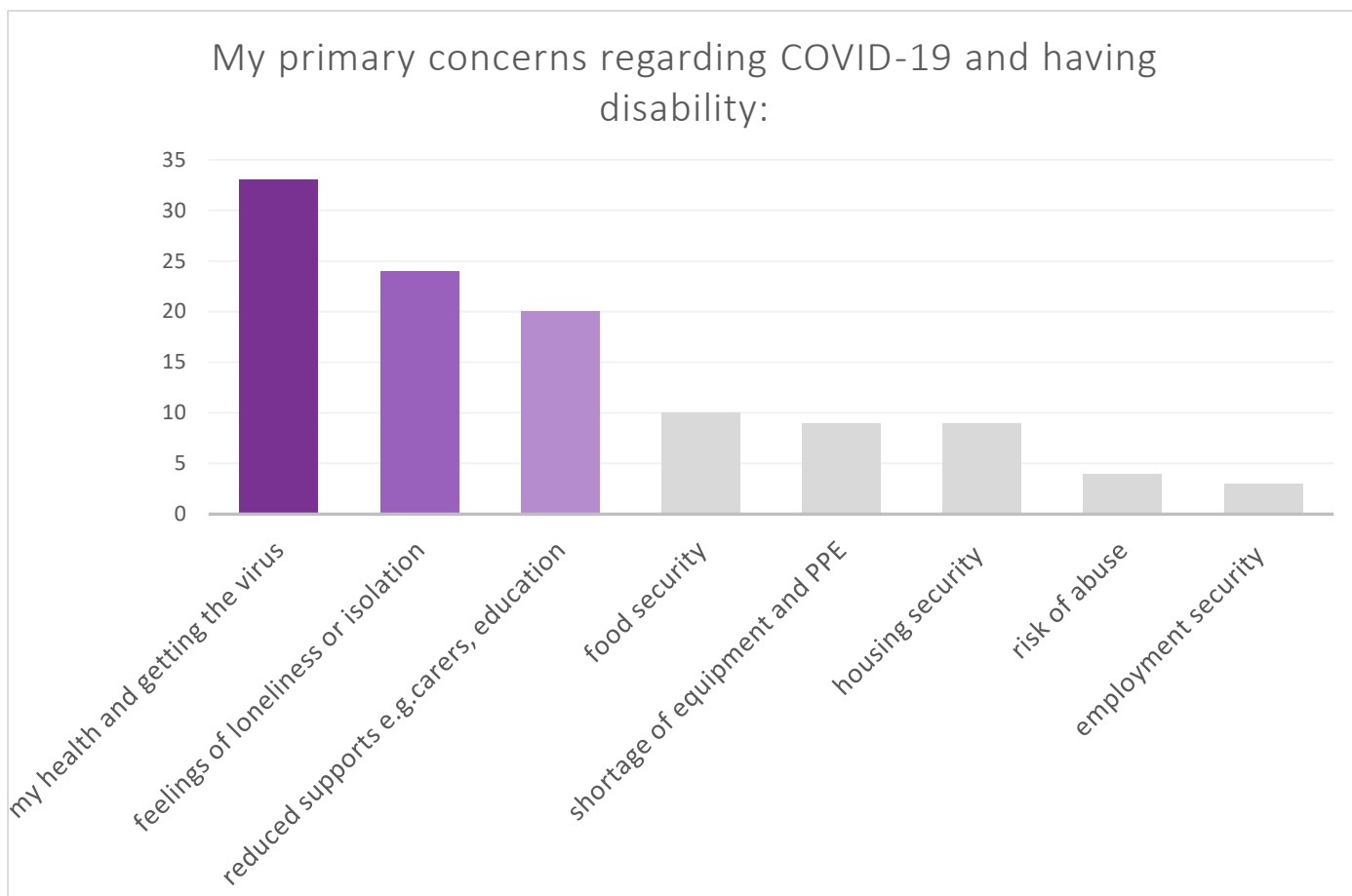


Figure 10 - Primary concerns

Question 4

“The thing that most concerns me about COVID-19 is...”

Participants were experiencing issues and concerns relating to the provision of supports.

Feelings among participants was confusion, frustration and discrimination as they noted huge inconsistencies with their service providers. **For example, some service providers were ceasing or restricting access to services, others were not.**

Parents of children with disability noted significant disruption and difficulty maintaining the high and complex needs of their children

during remote learning times. This had an impact on family wellness as many parents reported financial burden, disruption to work opportunities and a struggle to balance support requirements.

"I cannot access university at all now and cannot study at home as I cannot afford a computer. There needs to be a disability access room available during this time".

