

“The Responsibility has Fallen on Us”
Perspectives on the impact of COVID-19
on Women* and Girls with Disabilities in
the ACT and Region

for

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

Winner 2012 International Women’s Day Award, Community Category

Winner 2015 ACT Chief Minister’s Inclusion Awards, Excellence in Championing Human Rights

STRONG WOMEN STRONG VOICES

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I don't feel that the disabled have been heard throughout this pandemic.

Like those with temporary visas we have been forgotten. The disabled have not been talked about, their issues, the increased risk of abuse as we are locked down and the lack of services to the home as service workers are locked down. Able bodied people have issues too but they are not life threatening and immediate as those with a disability, especially the physically disabled who depend on outside services to literally survive and are expected to get by without those services during the pandemic.

- *WWDACT Covid-19 Survey Respondent.*

WWDACT

Women* with Disabilities ACT (WWDACT) is a systemic advocacy and peer support organisation for women, girls, non-binary and feminine identifying people with disabilities in the ACT. WWDACT follows a human rights philosophy, based on the Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Elimination of (all forms of) Discrimination Against Women (CEDAW). WWDACT is a Disabled People's Organisation, governed by women* with disabilities, and its proposals and recommendations to government are consistent with Article 4 (3), and Article 29 of CRPD which outline the imperative for consultation with disabled peoples.

* **Note:** Throughout this document, and generally, WWDACT uses “*Women * with disabilities*” to refer to women, girls, feminine identifying and non-binary people with disabilities.

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Women with Disabilities ACT acknowledge and pay respect to the Ngunnawal peoples, the traditional custodians of the ACT Region, on whose land our office is located. We pay our respects their Elders past, present and emerging. We acknowledge their spiritual, social, historical and ongoing connection to these lands and the contribution they make to the life of the Australian Capital Territory.*

1. Background

WWDACT has many years of experience researching and writing about the rights of women* with disabilities to have the freedom to make their own decisions and have control of their bodies, sexuality and relationships.

Recent relevant publications include:

- **Contraception and Consent: A Comparative Analysis of the Legal Frameworks for Accessing Contraception**, August 2017 (Part 1 of this project)
- **WWDACT Letter Supporting the Crimes (Consent) Amendment Bill 2018**, March 2018
- **WWDACT Submission to the Justice and Community Safety Directorate: Sexual Assault Guidelines – Restorative Justice Referrals**, February 2018
- **WWDACT Submission to Discussion Paper: Domestic and Family Violence – Policy Approaches and Responses**, September 2017
- **Contributing our voices! A summary of feedback from the Have Your Say! Forum with women with disabilities in the ACT**, September 2015

These publications are on the WWDACT website: www.wwdact.org.au/publications/.

In 2018 WWDACT agreed to expand membership to women, girls, feminine identifying and non-binary people.

2. Introduction

This has been a difficult year for the Canberra community, which is dealing with the impact of smoke, bushfires, hail and now COVID-19 ('COVID'). Early in the crisis WWDACT identified COVID-19 was affecting women* with disabilities disproportionately, given that this was the second major disaster the ACT was facing. The impact of gendered issues in emergency situations have been well proven and researched by bodies like the National Women's Alliance,¹ who have highlighted that women* are disproportionately impacted by disasters. The inequalities caused by disproportionate impacts increase within 'vulnerable cohorts,' such as disability.

WWDACT sought to analyse this issue through a feminist lens that is inclusive of the experiences of women* living with a disability in the ACT through this survey and interviews, the results of which are summarised in this report.

Ultimately, these findings should inform WWDACT's strategy in responding to the Royal Commission into Disability and help inform recommendations into how the risk of women* with disabilities experiencing violence, abuse, neglect and exploitation at these times can be prevented.²

¹ National Women's Alliance (March 2020). *Disaster Recovery, Planning and Management for Women, their Families, and their Communities in all their Diversity*. Joint Position Paper on the National Women's Alliance 2020. Available at:

<https://www.aph.gov.au/DocumentStore.ashx?id=37c90c3b-9a94-4ccf-ad85-ccde5dbce092&subId=680441>

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

3. Methodology

WWDACT was granted funding for a COVID-19 Project Officer by the Disability Advocacy Network of Australia, enabling them to survey and assess the needs to women* and girls affected by disability in the ACT and region during COVID.

The survey for women* with disabilities was written in plain English. WWDACT had access to a paid Survey Monkey account, enabling the design of a detailed survey with 25 questions. The questions were designed to elicit information about women*'s experiences during COVID.

The survey was distributed online through the following methods:

- By email to key stakeholders
- WWDACT Newsletter
- WWDACT website
- WWDACT Social Media
- ANUSA Social Media

Samples of social media promotions, distributed through Facebook advertising tools, have been included in Appendix 3.

While the survey was primarily intended for those living in the ACT, it was open for anyone to complete. A question on location was included so we could compare the data of those from areas other than the ACT.

Interviews

We were able to complete interviews with a total of 10 respondents. Due to time restrictions, it was determined that interviewing all 18 respondents may be impractical.

Each interview was designed to allow a free flow of conversation and cover key issues experienced by the respondents.

A skeleton questionnaire was designed as a guide, with questions dependant on the survey responses already provided and each interviewee's unique profile. Questions were also informed by the Issues Paper into Emergency Planning and Response issued by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disabilities.³ WWDACT had also identified that knowledge of ethical guidelines for people with disabilities in emergency response situations was a matter of key concern in emergency response planning.

A question around knowledge of ethical guidelines was introduced to better understand existing attitudes and knowledge around this. The responses received will allow us to make recommendations on improving awareness of rights in healthcare for women* living with a disability.

Survey for Women* with Disabilities

Seventy-two (72) women* with disabilities completed the survey. All completed the survey independently. The survey was followed by interviews conducted with a small group of respondents who consented to further contact from WWDACT for the purposes of informing this report, recommendations, and feedback.

³ Available at: <https://disability.royalcommission.gov.au/system/files/2020-07/Issues%20paper%20-%20Emergency%20Planning%20and%20Response.pdf>

4. Results

4.1. Survey – for Women* with Disabilities

Seventy-one (72) women* with disabilities completed the survey.

All respondents (72) completed the survey independently.

Question 1. Age of respondents

What is your age?

- *Under 18*
- *18-24*
- *25-34*
- *45-54*
- *55-64*
- *65+*

The survey was completed by women* from all categories above the age of 18, offering a generous range of opinions and perspectives on their experiences of COVID.

Table 1: The Age Distribution of Women Respondents.*

Age Distribution of women* respondents	n = 72
Under 18 years old	0
18-24 years old	12
25-34 years old	17
35-44 years old	10
45-54 years old	16
55-64 years old	9

65+	8
TOTAL	72

Question 2. Where are you located?

The survey primarily intended to gather responses from women and girls in the ACT, though the option for others from across Australia to complete this remained. The perspectives of those from regions other than the ACT remain relevant and the identification of their state allowed for analysis of similarities/comparison of circumstances. On review, this report does not touch on state by state comparisons as the responses provided by respondents were general and not necessarily specific to their state.

Most survey respondents (87.50%) were from the ACT. This was followed by four respondents from New South Wales, two respondents from Tasmania and Victoria each and one from Western Australia.

Table 2: Location of Survey Respondents by State

State	%	n = 72
ACT	87.5%	63
VIC	2.8%	2
NSW	5.6%	4
QLD	0%	0
SA	0%	0
NT	0%	0
WA	1.4%	1

TAS	2.8%	2
TOTAL	100%	72

Question 3. Are you a person with a disability?

The vast majority (64) of respondents out of 72 identified as living with a disability.

Table 3: Distribution of Respondents identifying as living with a disability

Respondents identifying as living with a disability	n = 72
Living with a disability	64
I do not have a disability	8
TOTAL	72

Question 4. Do you Identify as any of the following?

1. *Person of Colour*
2. *Refugee*
3. *Migrant*
4. *Female*
5. *Male*
6. *Transgender*
7. *Non-binary*
8. *Intersex*
9. *Gender non-conforming*
10. *Same-sex attracted*
11. *Bisexual*
12. *Pansexual*
13. *Aboriginal and/or Torres Strait Islander*
14. *I prefer to describe this myself/something is not listed here*

The majority of our survey respondents identified as women* and five respondents identified as gender non-conforming.

Table 4: Demographic Information

Demographics	%	Respondents n = 72
Person of Colour	13.9%	10
Refugee	0%	0
Migrant	5.6%	4
Female	84.7%	61
Male	0%	0
Transgender	1.4%	1
Non-binary	8.3%	6
Intersex	0%	0
Gender non-conforming	6.9%	5
Same-sex attracted	8.3%	6
Bisexual	20.8%	15
Pansexual	5.6%	4
Aboriginal and/or Torres Strait Islander	5.6%	4
I prefer to describe this myself	8.3%	6

Under the 'other' option, one respondent noted that they identified as 'genderqueer' and another respondent used this option to add that they identified as 'queer.'

Question 5. What language/s do you speak?

Most respondents noted that they spoke English, with some listing a second language. Second languages spoken by survey respondents include Mandarin, Chinese, Malay, Auslan, Greek, Japanese, Urdu, Darug/Iyora, French and Spanish.

Question 6. Do you require interpreting support and/or in-language information?

Most respondents noted that they spoke English and listed a second language, as noted above. None of our survey respondents reported that they required translated information and/or resources.

Question 7. Caring Responsibilities before and after COVID-19

Were you affected by any of the following caring responsibilities BEFORE COVID-19? Please select all that apply. You may select 'I prefer to describe this myself' if you would like to provide further detail or comments.

