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disability support workers:
The forgotten workforce in covid-19

# About this report

Researchers from the Disability and Health unit at the University of Melbourne and UNSW Canberra conducted an online survey of 357 disability support workers (DSWs) between late May and June 2020 about working during the COVID-19 pandemic. An overview of findings relating to physical distancing, COVID-19 infection control training, purchase of Personal Protective Equipment (PPE), COVID-19 testing, support provided, and financial and psychological stresses experienced by workers are summarised along with recommendations arising from the findings (Recommendations 1-8).

Further recommendations are also made to ensure continuity of disability support when COVID-19 infection occurs, while minimising transmission risk between workers and the people with disability they are supporting (Recommendations 9-11). These recommendations are summarised before turning to the results.

# Acknowledgements

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Recommendations

**Recommendation 1:** That governments consider updating their guidelines regarding PPE use among DSWs, particularly for DSWs working in areas where community transmission is high.

**Recommendation 2:** That governments are more proactive in reaching out to DSWs so that they receive the training they require. Resources on government websites needs to be more actively promoted. DSWs need clear information and detailed training about whether, when, and how PPE is used, including simulated training not just information online before being expected to work in high risk situations, such as a COVID-positive environment.

**Recommendation 3:** In areas where community transmission is high all DSWs should have access to appropriate PPE (minimum of masks) without cost to them. Governments need to make urgent decisions about access to PPE for workers elsewhere in Australia.

**Recommendation 4:** That governments make clear that DSWs are a priority group for testing along with healthcare and aged-care workers.

**Recommendation 5:** Paid pandemic leave is available to all DSWs who do not have access to paid sick leave and need to self-isolate or quarantine while waiting for a test result; or because they have COVID-19; or are a contact of a known case.

**Recommendation 6:** Governments and providers should ensure DSWs minimise the total number of people they support and the number of settings they provide support in, to reduce risk of transmission among multiple people with disabilities and DSWs, as has been witnessed in aged-care facilities. Particular attention should be paid to identifying workers who work for more than one provider and/or work across multiple group settings.

**Recommendation 7:** Government needs to prioritise ensuring financial security of this essential workforce through extension of JobKeeper or similar supports and paid pandemic leave. Without this, it may not be financially viable for many DSWs to remain in their current jobs resulting in an impediment to creating surge capacity in the workforce and an impediment to long term growth.

**Recommendation 8:** Governments and service providers need to provide mental health support to DSWs and comprehensive infection control training and access to PPE.

**Recommendation 9:** That governments identify, and have on standby, a skilled health care workforce that can be rapidly deployed to work alongside DSWs or replace them supporting clients infected with COVID-19, as has been deployed in aged-care.

**Recommendation 10:** A surge workforce of DSWs fully trained in infection control is created to provide back-up where needed (potentially from later year medical and nursing students).

**Recommendation 11:** That governments and service providers consider options to temporarily rehouse residents in group homes where infections have occurred to separate infected and non-infected residents.

Disability support workers (DSWs) are the forgotten essential workers in the COVID-19 pandemic, despite their vital role in supporting people with disabilities.

In June, University of Melbourne rand UNSW Canberra researchers asked disability support workers (DSWs) in an online survey, about their experiences during the COVID-19 pandemic.

They were asked about:

* Physical distancing
* COVID-19 infection control training
* Access to and purchase of Personal Protective Equipment (PPE)
* Testing for COVID-19
* Who they worked with and where they provided support
* Financial and psychological stresses

The findings from this survey are important for governments, services, people with disability and support workers to be aware of as they provide guidance on how to prevent SARS-CoV-2 infection among people with disability and the workers that support them.

## **Results and recommendations**

## **Who participated?**

357 DSWs from around Australia; 83% were women and 81% were born in Australia. DSWs ranged in age from 18 to 75 years, with 31% over the age of 50 and 7% over 60 years of age.

It is worth noting that, older workers are at more risk of complications if infected with COVID-19.

## **Physical distancing**

90% of disability support workers said they were NOT able to physically distance at work

53% provided support with tasks that require close personal contact like feeding and brushing teeth

Like health and aged-care workers, DSWs are unable to physically distance because of their work. This means that they need to wear masks at all times and possibly N95/P2 masks if there are concerns regarding assisting with tasks that generate aerosols.

**Recommendation 1:** That governments consider updating their guidelines regarding PPE use among DSWs, particularly for DSWs working in areas where community transmission is high.

## **COVID-19 infection control training**

* 23% of workers had NOT received any COVID-19 infection control training and 69% of those wanted more training
* Of the 77% of workers who did receive training, 48% would like more training
* Most workers who received training had online training (66%) and/or printed material (26%)

**Recommendation 2:** That governments are more proactive in reaching out to DSWs so that they receive the training they require. Resources on government websites needs to be more actively promoted. DSWs need clear information and detailed training about whether, when, and how PPE is used, including simulated training not just information online before being expected to work in high risk situations, such as a COVID-positive environment.