"I am concerned about being evicted during this time, despite the regulations that have been implemented by the government. If I get evicted, I will not have anywhere to live during this time. The government needs to completely suspend evictions for people with disability".



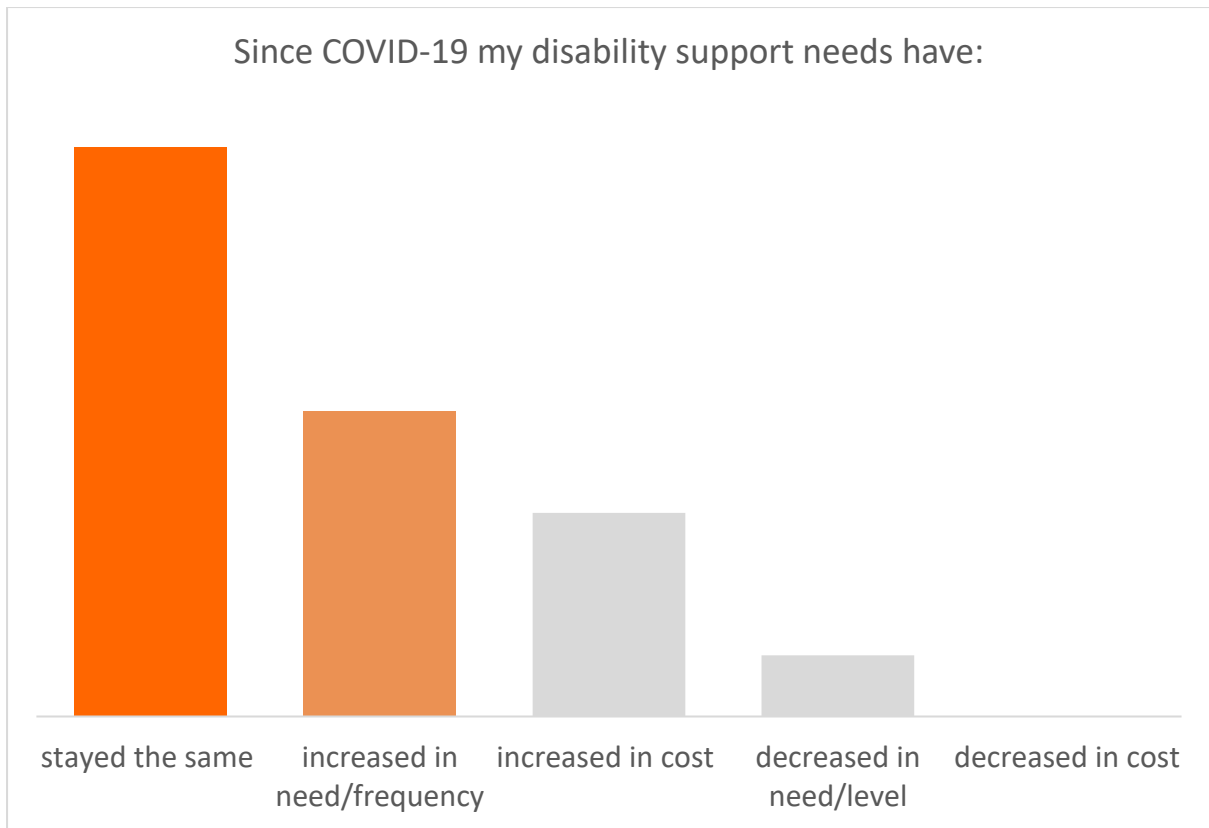


Figure 11 - Status of support needs

Question 5

"Since COVID-19 my disability support needs have..."

"I have greater reliance on people to do things for me as not to risk contracting the virus e.g. to get my medications".

"I have stopped using public transport to get to work and now rely on my wife to give me a lift".

"We've had to look for a new house during this time which has been incredibly difficult".

"I'm not getting any help and not hearing anything from my service providers".

"Things have definitely been harder as support workers haven't been available".

People with disability are more likely to rely on others for support. **COVID-19 physical distancing restrictions puts people with disability at risk of being denied critical supports** such as personal care, nutrition and community access.