- *I care for children*
- *I care for an adult*
- *I do not have any caring responsibilities*
- *I am supported by a carer*
- *I prefer to describe this myself*

A total of 68 respondents completed this question. Those without any caring responsibilities formed the majority of respondents, followed by those who care for children, those who care for adults and those supported by carers themselves.

Respondents who opted to describe their situation noted *ad hoc* caring arrangements where they may not identify as a full-time carer but supported family members who required care from time to time.

Table 5: Caring Responsibilities BEFORE COVID-19

Caring responsibilities before COVID-19	Responses (n=68 respondents)
I care for children	16

I care for an adult	7
I do not have any caring responsibilities	32
I am supported by a carer	10
I prefer to describe this myself	13

Q8. Changes since COVID-19

Has your situation changed since COVID-19? Please select all that apply:

- *I am now caring for someone as a result of COVID-19*
- *My caring responsibilities are the same but have increased as a result of COVID-19*
- *I have caring responsibilities and my situation has not changed*
- *I do not have caring responsibilities and my situation remains the same*
- *I have experienced disruption to my usual carer support*

Less than half of the 68 survey respondents who completed this question did not have caring responsibilities and reported that their caring situation remained the same post COVID-19. This was followed by respondents who reported that their caring responsibilities had increased and then by those who had experienced disruptions to usual carer support.

A small portion of respondents (3) reported that they were now caring for someone as a result of COVID.

Table 6: Caring Responsibilities AFTER COVID-19

Caring responsibilities AFTER COVID-19	Responses (Respondents n = 68)
I am now caring for someone as a result of COVID-19	3
My caring responsibilities are the same but have increased as a result of COVID-19	18
I have caring responsibilities and my situation has not changed	6
I do not have caring responsibilities and my situation remains the same	32
I have experienced disruptions to my usual carer support	16

Conversely, one respondent noted that the level of support they received during COVID had actually increased for the following reason:

“Unfortunately there was no option to select that my level of support has increased as a result of COVID-19. My partner works for the federal government and the shift to WFH [Working from Home] has allowed him to provide care and support for me in a much greater capacity than before. This has had significant benefits in that it has allowed for greater flexibility in managing our work and study commitments whilst reducing the impact of my illnesses on the structure of our lives.”

Many responses highlighted service and carer disruptions, leaving respondents with disabilities lacking support to go outside and complete essential tasks, like personal shopping and exercise, with a reasonable level of autonomy.

One respondent who selected that they had experience disruptions to their usual carer support explained:

As I am unable to drive due to health reasons, I often use public transport to get around. My family was uncomfortable with the potential risks of contracting COVID-19 while using public transport, so I have not used public transport for ~3 months now. This has meant I have to rely completely on my husband and my parents being able to get me to and from work and to take me anywhere else I need to go.

The impact these disruptions can have on long-term growth and recovery, physically and mentally, cannot be accurately understood from this survey alone. It is critical to recognise the ‘setbacks’ women* with disabilities have been forced to navigate due to issues like increased caring responsibilities and disruptions to their own carer support. The responses affirm the complex identities women* with disabilities must navigate and that the impact on their lives is on various levels, underlining need to intersectional approaches to response planning.

Q9. Living Situation

What best describes your living situation?

- *Living alone*
- *Living with a partner and nobody else*
- *Living with a partner and children*
- *Living with children as a single parent*
- *Living in a family home with other family members*
- *Living in a share house*
- *Private rental*

- *Government housing*
- *Private home (owned)*
- *University lodging*
- *Residential Care*
- *Other (Please specify)*

Most survey respondents reported living with a partner and nobody else. The second largest category were those living alone, followed by those who lived in a privately owned home, private rentals, share houses and those living in family homes. Five respondents reported living in government housing and none of the respondents selected university lodging or residential care.

Table 7: Living Situation of Respondents

Living Arrangements	Responses (65 respondents)
Living alone	16
Living with a partner and nobody else	20
Living with a partner and children	8
Living with children as a single parent	6
Living in a family home with other family members	6
Living in a share house	9
Private rental	10
Government housing	5

Private home (owned)	13
University lodging	0
Residential Care	0
Other (please specify)	3

The 65 respondents to this question about their living arrangements shows the range of caring responsibilities that they have and a diverse configuration of accommodation options. Of those who selected the 'other' option, one respondent noted that they were living in temporary short term accommodation, while another noted that they had temporarily moved back in with family whilst maintaining rental payments for existing living arrangements. The third respondent used this option to clarify that they lived at home with children and to care for their sick mother.

WWDACT found it was important to gather data on the various living situations of our respondents, as our survey is unique in gathering data on this particular cohort where the various identities of women* with disabilities are often lost, failing any intersectional approaches to analysis and response planning.

When analysing multiple response combinations, those who selected living alone as a single option composed most of these responses. This is followed by those living with a partner and nobody else, those living with a partner and nobody else in a privately owned home, those living in a share house only and those living in a family home with other family members only.

The following options and combinations were selected by three respondents each: living with a partner and children, living with a partner and children in private rental,

living with a partner and children in a privately owned home, living with a partner and nobody else in a private rental. Two respondents each selected the following: living alone in government housing, living with children as a single parent and living with children as a single parent in government housing.

These responses have been tabulated below.

Table 7.1: Living Arrangements – Response Table

	<i>Living alone</i>	<i>Living with a partner and nobody else</i>	<i>Living with a partner and children</i>	<i>Living with children as a single parent</i>	<i>Living in a family home with other family members</i>	<i>Living in a share house</i>	<i>Private rental</i>	<i>Government Housing</i>	<i>Private Home (Owned)</i>	<i>University lodging</i>	<i>Residential Care</i>	<i>Other</i>
<i>Living alone</i>	11											
<i>Living with a partner and nobody else</i>		8										
<i>Living with a partner and children</i>			3									
<i>Living with children as a single parent</i>				2*								
<i>Living in a family home with other family members</i>					5							
<i>Living in a share house</i>		1				7						
<i>Private rental</i>	1	3	2	1*	1	1						
<i>Government Housing</i>	2			2				1				
<i>Private Home (Owned)</i>	1	7	3	1					1			
<i>University lodging</i>												
<i>Residential Care</i>												
<i>Other</i>	1*											3
TOTAL	16	20	8	6	6	8	0	1	1	0	0	3

Total respondents: 65 of 72. Asterisked figures indicate a respondent who elaborated on responses through 'other.'

Question 10. Concerns about COVID-19

Does anything about your living situation concern you as a result of COVID-19?

- *I am concerned for my physical health*
- *I am concerned for my mental health*
- *I am concerned about my safety*
- *I am concerned about the cost of living*
- *I am concerned about employment*
- *Please describe your situation if you're comfortable*

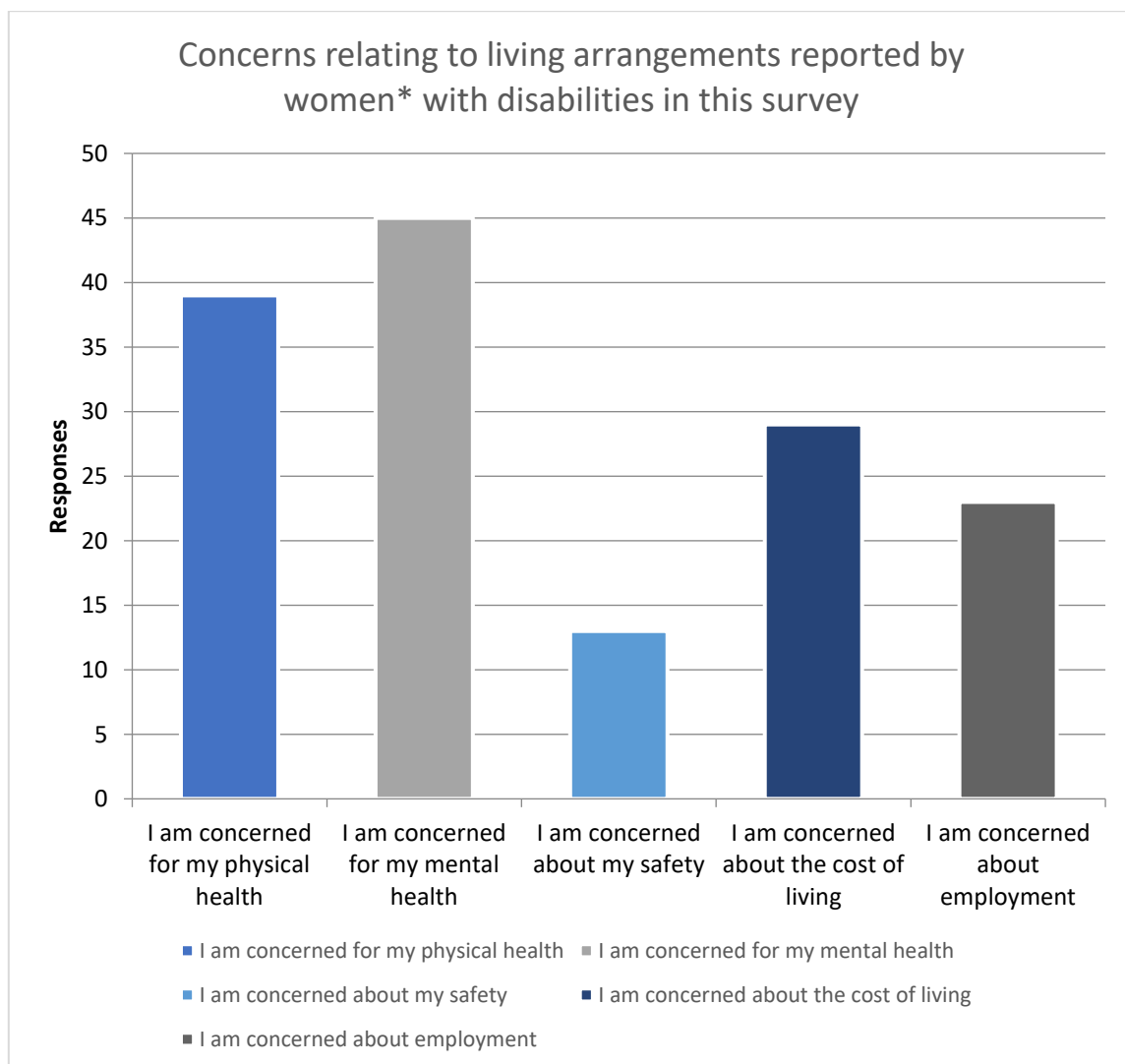


Figure 1: Respondent Concerns - Living Situations

Respondents could select all matters which concerned them. Most survey respondents reported concern for their mental health, followed by physical health, cost of living, employment, and safety.