## **Use of Personal Protective Equipment**

* 64% of DSWs had received or purchased some form of PPE.
* Over half (54%) had received gloves and 37% received masks (surgical and/or N95/P2) from their employer. Notably, 38% of DSWs purchased their own masks even if they had some from their employer.

**Employers provided PPE**

Gloves 54%
Masks 37%
Gowns 20%
Goggles 12%
Other 12%

**Workers provided PPE**

Gloves 28%
Masks 38%
Gowns 2%
Goggles 3%
Other 20%

Of the DSWs who had acquired PPE, 59% had received some PPE from their employer and 90% workers purchased some PPE themselves. 59% workers received PPE from their employer and also purchased PPE themselves. 4% reported that they didn’t receive any PPE from their employer. 41% didn’t purchase any PPE for themselves.

**Recommendation 3:** In areas where community transmission is high, all DSWs should have access to appropriate PPE (minimum of masks) without cost to them. Governments need to make urgent decisions about access to PPE for workers elsewhere in Australia

**COVID-19 symptoms and testing**

23% of workers had been tested for COVID-19 infection and 11% had wanted to be tested citing a range of reasons including ‘they did not have symptoms’, ‘they did not meet the criteria for testing’ even though they may have had symptoms, or they didn’t want to take time off work to wait for the results.

**Recommendation 4:** That governments make clear that DSWs are a priority group for testing along with healthcare and aged-care workers.

When time was taken off work because a worker was sick only 47% were paid, reflecting the highly casualised nature of this workforce.

**Recommendation 5:** Paid pandemic leave is available to all DSWs who do not have access to paid sick leave and need to self-isolate or quarantine while waiting for a test result; or because they have COVID-19; or are a contact of a known case. This should be paid regardless of their employment arrangement.

**Work settings**

* 14% of DSWs reported that they worked for more than one provider.
* 6% of DSWs worked in both the aged-care and disability sector.
* DSWs worked with an average of 6 people with disability in the week previous to the survey with a range of 0 to 50 people.
* 46% worked in private homes, 57% worked in group homes, 16% worked in centre based activities eg. day programs and 14% worked in disability enterprises.

DSWs worked across a number of different settings including private homes, group homes, day programs and supported employment. In the previous week, nearly 60% of DSWs had worked in a group home and nearly half had worked in private homes. A smaller proportion had worked in centre-based activities such as day programs or supported employment.

* 57% of workers provided support in a congregate setting including a group home, centre-based activity or supported employment.
* 30% of workers worked in two or more settings.
* 14% of workers worked in three or more settings.

**Recommendation 6:** Governments and providers should ensure DSWs minimise the total number of people they support and the number of settings they provide support in, to reduce risk of transmission among multiple people with disabilities and DSWs, as has been witnessed in aged-care facilities. Particular attention should be paid to identifying workers who work for more than one provider and/or work across multiple group settings

**Financial impacts**

DSWs have been adversely affected financially because of COVID-19.

* 16% of DSWs received JobKeeper and 10% received JobSeeker.
* 27% cancelled shifts because they were worried about COVID-19 infection and 35% had shifts cancelled by clients or employers because of fear of COVID-19.
* 37% worked fewer hours in April than in February 2020 because of COVID-19, 39% worked about the same hours, and 24% worked more hours.

Financial hardship

High levels of financial difficulties were reported overall with 17% of workers reporting that they could not pay an electricity, gas or phone bill on time and 20% asking for financial help from family or friends.

Overall, 20% reported that they could not pay a bill, or their mortgage or rent, or went without meals.

Financial difficulties were more frequent among those who reported reduced hours in April with 25% of these workers reporting that they could not pay an electricity, gas or phone bill on time, 16% unable to pay their mortgage or rent, and 13% going without meals. 20% asked for financial help from family or friends. 32% of DSWs who had experienced reduced hours reported that they could either not pay a bill, or mortgage or rent, or went without meals.

**Recommendation 7:** Government needs to prioritise ensuring financial security of this essential workforce through extension of JobKeeper or similar supports and paid pandemic leave. Without this, it may not be financially viable for many DSWs to remain in their current jobs resulting in an impediment to creating surge capacity in the workforce and an impediment to long term growth.

## **Psychological distress**

* DSWs are reporting high levels of psychological distress consistent with a clinical diagnosis of anxiety or depression. 16% were shown to have a probable serious mental illness.
* 22% of all workers experiencing financial stress had probable mental illness, compared to 14% who did not report financial hardship.

**Recommendation 8:** Governments and service providers need to provide mental health support to DSWs and comprehensive infection control training and access to PPE.

