The disability workforce and COVID-19: initial experiences of the outbreak

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1 Summary

This report provides analysis of workers' experiences of delivering disability services and supports in the early stages of the outbreak of COVID-19 in Australia. Data is drawn from a survey of 2341 disability workers, conducted in March 2020. The survey was designed primarily to help understand the experiences of disability workers, and the challenges they confront in the context of the National Disability Insurance Scheme (NDIS). It was planned and designed prior to the outbreak of the virus in Australia.

While the pandemic was not anticipated during survey design, the data collection period coincided with the period that social distancing measures were introduced and increased in Australia. As such, many workers provided comments in the survey highlighting the significant issues and challenges they faced in the context of COVID-19, and the need for urgent industrial responses and workforce supports to sustain quality service delivery through the pandemic and recovery phase.

The comments provided by workers highlight the ways that structural features of disability service systems, and the fee-for-service model underlying the NDIS, exacerbate the vulnerabilities of people with disability and the disability workforce, in circumstances of pandemic. Workers pointed to problematic features of disability service systems which whilst pre-dating the health crisis, were converging to generate unprecedented risks in the context of pandemic. These features include the fragmentation of service provision, under-resourcing, lack of management support at the frontline, low pay, poor job security, multiple job holding, high workloads and unpaid work.

Key findings are:

- There is an urgent lack of personal protective equipment (PPE) being supplied to staff and clients, and many workers feel their organisation's safety protocols have been inadequate in the context of COVID-19.

- There are widespread perceptions that the disability workforce is being dangerously overlooked in pandemic response, and many workers are worried about the ongoing impacts of lack of planning in their organisation and for the disability sector as a whole.

- Workers have been particularly worried about day programs and community access activities remaining in operation; group homes remaining open to other workers delivering NDIS services and supports to residents, along with visitors; and disruption to clients' routines and activities, which has created additional risks to client wellbeing and safety.

- Staff are extremely anxious about the situation, and workforce issues and additional workloads have made it difficult to respond to heightened health and safety needs.

- Some workers have lost jobs or shifts and are uncertain about the future of their work, and many expressed concerns about their inability to effectively self-isolate, and the financial impacts of doing so.

2 About the survey

Data comes from a survey of 2341 disability workers. The survey was co-designed prior to the pandemic in Australia by the research team in partnership with Health Services Union, Australian Services Union and the United Workers Union.[1] A link to the online survey was distributed to disability workers via the three unions in early March. Data collection began in early March 2020, before any social and economic responses were introduced to prevent and contain the spread of the virus. Survey participants included workers in a range of disability service settings, including accommodation settings, such as group homes and respite services; along with workers delivering home care; community access and day programs, coordination and advocacy supports, and mental and allied health. The majority (96%) were in roles involving direct work with clients or service users, most commonly with people with intellectual or cognitive disabilities (reported by 87% of respondents). Around two thirds of the sample (65%) said they worked with clients with higher level support needs.

Initially, comments relating to the impact of COVID-19 came through from workers unprompted. However, the growing number of these comments, and the increasing gravity of the situation throughout March led the research team to make a minor adjustment to the final open-ended survey question, in order to prompt respondents to comment on the impact of the virus on their clients, their work and working lives. This slight change to the survey was made early on 24th March, a week before data collection closed. Specifically, we made a small adjustment to the final survey question to elicit further comments about the ways coronavirus was impacting on clients, workers and workplaces, by changing the question from "Before we finish, would you like to say anything else?" to "Before we finish, would you like to say anything else, including anything about the way COVID-19 (coronavirus) is impacting on your clients, work or working environment?"

The report primarily draws primarily on responses from the 419 workers who completed the survey after the 24th of March, although relevant comments from respondents earlier in March are also included. While the information was collected through a period in which social distancing measures were increasingly impacting on disability workplaces, the survey closed prior to announcement of the Jobkeeper program. While the impacts of wage subsidy arrangements are not clear, it may be expected to have increased the sense of security among some workers, and the capacity of some employers to maintain employment of disability workers. However, it would not have affected the extreme health and safety risks highlighted by workers. These are outlined in the following sections.

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[1] A full survey report will be completed in mid-2020.