Those who chose to describe their situation and/or leave comments reported:

I am currently on COVID leave from my job as an educational Interpreter because of my risk if I contract COVID. The pressure from work is immense to make decisions on my return to work on the 1st June. I am still not safe I believe to do that. I have been given the option of going to my doctor and detail what my condition is and why I am vulnerable. This seems like a total breach of my privacy.

Difficulties in identifying as disabled and documentation for disabilities in the context of employment was a common issue raised by respondents. This is further discussed in the discussion portion of this report.

Case Study

There are many instances where these concerns intersect, with emergency situations like COVID forcing people in to difficult and unplanned circumstances. One respondent demonstrated this difficulty in their response:

Concerned about my physical health, finances, and mental health - I am barely getting by financially. Vulnerable people are being told to stay home for our own safety, but I can't afford delivery fees. I can't afford a car, so I have to risk public transport. I can't talk on the phone, so I can't attend my psychology appointments. My face-to-face therapies have stopped so I'm in significant pain, but my usual pain medication is too dangerous to take if I get COVID-19, so I have been prescribed more expensive (and addictive) medication.

The government apparently considers us not to be an important enough sector of society to warrant the coronavirus supplement (even if we lose employment), and has decided that because healthy people will find it difficult to self-isolate, the responsibility has to fall to disabled people to stay home or risk hospitalisation or death. We can't afford to stay home either financially or in terms of accessing vital health services. It's clear that the government thinks we're not worth protecting: if we're so expendable, what's the point in trying to struggle through another exhausting, depressing, painful day?

WWDACT is aware that delivery fees for groceries, pharmacy items and other services were applicable for most services. That is, unless someone was already receiving the pension, they would be charged a delivery fee by most services. We note that very few of our respondents reported that they were receiving the pension and this response is reflective of the fact that delivery fees were an important, added stressor in planning of household budgets during the pandemic.⁴

Question 11. Employment

Select all options that apply to your current situation:

- *Employed, working from home*
- *Employed, no changes to my working conditions following COVID-19*
- *Employed, working from home while caring for children*
- *I am not employed as I care for children*
- *Retired*
- *Unemployed before COVID-19 and looking for work*
- *Unemployed as a result of COVID-19*
- *Unable to work due to disability*
- *I am a student and am continuing study online*
- *I am a student but my course has been suspended due to COVID-19*

⁴ People with Disabilities Australia (PWDA) has reported in their survey that the expenses of people with disabilities has increased. While this survey was not focused on women*, it is a confirmation of the worsened economic situation for people with disabilities. See: <https://probonoaustralia.com.au/news/2020/06/new-survey-reveals-the-financial-costs-of-covid-19-for-people-with-disability/>.

- *Other (Please specify)*

It is noted that because this question allowed for multiple selections, a total of two respondents selected three options each leading to an anomaly in the data. This is further discussed in the limitations section of this report.

On review, WWDACT felt it necessary to provide the individual results of each survey respondent who completed this question and the tabulated version is presented under Appendix 2. Below is a brief overview of the key messages from those responses.

Employed and working from home

This is the largest group of respondents, receiving 28 responses in total. Of these, the highest number of responses were those who only selected this option. Those who selected further options include those who noted no changes to their working conditions, those employed while working from home and caring for children and students continuing study online while working from home.

Employed, no changes to my working conditions

This option was intended to distinguish those who were given the option to work from home as a result of COVID from those who worked in professions where this may not have been possible or this option was not made available to them. Respondent profiles under this option included those who exclusively selected that they experienced no changes to their employed followed by a student who was also continuing study online.

One student who could not continue studying throughout COVID noted:

I am a student but unable to continue study due to the loss of face-to-face therapies that helped keep me well enough to study. With other adults now working from home, I also no longer have access to a computer. Increased financial strain also means I can't afford textbooks, printing, etc. I have pulled out of my studies for the foreseeable future.

General Observations

When analysing responses where respondents selected multiple options, those who were working from home still formed the majority. We have extracted key profiles and comments from this data below:

One respondent, who is also a student and only selected the 'other' option, noted:

I would normally have casual work this time of year but it has been suspended. I am also a student but was unable to cope with online learning at home so had to withdraw from the course.

Another student who selected that they were unable to work due to disability and that they were a student continuing study online noted:

Part time Student but struggling due to disability. Made worse by COVID-19. Find it difficult to study online without proper structure and routine.

This impact of disability and caring arrangements were raised by one respondent, who used the 'other' option to note:

Self-employed, no changes to my working conditions. Cannot work full time because of disability and caring role.

Other respondents who selected the 'other' option either as the only option or as an additional option noted having to work reduced hours due to the economic impact of COVID. In a rather scathing assessment of the gendered impact COVID has had on employment, one respondent who selected only the 'other' option for this question noted:

*Made redundant by ACT Government (it was a non-genuine redundancy) and now refused re-employment in another role due to COVID and a policy so full of loopholes that many others made redundant (with fewer quals and less experience than me) are now being re-hired. **However, these others who have been re-employed seem to be mostly, men...[emphasis added]***

Mental illness was also an issue raised by a respondent in these results, with another respondent who selected 'other' noting:

Have temp work but will be looking for work when it ends. Expecting difficulty in current environment and given have been out of work due to mental illness.

Despite the challenges presented by the responses in this question, we found the availability of an 'other' option has provided WWDACT with a unique insight into the feelings of women* with disabilities and their relationship with employment during COVID.

Question 12. Safety Concerns

Do you have any safety concerns if you continued to work throughout COVID-19? Tell us about your experience of work during COVID-19:

This question received 59 written responses, with some noting N/A; we have included below common themes and extracted important comments made by our respondents. This question was designed to better understand the concerns women* with disabilities may experience whilst working during this pandemic. One survey respondent who does not work noted:

I do not work due to demands of caring for two children with disabilities, and my own pain and fatigue from my disability. Had I been employed outside the home, I would have felt considerably more vulnerable due to immune suppressants I take for my autoimmune condition.

Most respondents in this survey identified as working from home and noted fear in having continued access to working from home arrangements as restrictions lift, with the negotiation of 'reasonable adjustments' being a key matter of concern.

Working from home isn't a guaranteed right where I work, it should be for everyone who is able to be at least a little bit productive at home. Worry about whether I'll be allowed to continue working from home isn't a worry I needed on top of all the others!

Those who continued to work during the pandemic raised concerns about the availability of personal protective equipment and maintenance of social distancing measures in and out of their respective workplaces. One respondent who is a nurse stated:

As a nurse on the frontlines a big concern for me has been access to PPE and social distancing within the workplace. I'm very fortunate that my workplace, managers and co-workers have been diligent with enforcing social distancing between staff and patients (when able). They've also ensured we have access to the PPE we need and the education necessary to use it safely. It has been stressful working during a pandemic but I'm lucky to work with positive staff, we all help keep each other's spirits up even when it's hard.

The difference in learning style and preferences for flexible arrangement like working from home are also an important consideration raised in the comments, as they reflect the importance of choice when discussing personal protection as restrictions may ease. One respondent noted:

More pressure working from online rather than meeting folks face to face for work, as online it's harder for me to understand tone of the conversation, causing more stress and anxiety. Has lead to being unable to work as much.

Question 13. Centrelink Benefits

Were you receiving any Centrelink benefits BEFORE COVID-19?

- *Disability Support Pension*
- *Carer Allowance*
- *Newstart*
- *No, I was not receiving any Centrelink Benefits*

- *Other (Please specify)*

Just over half of the 61 survey respondents who completed this question noted that they were not receiving any Centrelink benefits. The second largest group of respondents were those receiving the Disability Support Pension (DSP), followed by those receiving the carer allowance and Newstart.

Table 8: Centrelink Benefits

Centrelink Benefits	Responses
Disability Support Pension	13
Carer Allowance	2
Newstart	1
No, I was not receiving any Centrelink benefits before COVID-19	32
Other (please specify)	13
TOTAL	61

Most survey respondents who selected 'Other' reported receiving Youth Allowance, family tax benefits, parenting payments, childcare subsidies and one respondent noted receiving the Commonwealth invalidity pension.

Question 14. Changes to Financial Support

Have you applied for any new payments as a result of COVID-19?