CONCLUDING REMARKS

The results of this survey show the many challenges that the disability support workforce has faced thus far in the pandemic. In places where community transmission is high (currently metropolitan Melbourne and Mitchell Shire in Victoria), the challenges will escalate further. We have made a number of recommendations to support this workforce in the pandemic including proactive reach out for training, access to PPE when required, financial support including paid pandemic leave, priority accessing to testing and mental health support.

These survey results reflect the situation for workers in late May and June when PPE was just being made available to workers after a marked shortage in March and April. Until recently PPE has not been recommended for DSW except when looking after a client who is close contact of a case and is quarantining, has symptoms or is a known case. The situation has changed dramatically since May/June in the context of the rising case numbers in Victoria. On the 17th of July the Commonwealth government stipulated the mandatory use of masks for DSWs in the Victorian hot spot areas, although this is not yet reflected in the national guidelines.

There are now also cases of COVID-19 infection among people with disability in group homes. More infections among support workers are also being reported. This presents very real difficulties for workers with little or no training who now have to implement meticulous infection control procedures and use full PPE. Some people with disability, particularly those with psychosocial, autism and/or intellectual disabilities, may find it very challenging to self-isolate or quarantine and may have difficulties with personal hygiene and physical distancing. Further, workers are themselves having to self-isolate or quarantine because they are infected or are a close contact of a case. This means that familiar workers are no longer available to support infected clients at a very stressful time.

Our next survey in August will attempt to find out more about some of these challenges but in the interim we make a number of recommendations to support the workforce at this time.

**Recommendation 9:** That governments identify, and have on standby, a skilled health care workforce that can be rapidly deployed to work alongside DSWs or replace them supporting clients infected with COVID-19, as has been deployed in aged-care.

**Recommendation 10:** A surge workforce of DSWs fully trained in infection control created to provide back-up where needed (potentially from later year medical and nursing students).

**Recommendation 11:** That governments and service providers consider options to temporarily rehouse residents in group homes where infections have occurred to separate infected and non-infected residents.

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**Resources for Disability Support Workers\***

**National**

* COVID-19 information and [referrals for people with disability](https://www.dss.gov.au/sites/default/files/documents/06_2020/fact-sheet-coronavirus-covid-19-information-people-disability-and-their-supporters.pdf) and their supporters about coronavirus (COVID-19)
* [Coronavirus (COVID-19) advice](https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/advice-for-people-at-risk-of-coronavirus-covid-19/coronavirus-covid-19-advice-for-people-with-disability)for people with disability
* [NDIS coronavirus](https://www.ndis.gov.au/coronavirus)information and support
* NDIS Quality and Safeguards Commission [coronavirus](https://www.ndiscommission.gov.au/resources/coronavirus-covid-19-information) (COVID-19) information
* [Head to Health](https://headtohealth.gov.au/)Australian Government website that provides information on mental health resources
* [AIHW MHSA](https://www.aihw.gov.au/reports/mental-health-services/mental-health-services-in-australia/report-contents/summary-of-mental-health-services-in-australia) is an Australian Government website provides information on mental health services in Australia
* [Beyondblue](https://coronavirus.beyondblue.org.au/?utm_campaign=hp_banner) - Information and referral to relevant services for depression and anxiety related matters
* [Black Dog Institute](https://www.blackdoginstitute.org.au/)- for treatment and prevention of mood disorders such as depression and bipolar disorder
* [Lifeline](https://www.lifeline.org.au/) 24 hour telephone counselling service.Tel 13 11 14 and SMS from 6pm to midnight Text 0477 13 11 14

**State**

* Coronavirus  (COVID-19) [Worker support assistance](https://www.dhhs.vic.gov.au/covid-19-worker-support-payment) from the Victorian  government
* Victorian Department of Health and Human Services (information for [service providers](https://providers.dhhs.vic.gov.au/) and for [people with disability](https://www.dhhs.vic.gov.au/information-people-disability-coronavirus-disease-covid-19))
* NSW government advice for [providers and people with disability](https://www.health.nsw.gov.au/Infectious/covid-19/Pages/disability-support.aspx)
* [Queensland](https://www.qld.gov.au/disability/service-providers) government for providers, people with disability and their supporters
* [Tasmanian](https://coronavirus.tas.gov.au/families-community/disability-information) government advice for people with disability and providers
* [ACT government](https://www.communityservices.act.gov.au/covid-19-community-service-information3/act-covid-19-disability-strategy) COVID-19 disability strategy

**Victorian Lockdown information**

* What you need to know about [Stage 4 in Victoria](https://www.dhhs.vic.gov.au/stage-4-restrictions-covid-19)
* [Workplace restrictions](https://www.afdo.org.au/which-workplaces-close-during-stage-4-restrictions/)
* Media statement from DPOs to protect [people with disability during Victorian lockdown](https://www.afdo.org.au/the-ndia-and-victorian-government-must-prioritise-people-with-disability-so-they-do-not-suffer-in-stage-4-lockdowns/)