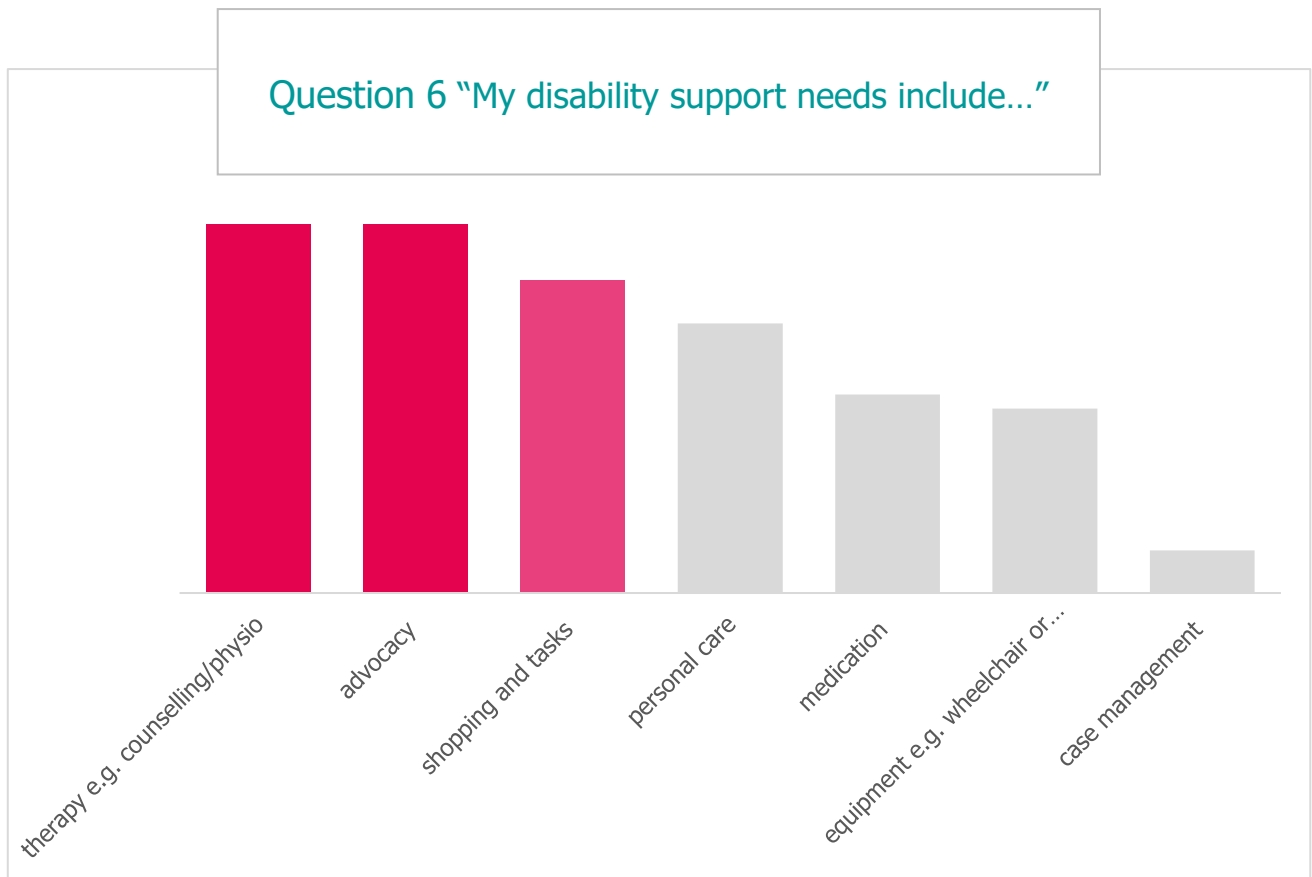


Figure 12 - Types of support needs

"My access to my Social Worker has been reduced".

"I am discouraged from having face to face appointments with my GP".

"I am struggling to get to different supermarkets to find toilet paper. I am limited to my regular/local stores, and I cannot get a delivery".

"I have to have meetings via Zoom which makes it very difficult for the Auslan interpreter".

"I don't know where to go for support".

For those who identified their needs had increased in frequency or amount of support, those supports usually pertained to therapy or daily living assistance. These supports were those most affected by social distancing measures. As such, **these were the supports people identified as the most important but unable to be accessed.**



Per figure 12, participants reported that their disability related needs had stayed the same or increased. Pertinent is the fact that those who reported their needs had stayed the same or increased, often reported that their support needs were harder to access. See figure 13.