3 Lack of safety equipment

Most commonly, comments left by workers focused on the lack of protective equipment provided by employers which meant workers felt unable to safely carry out their usual work tasks. Employees in accommodation settings, such as supported independent living facilities, group homes or respite services explained:

> *NO PPE supplied to staff or participants. Concerned that staff are working across locations and that NDIS providers are coming into residence to provide services increasing chances of infection to all involved across whole of area.*

> *Dangerously unprepared with lack of PPE. We had to ask other houses for hand sanitiser. No face masks or protective eye wear for personal care procedures. Made me feel very unsafe working with children and I don't want to go back to work and be put at risk.*

Others similarly explained:

> *No provision for PPE, we supply hand sanitizer ourselves, not enough support from management, they seem to be burying their head in the sand, don't feel supported by them either, they are not following the government ruling regarding isolation.*

In many cases, workers felt exposed to increased risks and very unsafe:

> *Since the arrival of COVID19...every time I head to work it feels like Russian Roulette. Knowing that we have not been supplied with basic safety equipment e.g. hand sanitizer, anti-bacterial hand wash, masks, shoe covers etc, does not make me feel safe. Knowing that there are no guidelines re: an outbreak of the disease in the houses, and knowing how vulnerable some of the clients (and staff are) is terrifying. Having to go shopping for anything for the house is also a risk we should not have to take due to the fact that the employers have not set up shopping delivery yet (even though this service is available for the vulnerable).*

Workers also perceived the disability sector to have been dangerously overlooked in the national response to COVID-19. Many were extremely worried about the lack of planning in their workplace. For example:

> *I don't feel that my work site has received adequate instructions or equipment to deal with the current COVID-19 situation safely and confidently.*

> *We are totally unprepared with no PPE. As soon as one of our staff or clients tests positive we are going to fall apart with no plan at all.*

Workers were very critical of the failure of organisations to provide equipment, put plans in place, or provide guidance to staff. Numerous worker accounts attest to lack of support from management to access equipment or develop appropriate plans and protocols and descriptions of the situation show this raised very high risks for clients and workers:

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> *[My] organisation has been very slow to be proactive about taking precaution measures to slow the spread of the virus. Not provided with antiseptic wipes to clean the company vans for Day Program. Only use of one container of antiseptic gel for everyone entering the building! Very disappointed! No meetings held for staff...only posters.*

> *We should be more protected than we are. I also believe we should not be taking the clients out even if management requests this.*

> *[Our] organisation was very slow to isolate vulnerable residents from day programs which we can only assume related to the budget.*

> *We did not get any information about how to be prepared, what do we need to do etc. It seems employers do not care about employees getting this virus. NO PPE, no training, half of the work force already lost due to school closure. One parent has to stay home. Coming weeks going to be extremely hard. We need PPE and strict rules how to manage group homes.*

Lack of leadership in services was a serious impediment to effective response. In some cases, managers were described as unreachable, and many staff described feeling abandoned:

> *[My organisation] are completely unprepared for an outbreak with no clear contingency plans, lack of PPE & inadequate training. The General Manager displays lack of leadership & decision-making capabilities, referring to the pandemic as "just the flu" & suggesting people are panicking. The inaction & attitude thus far could lead to loss of lives amongst our vulnerable client group & older staff.*

> *I do not like working for [this organisation], I feel there is no care factor with that company for our clients. There is no contingency plan concerning coronavirus as far as I know. They seem to be very slow in doing anything and are unreachable if you need them, maybe their office is overseas, that would explain things.*

> *There are no contingency plans and not enough PPE to protect staff and residents from contagion. We cannot follow social distancing and no one seems to care.*

> *[My employer] has not addressed in any way staff protection from cross contamination. But expects us to turn up for work every shift regardless. Three things have been put in place. 1. reams of paper information that cannot be implemented eg. safe distancing. 2. Management are no longer visiting workplaces. 3. A management number to ring if someone is showing systems …. Clients are still expected to go to day placements. No social distancing on a bus and outings.*

A perspective on social distancing in a group home

We have no clear procedures in relation to social distancing and infection control for COVID 19 - the standard guidelines given to the community are simply not workable with the majority of our clients. We are continually sneezed on, drooled on, spat at, breathed on and coughed on and it is impossible in many situations to do our job and assist these clients without getting close up enough for this to happen. This outbreak calls for more protective measures than just wiping things down and using the infection control kit.

We need masks and protective clothing and appropriate guidelines for our line of work tailored to the people we are assisting. We risk infection every shift. We risk infecting our clients every shift and then we risk infecting our families and the community when we go home - even if we follow the social distancing rules outside of work, we are still a risk to our families and communities because we are so exposed and unprotected when we are at work. Casuals who move from group home to group home also risk bringing the virus with them from one client group to another.

Our clients are THE most at-risk group because they have so many medical and immune system issues in addition to an inability to understand or grasp the rules or importance of social distancing. My fear is that they will suffer significant loss of life if COVID-19 gets into the group homes and intellectually disabled community and respite services and that they and us, their carers, will function as incredible virus spreaders as a result of workers just being left to just figure the infection control stuff out on our own with no additional equipment or useful input regarding the practicalities of personal care from our employer or our union. If this is to be stopped our government, employers and union must act now!