- Yes (please specify)
- No

A total of 61 respondents completed this question. A clear majority (95.1%) of respondents reported not having applied for any new payments because of COVID. Of those who selected 'Yes' (4.9%), two respondents reported applying for the Jobkeeper payment⁵ and one reported accessing early withdrawal of superannuation.⁶ Analysis of applications⁷ for early withdrawal of superannuation shows that women are withdrawing a greater proportion of their super balance than men, with a significant proportion withdrawing their entire balance. In the long term this will widen the gender superannuation gap.

Question 15. Coronavirus Supplement

The Government has excluded those receiving the DSP and/or Carer allowances from the \$550 coronavirus supplement payment. How do you feel about this?

A total of 61 respondents completed this question.

Almost all respondents noted the unfairness of people with disabilities having been excluded from this scheme.⁸ Their comments included:

- *It's not good enough! People with a disability are more likely than most to be impacted by COVID and not able to work, so it makes no sense that we have been excluded from the supplement payment.*

⁵ The JobKeeper payment is open to eligible employers to enable them to pay their eligible employee's salary or wages of at least \$1,500 (before tax) per fortnight. More information available at: [https://www.business.gov.au/Risk-management/Emergency-management/Coronavirus-information-and-support-for-business/JobKeeper-Payment-for-employers-and-employees#:~:text=Australians%20in%20jobs,-.The%20JobKeeper%20payment%20is%20administered%20by%20the%20Australian%20Taxation%20Office,\(before%20tax\)%20per%20fortnight.](https://www.business.gov.au/Risk-management/Emergency-management/Coronavirus-information-and-support-for-business/JobKeeper-Payment-for-employers-and-employees#:~:text=Australians%20in%20jobs,-.The%20JobKeeper%20payment%20is%20administered%20by%20the%20Australian%20Taxation%20Office,(before%20tax)%20per%20fortnight.)

⁶ The Government made early access to superannuation available for those experiencing financial hardship due to COVID-19. More information can be found at: [https://www.ato.gov.au/individuals/super/in-detail/withdrawing-and-using-your-super/COVID-19-early-release-of-super/.](https://www.ato.gov.au/individuals/super/in-detail/withdrawing-and-using-your-super/COVID-19-early-release-of-super/)

⁷ Covid-19 has had a very gendered impact. During April 2020, women represented 55% (325,000) of those who lost jobs. In addition female work hours reduce by 11.5% compared to a 7.5% reduction for men. More information can be found at: <https://corporate.amp.com.au/newsroom/2020/MAY/early-super-release-gender-data>

⁸ The Government made a \$750 one-off economic support payment available to those on the DSP. More information on this available at: https://www.dss.gov.au/sites/default/files/documents/05_2020/atd_COVID-19-impact-dsp-and-cp-and-jobkeeper-recipients20200501.pdf

- *My partner carer is now my only carer. I am tired of him never being acknowledged by the government for his work.*
- *I don't feel this is a justified policy decision. Many people on the DSP/Carer allowance struggle with the cost of living. Although these allowances are comparatively higher, this is only in relation to the poverty rates of Newstart.*
Given how vulnerable people, particularly women with disability are and how they are often structurally excluded from the labor markets, it is senseless that they have been excluded from the supplement payment
[emphasis added].
- *I think it's disgusting that with the added disruption and difficulties faced during these times, that people who are either some of the most vulnerable, or caring for them, are left out in the cold. The payments they receive currently aren't nearly enough, just like the regular Newstart payments. I'm disgusted and angry about the lot of it.*
- *Horrified. This is absolutely disgusting and ableist.*
- *The Government should treat everyone equally! **Any extra payment would have helped me with some essential household items and therefore any money would have gone back into the economy.***
- *Discriminated against. **People with or caring for other with disabilities already face higher living costs associated with accessing aids and equipment needed to assist with daily living** [emphasis added]. The costs of food increased and the scarcity of products meant repetitive trips to supermarkets in order to ensure daily food needs were met. The rate of DSP alone does not cover the costs of living with rent, utilities and mobility needs, let alone for those such as myself who was denied access to the NDIS to help me with the*

additional costs that comes with having a physical disability that is degenerative and needing ongoing support.

The comments received from survey respondents were further echoed in interviews conducted following this survey. Increase in the cost of living caused by shortages of essential items during lockdown periods was of particular concern, with some respondents noting that the scarcity of items they would have normally purchased meant having to purchase different or more expensive brands. The cost of products also went up in response to demand, further impacting household budgets.⁹

Case Study

My husband is on DSP and the cost of medication even simple Panadol is increasing. Before COVID we could buy 100 tabs for around \$1.79 during COVID we had to buy 24 for \$6. Also the Telehealth implementation is crap, so much for bulk billing [it] all. My husband had to have a lung special Telehealth appointment they wanted to charge us \$125 out of pocket. I queried this and the practice manager reduced it to \$100 because of the Telehealth new rates. I actually said we would decline the service if they couldn't bulk bill. They bulk billed.

This response highlights the experience of a disabled woman* navigating experiences as a carer in addition to their own responsibilities during this time. It is a straightforward representation of the impact of increases in the cost of living on essential items like medications.

Question 16. Medical Care during COVID-19

What has been your experience of medical care during this time?

Please select all that apply to your situation.

⁹ AFDO (2 July 2020), 'Australians with Disabilities Sidelined during Coronavirus Pandemic,' available at: <https://www.afdo.org.au/australians-with-disabilities-sidelined-during-coronavirus-pandemic/>.

- *There have been disruptions to my usual medical care*
- *There have been disruptions to medical treatment I am waiting to receive*
- *There have been NO disruptions to my usual medical care*
- *I have reduced contact with medical services due to COVID-19*
- *I have been able to access telehealth services*
- *I have been unable to access telehealth services*
- *I have experienced issues with accessing interpreters and in-language information*
- *I prefer to describe my experience with medical services:*

Table 9: Experiences of Medical Care

Options	Responses (60 respondents)
There have been disruptions to my usual medical care	25
There have been disruptions to medical treatment I am waiting to receive	19
There have been NO disruptions to my usual medical care	12
I have reduced contact with medical services due to COVID-19	28
I have been able to access telehealth services	33
I have been unable to access telehealth services	3
I have experienced issues with accessing interpreters and in-language information	0
I prefer to describe my experience with medical services:	13

Some respondents who selected that they preferred to describe their experiences reported:

- *I have been hesitant to seek care for my respiratory issues, even though it is unlikely that I have contracted Coronavirus.*
- *Although I was lucky to have an emergency scope done to confirm one of my autoimmune conditions has relapsed. The other surgery has been put off because it wasn't deemed urgent although I have pain.*

None of our survey respondents indicated that they required interpreting support and/or in-language information and the responses in this question reflect the absence of this perspective.

Question 17. COVID-19 Testing

I have been tested for COVID-19

I have not been tested for COVID-19

I want to be tested for COVID-19 but experienced issues with getting tested.

Prefer not to answer

Other (please specify)

A total of 60 respondents completed this question. Of these respondents, the majority (76.7%) reported that they had not been tested for COVID at the time of taking this survey. A small group (8.3%) of respondents reported that they wanted to be tested but experienced issues.

Those who selected 'other' reported being fearful of venturing outside during lockdown periods to try and get tested. Another respondent noted:

"All family members, even one immune-compromised and one who actually TRANSPORTS possible COVID 19 infected blood samples have been refused medical advice and testing..."

Respondents echoed that there were ongoing frustrations with information, availability, and accessibility around COVID testing.

Question 18. Reporting issues with Medical Services

Do you know where to report problems and get help with accessing

medical services?

- *Yes (please specify)*
- *No*

A total of 60 respondents completed this question. It is concerning that 40 respondents selected 'No,' while 20 respondents indicated that they did know where to report problems with accessing medical services.

Those who selected 'yes' were asked to provide details:

- *COVID-19 station & telehealth contact now.*
- *Aware of various ACT government services and organisations. I also contact doctors /providers directly if there are issues.*
- *I'm able to talk to my GP and escalate my care if needed. I know my GP and specialist are open for appointments via telehealth if I need a referral, medications or immediate medical care. I also know I can be triaged at ED if I run out of options.*
- *I am a member of the Health Care Consumers Association and they are very helpful if those issues arise.*

WWDACT created and distributed infographics in response to this information, which has been shared on our social media channels. These images are included in Appendix 4.

Question 19. Information Sources

What has been your main source of information on COVID-19?

- *Government Website*
- *Government COVID-19 App*
- *Social Media*
- *Family, friends or support persons*
- *Medical professional*
- *News, radio*
- *Other (please specify)*

A total of 59 respondents completed this question. News and radio were the most popular source of information, followed by social media and government website, which received even responses, with 30 respondents each selecting those options.

The Government's COVID-19 app was the least popular information source identified by our respondents, with 7 out of 59 survey respondents selecting this option.

One respondent noted:

- *The disability COVID helpline is a total waste of time and effort. I was asked if my disability was? Mmm why? Would that have had an impact on the information I received? I also rang only yesterday to talk about the safety of my return to work. They actually can't give you any answers and have no information on where to get the answers.*

Those who selected 'other' detailed the following:

- Work staff emails
- The Canberra Times
- Newsletters at work
- WHO Website
- Word of mouth

Question 20. Information Sources

What has been the most helpful source of information and why?

A total of 59 respondents completed this question. Most respondents detailed that ABC News Radio, Social Media, medical professionals and ACT Government websites were most helpful.