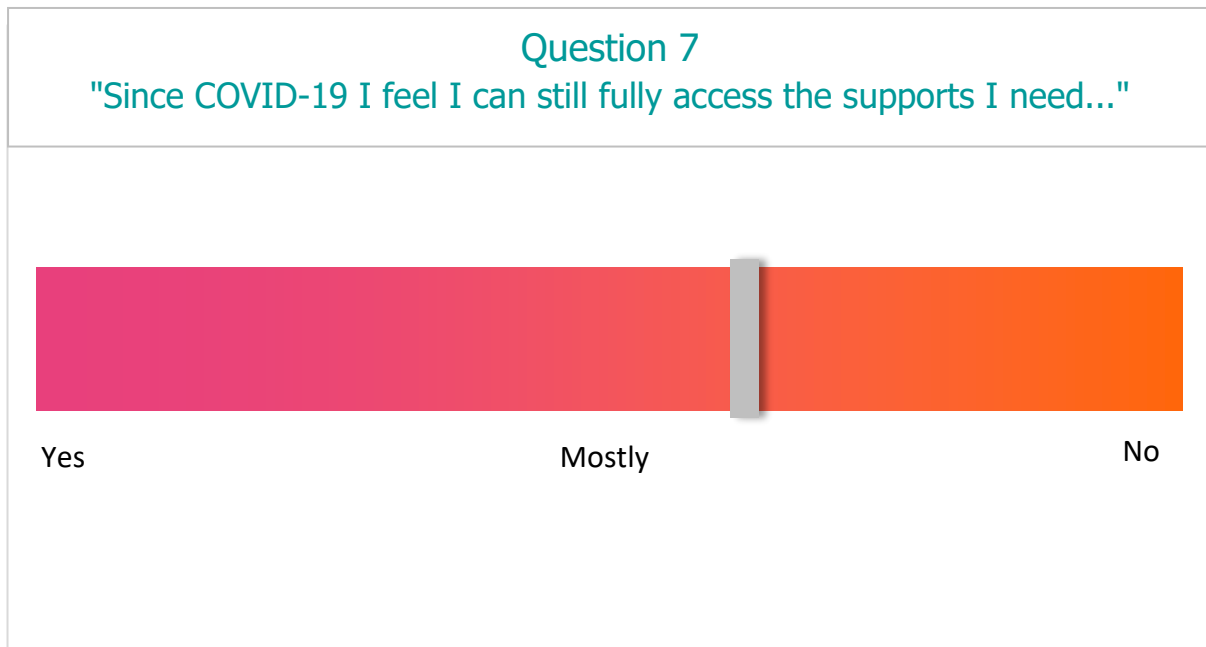


Figure 13 – Access to required supports

Per figure 12, participants reported that their disability related needs had stayed the same or increased. Pertinent is the fact that those who reported their needs had stayed the same or increased, often reported that their support needs were harder to access. See figure 13. There was an instance reported by a participant whereby COVID-19 restrictions affected the delivery of critical feeding supplies for a young person with profound disability.

"I have lost my job so I'm feeling vulnerable with that and the employment agency hasn't been much help".

"I lost my nursing services and was not informed how they'd be reinstated"

"I am feeling very confused and do not understand why I can't attend my day options"

"I haven't been able to get into the hospital to get a new orthotic fitted".

"Food and supplies for PEG have experienced delays of up to a week which puts her at huge risk and me".



Question 8

“During emergencies such as COVID-19 I could be better supported if...”

