Disability support workers: the forgotten workforce in COVID-19
Tuesday, 21 July 2020

Authors

Professor Anne Kavanagh, Head, Disability and Health unit, Melbourne School of Population and Global Health and Academic Director Melbourne Disability Institute, University of Melbourne
a.kavanagh@unimelb.edu.au | 0418 900 270

Stefanie Dimov, Project Manager, Disability and Health unit, Melbourne School of Population and Global Health, University of Melbourne
stefanie.dimov@unimelb.edu.au | 0424 518 552

Dr Ashley McAllister, Research Fellow, Disability and Health unit, Melbourne School of Population and Global Health, University of Melbourne
ashley.mcallister@unimelb.edu.au

Professor Helen Dickinson, Professor of Public Service Research and Director of the Public Service Research Group at the School of Business, UNSW Canberra
h.dickinson@adfa.edu.au

Mellissa Kavenagh, Project Coordinator, Disability and Health unit, Melbourne School of Population and Global Health, University of Melbourne
mellissa.kavenagh@unimelb.edu.au

Project Contact

Stefanie Dimov
stefanie.dimov@unimelb.edu.au
0424 518 552
Disability Health Unit
The University of Melbourne
About the report

Researchers from the Disability and Health unit at the University of Melbourne conducted an online survey of 358 disability support workers (DSWs) between late May and June 2020 asking them about their experiences 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 on pages 4-7 along with recommendations arising from the findings (Recommendations 1-8 below).

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 below before turning to the results.

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. Comprehensive infection control training and access to PPE, where required, would reduce the psychological stress many workers are experiencing.

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 – The forgotten workforce in COVID-19

Wave 1 survey results

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

Researchers from the Disability and Health unit at the University of Melbourne conducted an online survey of 358 disability support workers (DSWs) between late May and June 2020 asking them about their experiences during the COVID-19 pandemic.

They were asked about:

- Physical distancing
- COVID-19 infection control training
- Access 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 disabilities and support workers to be aware of as they provide some important guidance on how to prevent SARS-CoV-2 infection among people with disabilities and the workers that support them.

Survey results and recommendations

Who participated?

358 DSWs from around Australia; 83% were women and 82% were born in Australia. DSW ranged in age from 18 to 75 years, with 35% over the age of 50 and 8% 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

- 22% of workers had NOT received any COVID-19 infection control training and 69% of those wanted more training
- Of the 78% 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 PPE

64% of DSWs had received or purchased some form of PPE.

The figure below shows the proportion of DSWs who received PPE from their employer and proportion who purchased PPE themselves by type of PPE.

Over half (54%) had received gloves and 37% masks (surgical and/or N95/P2) from their employer. Notably, 38% of DSWs purchased their own masks.

Of the DSWs who had acquired PPE, 59% had received some PPE from their employer for free and 90% had purchased some PPE themselves. 57% workers received PPE for free from their employer and also purchased PPE 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 10% 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 of work to wait for 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.
Settings where support provided

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.

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.

69% 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 on DSWs

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

16% of DSWs received JobKeeper and 10% received JobSeeker.

Hours worked

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.

40% worked less hours in April than in February 2020 because of COVID-19 and 11% worked more hours.

Financial hardship

The figure below shows the proportion of DSW who experienced different types of financial hardship in April 2020 with the overall levels of reported difficulties in dark blue and financial difficulties reported by DSWs who experienced a reduction in hours in lighter blue/aqua.

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 with 4% reporting very high levels of psychological distress consistent with a clinical diagnosis of anxiety or depression. 16% were shown to have a probable serious mental illness.
Lack of COVID-19 training was associated with high levels of distress with 86% of those who had high distress reporting that they had not had training.

Similarly, lack of access to PPE was associated with high levels of distress, with 85% of those with high distress reporting that they had not received PPE.

These findings imply that lack of knowledge and protection contribute to anxiety among DSWs.

**Recommendation 8:** Governments and service providers need to provide mental health support to DSWs. Comprehensive infection control training and access to PPE, where required, would reduce the psychological stress many workers are experiencing.

### 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 a group home. 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 future 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 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.

### Acknowledgements

This work was funded by the Melbourne Disability Institute, University of Melbourne special COVID-19 funding round. We thank the Advisory Group of DSWs and the DSWs who participated in the survey for generously giving their time and sharing their insights.