Some helpful comments on the effectiveness of information from various sources has been extracted below:

- *ABC News. Reliable, but more trustworthy than government sources, which mostly seem concerned with trying to convince us the government is doing things right. It's unreasonable to expect us to believe that "we're all in this together" when you know that you're not considered an important or valued part of that "all". And expecting people with NDIS plans to be glad providers'*

will receive 10% more when our plan budgets have not correspondingly increased is insulting.

- *News reporting with links to verified sources (such as government and health institutions) have been the most accessible way of obtaining clear, facts-based information.*
- *Government websites have been helpful, but it is really difficult to know whether you are getting the most up-to-date information. It is really unclear.*

The availability of up-to-date information through workplace messaging arose as an important mechanism for some of our respondents, with one respondent noting:

- *Newsletters at work: I am already reading emails as part of my day to day activities so it does not add to the load of things that I need to complete in a day.*

The availability and impact on carers is also an important issue for this cohort, and one respondent noted:

- *My carer listens to the ABC news and checks the government websites for updates, has been helpful.*

It became clear that feelings of frustration and abandonment also informed the choices of our respondents when it came to information sources, in addition to their accuracy and accessibility. One respondent exemplified this sentiment by stating:

- *ABC News. Reliable, but more trustworthy than government sources, which mostly seem concerned with trying to convince us the government is doing things right. It's unreasonable to expect us to believe that "we're all in this together" when you know that you're not considered an important or valued part of that "all". And expecting people with NDIS plans to be glad providers' will receive 10% more when our plan budgets have not correspondingly increased is insulting.*

In interviews, our interviewees reiterated the obvious issues of accessibility of important information like press briefings with leaders. Some interviewees reported discrepancies with some news briefings early in the pandemic not being televised with appropriate interpreters to aid those with hearing issues and noted accessibility issues with Government websites.

Some positive feedback on Government websites was provided by our survey respondents, though they also noted that it was complicated to navigate these sites. In interviews with young people, they reported difficulty understanding rules around isolation and how/when they could visit friends, relying on social media to provide targeted updates.

Question 21. Concerns during and after COVID

What concerns you the most during and after COVID-19? Please select all that apply.

- *Ability to afford housing*
- *Ability to afford medical care*
- *My physical health*
- *My mental health*
- *My safety*
- *Ability to see friends and family*
- *Caring responsibilities*
- *Employment*
- *Access to information*
- *Other (please specify) What concerns me the most is...*

Mental health stood out as the matter of most concern, receiving 44 responses from the total 59 respondents to this question.

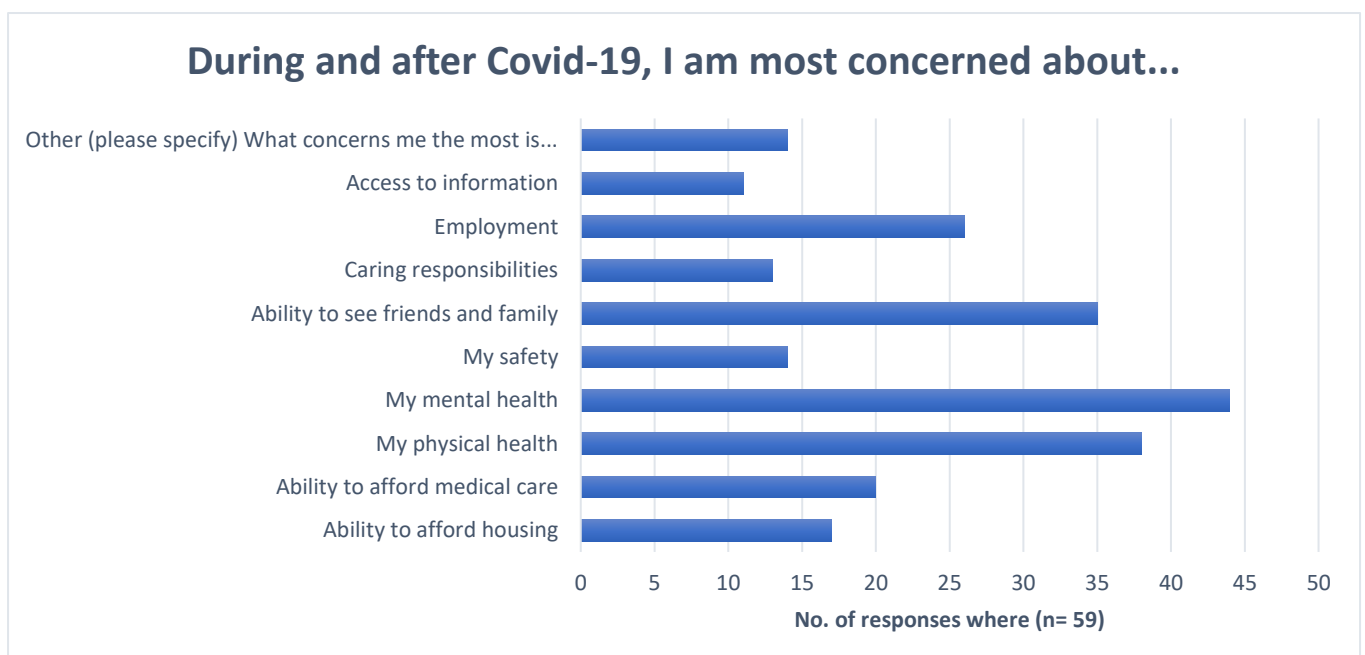


Figure 2: Concerns During and After COVID

Other concerns noted by respondents included:

- *The welfare of persons more vulnerable, including my grandfather. People who are ignoring advice by government and placing the safety of others at risk. The high likelihood of a second wave of the virus, putting more strain on people, connection, relationships, mental health, economics, health services.*

Respondents who fell within younger demographics and identified as students noted concern and longing for disruptions to their long-term plans to be over. For example, on disruption to university classes some respondents said:

- *Disruption to my routines and trajectory in 'growing up' (taking steps back in my journey towards independence). I am also worried that my plans for the future will be put on hold and that connections I've made through physical interactions will be lessened, leaving me with a reduced support network.*
- *The closure of campuses for learning, especially libraries. Had they remained open I would not have to withdraw from my course.*

These matters are addressed in more detail below, in our discussion.

Question 22. Where to get help during COVID-19

Do you know where to get help during COVID-19?

This question is not asking about medical assistance but is about other supports. E.g. Where to get legal help, report workplace issues, financial assistance.

No

Yes (please specify)

Over half of the 59 respondents who answered this question (55.9%) noted that they did know where to get help for matters other than issues with medical services.

This question was added to the survey in response to the unique concerns and issues that may arise for people with disabilities during emergency situations such as COVID-19.

Question 23. Final Comments

Is there anything else you would like us to know about how COVID-19 has affected your life?

Some prompts to consider:

- Have you experienced issues with accessing NDIS?*
- Are you concerned about workplace flexibility?*
- If you are now working from home were you able to do this before COVID-19?*
- Do you feel like the voices of people with disabilities have been heard throughout COVID-19?*

A total of 39 respondents completed this optional question. Of these, a majority of respondents noted concerns about employment. This was followed by concern around maintaining communication in an online world, poor service navigation knowledge and need for services like telehealth to continue.

Regarding telehealth, one respondent stated:

The medical appointments over the phone or video call are fantastic- meaning if I'm unwell I can inquire about doing my appointment from home to keep up with the therapy required if its [sic] able to be done via call/video, as most of my health professionals I need to see privately, and charge a cancellation fee. If I'm unable to leave the house this gives me a way to still continue through with the appointment without the added stress.

The availability of flexible work arrangements, maintenance of social distancing measures and vulnerability of those with disabilities were key concerns raised when respondents discussed employment.

One respondent noted:

I'm concerned about the move back toward austerity after the panic surrounding COVID dissipates. I'm worried that many of allowances and flexibility put in place for myself and my partner (such work/study from home capacities, access to tele-

*health and increases in welfare payments) will be removed rapidly and without any consultation. Due to WFH arrangements for my partner, I have been able to access a much higher level of support and care in contrast to when they were working on-site. I'm unsure if they will allow him to negotiate flexible working arrangements afterwards. **I feel as though people with disabilities (particularly first-nations and people of color) have been systemically excluded from the national conversation around public health. I am concerned as a Chinese-Australian, that I will face heightened racism and systemic discrimination in areas like employment.***

Many respondents articulated feeling abandoned in the move to online work, education and activities. They expressed that knowledge of navigating videoconferencing tools and other online communication platforms should not be assumed knowledge, with the availability of simple tutorials and/or resources important to feeling included, supported and connected throughout periods of lockdown. One respondent said “*How to use packages such as Zoom. Assumption you know*” in response to this question.

Another noted:

I believe persons with a disability and people experiencing high levels of vulnerability were not accommodated for during this time. People who don't have access to phones and internet were essentially cut off from their support services and daily routines. There was a lack of resources for persons living with vision or hearing impairment, particularly in a home context with online meetings. Those are risk of social isolation before COVID-19 have had reduced access to services.

Requests for better instruction and support around navigating digital technology were also raised interviews with respondents. While it is often assumed that those from older age groups would require extra support, young respondents expressed that choice is important. Having choice recognises the complex needs that various disabilities and personal situations may present. Inclusive information means better choices for everyone and our respondents certainly highlighted this sentiment.