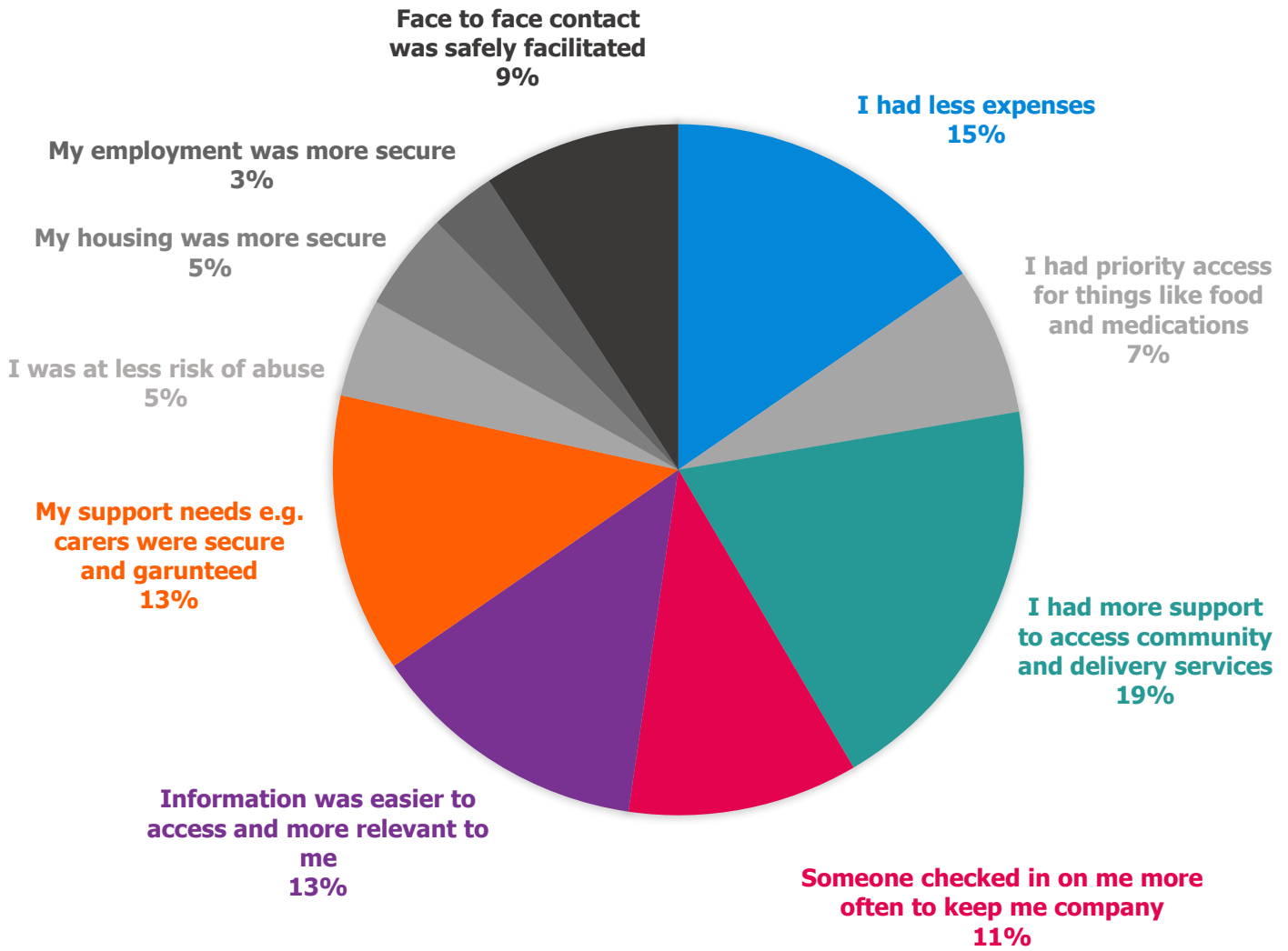


Figure 14 - Opportunities for systems reform to safeguard people with disability

DACSSA implores the state and federal governments to act in the interests of people with disability to protect their rights, safeguard them from abuse and ensure equitable access supports services.

Conclusion

DACSSA serves to highlight the lived experiences of people with disability. Conclusions and recommendations about reforms the Australian government urgently need to make are captured in the quotes from participants.

Key findings of this report:

1. Participants who identified that their support needs had increased, also reported these support needs weren't adequately facilitated. This was inclusive of NDIS supports but also pertained to supports relating to health, transport, facilities and education.
2. A systems response was insufficient in ensuring critical supports could be continued safely. This was evident in the concerns for access to personal protective equipment.
3. Discretion of providers to deny or postpone supports was felt by participants to be discriminatory as a consistent service response wasn't evident, rather some providers continued supports while others didn't.
4. Participants highly value face-to-face support for the purposes of maintaining daily living needs and accessing community. Participants were largely dissatisfied and struggled to derive the same satisfaction or support from services that were required to be via video or teleconference.
5. Participants felt an increase in the need for clear communication and information and as such relied more on advocacy to understand the current situation.

Relevant Literature, Documents & Policy

- On the 31st March 2020 a letter from the United Nations Special Rapporteur to the Disability Royal Commission Chair was issued, outlining key concerns for considerations of disability amidst a pandemic.
- On the 3rd April 2020, the Disability Royal Commission Chair responded to the letter from the UN Special Rapporteur.
- On the 15th April 2020, a Statement of Concern written by experts in human rights and bioethics addressed the Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19) and outlined concerns for people with disability. The statement was endorsed by DACSSA and included recommendations for ethical decision making with regards to disability supports and health care.
- In April 2020, the Australian Government established the Advisory Committee on Health Emergency Response to Coronavirus (COVID-19) for People with Disability (the Advisory Committee).

- In April 2020 the Australian Government published the Management and Operational Plan for People With Disability as part of the Australian Health Sector Emergency Response Plan for Novel Coronavirus (COVID-19).

Other References:

Creswell J 2016, '30 essential skills for the qualitative researcher', united states of America, SAGE

Denzin N, and Lincoln Y 2011, 'The Sage handbook of qualitative research' 4th edn. SAGE publications, thousand oaks, California.