Results presented earlier indicated disruptions with essential services and one respondent noted:

I applied for shopping (from Woolworths) to be delivered as a person with a disability. The application asked for a pension number but I'm not on a pension. It didn't ask for an NDIS number which I had. Organisations don't seem to understand that a person can have a disability yet still work. I never received notification of approval for delivery of shopping. I just had to go myself. Delivery has opened up again now anyway.

Many responses noted issues and disruptions to NDIS services. Comments left in this question by two separate respondents have been extracted below:

- *The NDIS has not been proactive during C-19. After weeks with shop problems, I received an email saying they had reached an agreement with supermarkets. The NDIS had decided what I was going to eat and how much it would cost me. They never considered my Carer who was isolating due to my needs to isolate.*
- *No access to NDIS. Cannot access my usual Dr to fill out paperwork to update my disability parking permit or get a medical clearance to renew my licence and access affordable mental health services.*

This is further affirmed by responses indicating the availability of simple, accessible and tailored information that included the needs and perspectives of people with disabilities were lacking from Government. One respondent stated:

"As always information is targeted at the general population and as a pwd [people with disabilities] you never quite know how the impacts are for you."

Question 24. Resources

Are there any resources that would assist you during and after this time?

A total of 57 people out of 72 survey respondents completed this question.

Some recommendations include:

- **Better mental health plans:**

“I've been having weekly appointments with my psychologist at \$230 each, with the \$84 rebate. I'm now having to wait another month and a bit before I can get the review of my mental health plan approved for the extra 4 rebated sessions. I can't afford to see my psych as often as needed. I'm in crisis mode and don't have the financial resources to get the help I need. The government rebate system of 10 sessions is a joke. It is inadequate and in my view a dereliction of care.”

- Access to **ergonomic home office items**
- Availability of **accessible, clear and concise information**
- Access to **employment opportunities**
- Continued availability of **telehealth**

These requests are reflected in our discussion and recommendations.

One respondent stated the following, regarding the need for training/educational resources on navigating online tools:

Step by step information in plain English on how to use certain applications like Zoom would have been invaluable when the lock down started. Having the choice of subtitles is very important to me especially for training purposes.

Some respondents noted information around navigating key services, like Centrelink, are essential. This is reflected in survey data indicating that many respondents did not know where to get help for issues not related to medical care:

Information and support regarding navigating Centerlink would be useful. My study history has been interrupted due to my disabilities, but as I am not on the DSP I have had difficulties requesting permission for reduced study loads whilst still receiving a student support payment.

WWDACT has created infographics in response to this information, which has been shared on WWDACT's social media channels (see Appendix 4). The feedback on access to services should be an ongoing process of learning and adjustment across the disability and healthcare sector in the ACT.

Question 25. Interviews

WWDACT would like to conduct in-depth interviews about the questions in this survey. Your responses are incredibly valuable and will help inform the work we do. Please provide your contact details if you'd like to be interviewed:

A total of 18 respondents provided their details and agreed to be interviewed to help inform this report. WWDACT were able to engage with and interview 10 of these survey respondents. The remaining survey respondents have consented to maintaining contact with WWDACT, should we seek to conduct further research on the matter and/or involve them for feedback on further work WWDACT may undertake.

5. Discussion

5.1. Limitations

Seventy-two (72) women* participated in this survey. The survey was publicised by email to key stakeholders, through WWDACT's newsletter, website and social media.

The number of responses from women* with disabilities exceeded WWDACT's expectations. Following this, the large number of respondents who agreed to interviews also exceeded our expectations.

It should be noted that out of the 72 responses, not all responses are 'complete' responses as some questions remained optional. We have identified the number of respondents who completed each question to clarify this.

Due to time restrictions, we were not able to interview all 18 respondents who had indicated interest in being interviewed. It is also noted that some interviews which were scheduled to take place could not due to changes in the availability of some respondents and following

this, any intentions to interview certain respondents due to their profile shifted to prioritise those with availability. All respondents have provided consent to be contacted by WWDACT in the future, should we require further insights into the responses they have provided and/or for any further work WWDACT may conduct on this matter.

While many respondents reported speaking a language other than English, it is important to recognise that this data lacks the perspective of those from cohorts that may require translation assistance.

Under Question 11, which discussed employment, the 'other' option provided for some anomalies in the data. Some respondents also selected three options; where this was the case the third option was always 'other.' Some respondents 'doubled up' by selecting working from home and employed, no changes to my current working conditions. These options may have benefited from clarity in instructions, as the intended distinction between these options was that working from home was a change in employment. Despite this, only a few respondents selected both these options. The responses do, however, provide great insight into the employment situations that our survey respondents were managing.

5.2 Discussion of Survey and Interview Responses

The survey answers we have collected are a powerful representation of some underrepresented issues experienced by women* with disabilities during COVID. We are grateful to the women* who generously donated their time and further expanded on their experiences during this pandemic.

Several common themes were identified in working with the survey data and interviewees. The matters raised in our survey have been detailed in combination with responses provided by our interviewees below.

5.3 Themes

Being left Behind

At the time of writing this report, the coronavirus supplement has still not been extended to those on the DSP despite collective calls by peak disability advocacy bodies for this to be implemented.¹⁰ Our survey respondents have affirmed the need for this payment and largely viewed this as a matter of equality, where the DSP is already viewed as inadequate for people with disabilities. The added pressure of a pandemic, panic buying, scarcity of supplies, forced isolation due to vulnerability caused by illness and disruptions to carer supports reported in this survey alone point to growing inequalities.

The added knowledge that the coronavirus supplement would not be extended to people on the DSP was a further example of this inequality to those who complete our survey.

Anglicare has reported that people on the DSP would have been better off and that they would have experienced higher chances of rental affordability had this supplement been extended to people on the DSP as well.¹¹

Living with a Disability

A majority of our survey respondents reported living with a disability and many detailed the conditions they live with, representing a diverse range of disabilities and illnesses that impact their life.

The responses to the question regarding Centrelink benefits, when compared with the high number of respondents who identified as living with a disability, challenge ongoing stereotypes which can often assume those who are disabled do not work. When comparing

¹⁰ Pro Bono Australia, *New survey reveals the financial costs of COVID-19 for people with disability*, 10 June 2020, available at:

< <https://probonoaustralia.com.au/news/2020/06/new-survey-reveals-the-financial-costs-of-covid-19-for-people-with-disability/>>

¹¹ See: Anglicare Australia, *Rental Affordability Snapshot. National Report/April 2020*, available at: <<https://www.anglicare.asn.au/docs/default-source/default-document-library/rental-affordability-snapshot-2020.pdf?sfvrsn=4>>

this with the lack of respondents who had applied for any new payments, there is a clear indication that existing systems are allowing women* with disabilities to ‘fall through the cracks.’

Despite identifying only one respondent who accessed early withdrawal of superannuation, further research into the extent to which this mechanism was accessed and utilised are essential to gaining an understanding of the financial impact this cohort has experienced. This is especially significant as it is well reported that women* retire with lower levels of superannuation in comparison to men. Effort needs to be taken to ensure women* with disabilities are not forced to access these funds even in emergency situations like COVID, as the long-term impacts of such a pandemic are already bound to leave them financially disadvantaged for some time.

Many of our respondents shared that they were reliant on family for care and assistance, which made them ineligible for any income support and/or they were reluctant to apply for assistance because they had such support. They spoke of how it was easier to try and manage their situations without attempting to access other supports, as struggling with the identity as someone who is ‘disabled’ was complicated enough, especially in terms of employment.¹²

Social isolation

All 10 of our interviewees spoke to the unique challenges their circumstances presented for their mental health and social wellbeing. Respondents felt strongly about being able to connect with others during this uncertain time and expressed fear of how they would be able to return to their relationships.

¹² Diversity Council Australia’s *Inclusion@Work* index reports that people with disabilities experience high rates of discrimination: <https://www.dca.org.au/inclusion-at-work-index>.

Social isolation is a significant issue for all age categories and many respondents and interviewees noted using online platforms to maintain connections with their loved ones. A key issue for this cohort of women* with disabilities are the heightened risks for those affected by conditions that mean they are immune compromised. This meant many of those affected were forced to make decisions about social distancing and isolation early on, with some interviewees reporting that they went into lockdown prior to official restrictions taking effect.

In our interviews with young people, the importance of maintaining social connection was further emphasised as an essential element of growth. It was also an important contributor to mental health and overall wellbeing, which undoubtedly impacts our ability to maintain a positive outlook as to professional and personal futures. In interviews with young people who are university students, respondents expressed a sense of abandonment by institutions and government in their responses. Most had sought alternative accommodation as soon as universities closed down and many sought to return to their family homes as soon as possible.

One interviewee, who is also a young person at university, explained that she was unable to stay with her family as she has a family member who is immuno-compromised and was instead invited to stay with a friend temporarily so she would not be alone.

Case Study – *Social Isolation*

When exploring this issue in interviews, one respondent who is retired, living with a disability and with a partner spoke about her experience of managing social isolation. This respondent reported that the support of her partner was essential to their combined wellbeing.

For example, her partner was able to complete their shopping and when lockdowns were officially implemented in the ACT, they made use of priority shopping hours to be able to obtain their essential items.

The respondent noted that she and her partner would have dinner once a week--an important part of their social life--and that they would spend time with their grandchildren. This respondent explained that they had made the decision to isolate prior to official lockdowns, out of concern for their friends who are elderly and/or vulnerable to COVID. Despite describing her experience as “mostly positive,” the respondent attributed this positivity to having a strong support network within the ACT and being able to rely on her partner, who is not disabled. She said *“I remember going to go see my doctor and ended up in tears because I was depressed. So not all positive.”*

Disruption to essential services

Many survey respondents noted that lockdown periods and increased safety concerns meant their access to personal care services including cleaning, carer support and other services that would have benefitted their health and wellbeing. Access to basic supports are enshrined human rights and expose the ongoing failures of current systems to cope with changes.¹³

Some respondents who tried accessing online shopping reported that products needed for their specific diets (e.g. coeliac) were difficult to access. When exploring issues with online shopping in interviews, one respondent described how some items were often ‘swapped’ for other brands or products without notice, and that they would be wasted as they could not consume them due to having conditions like coeliac disease. They reported that even if

¹³ UN General Assembly, *Convention on the Rights of Persons with Disabilities*, 13 December 2006, A/RES/61/106, Annex I, available at: <https://www.refworld.org/docid/4680cd212.html> [accessed 30 June 2020]

they had been able to access priority shopping hours (this respondent was ineligible),¹⁴ the allotted early morning time was incredibly restrictive.

This was a concern echoed by another interviewee who cared for young children. She reported that waking early in the morning to queue for groceries was simply was not practical while also juggling the needs of her children.

For those on low income, the disruptions to essential services like grocery stores meant not being able to maintain a shopping list designed to meet their budget. These respondents emphasised that they do not have the luxury to deviate from their usual items of choice or stockpile groceries, where difference in cost can have a huge impact.¹⁵ One interviewee who is also a mother explained that the scarcity of items like tinned food in certain low cost brands meant she was forced to purchase more expensive brands and/or go without until a suitable option could be sourced. She relied on donations from local service providers, which were helpful and was otherwise forced to make difficult decisions when attempting to purchase essential items during periods of high demand. In this case, the interviewee was a single parent of more than one child who reported that priority shopping hours were restrictive and inaccessible in her situation.

Knowledge of Ethical Standards

On ethical standards for people with disabilities, all respondents we interviewed did not have a clear understanding of the local or international human rights frameworks protecting people with disabilities. They also indicated a desire to learn about this and be better advocates for themselves or for their loved ones with disabilities. One interviewee noted

¹⁴ Many services required that those needing to access priority shopping hours show identification such as a Health Care Card, Pension Card, proof of NDIS assistance.

¹⁵ A recent survey conducted by People with Disabilities Australia (PWDA) confirms that people with disabilities have experienced an increase in their cost of living. This survey was not focused exclusively on the experiences of women.* The survey results are available at: https://pwd.org.au/wp-content/uploads/2020/06/PWD_and_COVID_report-final.pdf

concern about how they would be protected in an emergency where medical equipment may be in short supply:

It's something that was concerning me a lot. Once I started reading reports from other countries about the prioritization of disabled people when it came to access to ventilators. I have a history of like a serious lung infections and just respiratory issues. And the idea of potentially being denied a ventilator, because my likelihood of surviving because of that is probably less than somebody else.

WWDACT contributed to the development of the Commonwealth *Management and Operational Plan for People with Disability*, and to the development of the *ACT Covid-19 Ethical Decision-Making Framework* conducted through the ACT Clinical Health Emergency Coordination Centre (CHECC). WWDACT contributed to the development of the Commonwealth *Management and Operational Plan for People with Disability*, and to the development of the *ACT Covid-19 Ethical Decision-Making Framework* conducted through the ACT Clinical Health Emergency Coordination Centre (CHECC).

WWDACT was able to interview a survey respondent who is a medical professional living with a disability, while living and working in the ACT. They spoke to the experience of being an essential worker during the pandemic and highlighted that their sense of duty outweighed the very real personal concerns for their safety. A dedicated team who followed health and safety protocols were critical indicators of success to this respondent.

This respondent also emphasised that staff should be well trained in working with people with disabilities. They expressed concern about the attitudes of medical staff toward people with disabilities and emphasised the need for increased training so staff can better empathise with and treat their patients. The respondent noted that this may aid in shifting negative attitudes and stereotypes around people with 'invisible illnesses' or those who

suffer from chronic conditions, who otherwise tend to experience poorer levels of care. This is an important consideration as the respondents in this survey reported living with a wide range of disabilities, with some falling under the category of ‘invisible illnesses’ and conditions that overwhelmingly impact women*.

These responses, when viewed in combination with data indicating poor service knowledge, poor knowledge of reporting processes and the high number of mental health concerns are powerful representations of the underserved needs of this cohort.

Youth Issues

WWDACT sought to interview a representative of a peak student body--ANUSA’s Disabilities Officer--and a number of survey respondents who fell within the youth demographic.¹⁶ The analysis of the issues faced by young women* with disabilities is especially pertinent to planning for the ACT, considering a large concentration of its youth population are young people pursuing higher education.

a) Disruption to Education

The closure of campus facilities such as libraries, study spaces and common areas compounded the negative impact that the loss of face-to-face learning has had on the student population. One respondent had noted that the elimination of study spaces contributed to their decision to withdraw from study.

¹⁶ Those aged 18-25 years old. We also extended this category to consider the input of a woman* under 30 who was affiliated with a university within this data.

When interviewing young respondents, they expressed feelings of frustration that the accommodations students with disabilities may have been requesting for a long time, like online learning, were suddenly made available by universities almost overnight.

However, individual learning styles arise as a key indicator of the successes of the online learning model. When exploring issues with online learning further in interview with ANUSA's Disabilities Officer, Zoe Ranganathan ('the Officer'), she expressed resources and lessons were not always accessible to students with disabilities. It was reported that little to no consultation was made with Disabilities departments to support students in this transition and that many students who did have learning access plans or adjustments were not being directed to the Disabilities Officer for support by staff. The Officer also expressed concern that many students were fearful of contacting her or other services for support due to the following reasons:

- *Young people not understanding their own identity as a disabled person*
- *Young people not understanding whether they fit the definition of disability*
- *Young people fearing repercussions to their personal or professional reputations if accessing disability adjustments*
- *Young people not being aware of the role of the Disabilities Officer and/or support services available to them at university or in the broader ACT community*

Overall, the Officer noted pointed to poor confidence levels when it comes to self-advocacy as also being a key barrier to young women* with disabilities accessing services in the ACT. The ACT should especially look to support their significant student population in resuming their academic and professional lives and bolster supports within tertiary institutions so women* with disabilities do not lose faith in their ability to fully participate in these environments.

b) Social Isolation

When exploring this issue in interviews with young respondents, they echoed concerns that this period of isolation would 'stunt' their emotional growth. The feelings of loss in young people and yearning for the things they would otherwise enjoy, such as social activities and the face-to-face connections made through on-site learning, should not be undervalued in any analysis of the impact that COVID has had on this cohort.

This is consistent with research from Headspace, the National Youth Mental Health Foundation, which showed the disruptions arising from the pandemic have made young Australians fearful and uncertain about their future. Young women identified in the survey of over 2000 young people aged 15-25 and about 160 parents had higher levels of anxiety than their male counterparts.¹⁷

c) Lack of Service Engagement

It is concerning that more than 50% of our survey respondents reported that they did not know where to seek help for medical and non-medical issues. These questions were separated to understand the confidence levels of respondents in advocating for themselves in these distinct settings. It is important to recognise the different supports needed in essential settings like healthcare, while other services like Centrelink, NDIS and employment may not apply to *all* respondents.

This is reflected in the data received under the question our survey asked about what Centrelink benefits respondents were receiving, with many not registered as a recipient of any payments despite identifying as living with a disability.

¹⁷ Headspace, 2020, *New Research: Young Australians fearful and uncertain for their future*, https://headspace.org.au/blog/new-research-young-australians-fearful-and-uncertain-for-their-future/?fbclid=IwAR3YnhuFKgjFbTiUpkaDHU9g9nY_7VWdIC0xn7fx6ravZ0y6UXMS8Kufhi8

These responses indicate a strong need to bolster education around support services and reporting processes, which must be made accessible to women* with disabilities, like the respondents in our survey.

5.3 Learnings from the Survey Process

WWDACT used a paid account on Survey Monkey to create the survey, meaning that survey questions could be created and modified without restrictions. This allowed for a broad range of responses to be collected and allowed for the use of data analysis tools post-survey. A number of questions remained optional in this survey and despite this, we still received one of the largest response rates in comparison to past surveys conducted by WWDACT.

Data analysis tools through the Survey Monkey software were useful in summarising the data, though we note some questions had multiple responses options. It is important to recognise any profiles that arise where respondents may have selected multiple option. This matter was addressed through careful analysis of the data, with any important patterns or comments identified and noted in our presentation of results and in the discussion of this report.

The availability of face-to-face meetings may have also allowed for more collaborative processes in exploring issues and formulating recommendations through co-design processes. Nonetheless, the availability of interviews meant WWDACT was able to explore potential solutions to problems faced by the respondents, which are reflected in our recommendations.

Some survey respondents noted that they did not understand what was meant by 'workplace flexibility.' However, these terms had been deliberately left undefined to allow

individual interpretation and highlight any existing gaps in knowledge around ‘flexible work.’ Another question which respondents said was unclear was the question regarding the coronavirus supplement payment. This question intentionally did not provide extensive background on this issue as the aim was to understand existing attitudes, knowledge, and background on the matter. Some respondents even explained their knowledge on this issue and why they felt the policy was justified or not.

The availability of a paid SurveyMonkey account has meant this survey was simple and easy to complete. More importantly, the use of paid Facebook promotions to advertise the survey was a great success.

5.3 General Comments

This data presents an important reminder as to the complex identities that women* with disabilities navigate, and that stereotypical ideas that people with disabilities are unable to work entirely, that they are solely dependent on Centrelink benefits or that they are ‘too difficult’ to reach, continue to be extremely unhelpful. They are a hindrance to good policymaking that should otherwise seek to promote intersectional views of the needs and issues faced by women* with disabilities in the ACT.

The women* who responded to this survey and those who had conversations with us expressed their own methods of dealing with the pandemic, largely influenced by their survival skills developed over a lifetime of feeling ‘abandoned’ and ‘neglected’ by a society that does not view the needs of this cohort as equal. These responses were largely reflective of failures in our system to include, identify and implement processes and services that actually address the needs of women* with disabilities in this region.

In-depth research into the cost of living that accounts for factors like gender, age, disability, cost of living and more should be prioritised to understand the full impact of the COVID

pandemic on women* with disabilities in the ACT, in order to develop a robust plan for any recovery strategy and future emergency response planning.

Concluding comments

This report has benefitted from the wide range of experiences reported by the women* with disabilities who completed this survey, though we need to do more to reach and understand the experiences of disabled women* from linguistically diverse backgrounds as well. While the range of experiences has allowed for discussion of a wide range of topics, evidenced by the length of this report, which still could not contain many comments made by the women* we reached, it must be understood that these issues are not new.

Women* with disabilities in the ACT and across the country have for a significant period, experienced feelings of neglect and abandonment. These sentiments have resulted in a constant survivalist instinct that has forced these women* to persist and struggle with access to the workforce and access to services while planning for personal emergencies. Emergencies like pandemics simply broaden these gaps and add weight to a burden they already carry. Every effort should be taken to ensure women* like those in our survey are not left **further** behind.

This will only be possible through a dedicated process of consultation and co-design with diverse groups of women* with disabilities at every stage of emergency response planning processes at Government and service levels.

6. Recommendations

The survey has clearly shown that government responses and processes put in place for the ACT community, were not tailored specifically enough to enable women* with disabilities to get the information or get access to services they needed, so that they ended by feeling left out, lacking essential information and were isolated to a greater degree than they usually experienced, with significant impact on their mental health.

WWDACT recommends that the ACT and Federal governments take action to incorporate the following recommendation as they refine their response to this pandemic and to future community emergencies.

1. Governments should work to remove the need for documentation and/or explanation around need to work from home due to disability
2. Governments should support and direct employers to provide education or 'how-to' guides on requesting workplace flexibility and/or adjustments. Workplaces should be adopting clear policies around these processes.
3. The ACT Government must simplify processes for reporting issues with medical services
4. Disability services and related organisations should prioritise resources and education of workplace rights for those with a disability early on, targeting tertiary education institutions with a focus on promoting self-advocacy
5. Governments and disability support organisations should increase knowledge of the role support persons and/or advocates for those needing to negotiate issues with an employer
6. Governments should dedicate more funding toward making trained disability advocates readily available and accessible in emergency situations
7. Universities need to dedicate more funding to increase the availability of disability advocates at their institutions
8. Governments should dedicate funding toward disability services and related organisations so they may prioritise education, resources and training for people with disabilities on preparedness for emergency medical situations

9. The ACT Government should continue the availability of Telehealth services indefinitely

10. Workplaces must ensure women* with disabilities are adequately resourced with ergonomic home office equipment, where working from home is applicable in their profession.

11. Ensure that personal care services are trained and prepared to continue providing services essential to the health and dignity of women* with disabilities in emergency situations like COVID-19

12. The ACT Government should provide clear resources and education on the frameworks protecting people with disabilities.

13. Fund services that bolster the advocacy skills of women* with a disability and support them in preparing information and procedures in case of a medical emergency.

14. The ACT Government should seek to adopt an emergency hotline service to help keep people with a disability safe and informed during an emergency like COVID. The hotline must be staffed by trained advocates who are supported by training and resources on local support services.

Appendix 1 – Interview Questions

Skeleton Questions for Interviewees:

Each interview will also be informed by the responses provided in our survey- participants will be given the opportunity to expand on anything they already said in the survey at the end of the interview.

This is merely a guide and questions may be added or altered depending on the conversation.

EMPLOYMENT:

Depending on survey response

What in industry do you work in?

What is your job title?

Did you have access to flexible work arrangements prior to COVID-19?

As restrictions begin to lift, what concerns you the most about returning to work?

Do you feel comfortable about discussing your needs for any adjustments/equipment to stay safe at work?

Will working from home continue to be an option for you and if so, would this be a positive or negative thing?

How do you think the needs of people with disabilities are treated in workplaces?

How do you feel the government and services can best support people with disabilities in return to work as restrictions are lifted?

Were there particular supports in place during COVID-19 related to work that helped during this time?

Respondents on DSP/other payments and partially employed:

Add question:

How was your income affected during COVID-19 (if any)?

Do you believe the coronavirus supplement would have assisted you and how?

Do you believe the government's responses to COVID-19 has been helpful? What would you change?

How do you think the Government can better understand the needs of those employed part-time due to disability?

How do you think the public and services can be better informed of your needs around employment?

What service responses have been most helpful in terms of employment?

Respondents on DSP/other payments/not employed for other reasons:

What has been your source of financial support?

How have your financial needs changed during COVID19?

Do you believe the coronavirus supplement would have assisted you and how?

What service responses have been most helpful?

Questions regarding Safety:

Are you comfortable discussing questions around your physical safety?

These questions are to be informed by the responses to questions around knowledge of reporting problems and information access:

Have you ever reported a problem with medical services, Centrelink, your personal safety or anything else?

Do you feel safe reporting any problems you may be experiencing?

Did you feel like this process was accessible and what can be done to improve this?

How can Government make reporting processes more accessible and/or how can services be supported to make reporting processes easier?

Would a hotline to provide information about emergency situations and/or report issues be of assistance?

If not, why not.

If yes, how can we ensure it is accessible?

What would a positive experience with a hotline look like/sound like/feel like?

Access to essential services:

What has concerned you the most about access to essential services since Covid-19?

Have priority shopping hours, grocery delivery and other accommodations made by shopping centres/supermarkets been helpful to you?

Have you had support with access to groceries, medication, and/or medical attention?

How do you feel about medical service responses to the needs of people with disabilities during this time?

- Community expectations
- Ethical concerns around *who gets help first*
- Do you understand what ethical guidelines exist to treat people with disabilities during emergency situations?
- Are you worried about your rights in healthcare and safety in Healthcare because of triage protocols
- Do you feel comfortable advocating for your own safety?

How can access to essential services be improved?

What could have been improved in this response – e.g. what should government and services know in the future so they can better assist PWD in emergency situations like this?

Appendix 2 – Responses to Question 11: Employment

Employment: Select all options that apply to your current situation											
Employed, working from home	Employed, no changes to my working conditions following Covid-19	Employed, working from home while caring for children	I am not employed as I care for children	Retired	Unemployed before COVID-19 and looking for work	Unemployed as a result of COVID-19	Unable to work due to disability	I am a student and am continuing study online	I am a student but my course has been suspended due to Covid-19	Other (please specify)	Total options selected by respondent (n=72):
											0
X											1
					x			X			2
				x			X				2
											0
			X								1
	X										1
								X			1
						X		X			2
X								X			2
X										X	2
											0
X										X	2
											0
X											1
				X							1
										X	1
							X				1
							X				1
X											1

									X	1
X		X								2
						X		X		2
X								X		2
						X		X		2
X										1
X										1
	X									1
				X						1
							X			1
							X			1
X	X								X	3
								X	X	2
						X				1
									X	1
										0
		X			X			X	X	4
			X				X			2
X		X								2
										0
				X			X			2
							X			1
						X				1
							X		X	2
X										1
	X							X		2
	X									1
X										1
			X					X		2

							X	X			2
X											1
X											1
X											1
X											1
										X	1
X											1
X	X										2
		X									1
X											1
											0
							X				1
X								X			2
										X	1
X											1
X											1
X											1
				X							1
							X	X		X	3
X								X			2
X											1
28	6	4	3	5	2	5	12	15	0	12	

Appendix 3 – Survey Promotion



**HOW HAS COVID-19
AFFECTED YOUR LIFE?**



HAVE YOUR SAY



WWD ACT would like to hear about your experiences with Covid-19.

● **Take the WWD ACT Covid-19 Survey** ●

Have you been able to access the right support during Covid-19?



● **Share your thoughts by completing WWD ACT's Covid-19 Survey** ●

<https://www.surveymonkey.com/r/WWDACTCovid-19Survey>



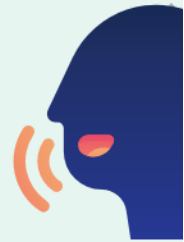
What supports do you need during Covid-19?



**Share your thoughts by completing
WWD ACT's Covid-19 Survey**

<https://www.surveymonkey.com/r/WWDACTCovid-19Survey>

**How can we ensure that
the voices of women and girls
with disabilities are heard in
Covid-19 response planning?**



● **Share your thoughts by completing
WWD ACT's Covid-19 Survey**



Appendix 4 – Follow-up Information

Samples from follow-up information tiles created by WWDACT to improve local service knowledge:

**COVID-19
employment
problems?**



Fair Work Ombudsman
13 13 94
coronavirus.fairwork.gov.au

Women's Legal Centre
(02) 6257 4377
admin@womenslegalact.org

Money
troubles?

There's help
available.



Care Financial Services
1800 007 007
admin@carefcs.org