(Worker in a not-for-profit accomodation setting in regional Victoria)

4 Slow action on client safety

Slow action to keep clients safe was a very strong theme in the comments provided by workers in the survey. Concerns about social distancing in the context of day placements and the difficulty of managing movement through group homes were very strong. Workers in group homes were particularly concerned about the risks associated with the numbers of casual staff working across facilities, and with other staff and visitors attending their workplace to deliver NDIS services and supports. For example:

> [My employer] is slow to act. We do not have enough PPE equipment in the houses if residents become unwell with COVID 19. I'm concerned about the amount of casual agency staff coming into the facility to support the residents, increasing the risk of spreading COVID 19 to are vulnerable residents. And what happens during lockdown? We need a plan.

> We are exposed to too many people coming to the group home

> I don't believe staff are being protected enough, it should be a total lockdown for the houses for people with disabilities. Try to keep to regular staff. Stop random people coming into the home environment.

Workers in group homes were very concerned about the risks associated with residents attending day programs, which had remained in operation without appropriate social distancing measures in place.

> Placement hasn't stopped at our house still out not in lock down mixing with others vulnerable people with very low hygiene skills

> Still management sending [residents] to placements and so many different staff coming do the shifts everyday. It's risk for us and clients.

> I am very worried about the clients and staff regarding safety measures that don't seem to have been put in place to protect us, allowing day placement and programs to continue at this time. I also worry about the isolation for the clients yet to come in this unknown time ahead.

5 The challenge of supporting clients through pandemic

Workers expressed extreme anxiety about the safety of the people they were providing services and support to, and were either unclear about the ways they should be working with clients and ensuring safety through the pandemic, or felt resources to effectively support clients were lacking:

> *How are we to apply the safe distance rule when working and caring showering / dressing people and have no safeguard equipment no masks no aprons no protective eye wear and some are still sending them to day placement or work training? How do we keep the people we support and staff from risk of COVID-19?*

The issue of day programs being left in operation was a particular point of concern:

> *This is a very stressful time for everyone in Australia, but I feel disability has been neglected in a lot of decisions made. Day placement should have been shut down immediately and residents' health needs put first, along with staff. Day placement is not an essential service and by us sending these most vulnerable people to them where all the social distancing guidelines could not be met only puts them and their carers at a greater risk.*

Those supporting people with intellectual disabilities described working in increasingly challenging contexts. For example:

> *Participants are very confused about not having their usual community access programs.*

> *Clients don't understand why things aren't happening as before, it is difficult for them to comprehend.*

> *Covid-19 has affected our clients in a big way. They do not understand why they are suddenly not going to their day programs, why we aren't going out anywhere on weekends etc, why they can't have that "extra" roll of toilet paper or piece of toast (due to shortages in availability). It has led to B.O.Cs (behaviours of concern) and frustration for the clients. We are doing our best to keep them busy and entertain them, but it is becoming increasingly difficult to manage.*

At the time of the survey, some organisations had introduced measures in response to the crisis, including 'lockdowns' or isolation protocols, while others had not. Where social distancing measures had been taken, this created additional tasks and exacerbated already high workloads. Workers explained how measures in place meant that in addition to their usual tasks, they needed to support people with disability to understand and adjust to changes in routine, and to address the additional needs associated with, and arising from, disrupted routines. For example:

> *Even though it is explained every day, most clients are unaware of the COVID virus and don't understand that to keep them safe, we do not shake hands and stay 1.5 metres*

distance. Their regular weekly community access has ceased and this is causing frustration, disappointment and heightened behaviours.

Our clients are now mostly contained in the house, which because of some challenging behaviours, causes them to be anxious, fearful and sometimes violent. I'm also very concerned about my family and now feel that I'm at risk.

The participants that I support, [their] support needs have changed due to their underlying health conditions and therefore lockdown. This resulted in further support being needed to help these people both emotionally and physically (helping with groceries etc).

Clients don't understand what's happening, no outings or community access, no contact with group friends.

They do not understand why they are home from their day placement. Staff have to get creative with limited resources to provide programs for them. They like their routine and get depressed when they cannot go. Very tough on them.

Among workers in contexts where distancing measures had been taken and those where they had not, a particular concern was that managers had failed to recognise and address the increased needs of people with disability, and were also overlooking the additional demands on frontline staff:

I don't think we've got enough support from management to date. No one has rang to see how our clients are doing and the well-being of staff who are supporting the clients. Some staff are stressed and anxious. All we get is emails informing us about the COVID-19. Would be nice if someone from management rang and (had) knowledge (of) the work that staff are doing in the forefront.

Insufficient staffing levels presented a barrier to providing the additional support clients were observed to need:

Due to lack of staffing we have 1 staff to 5 residents & with the general workload & extra workload because of the virus we don't have time to also do extra activities & keep their spirits up with being shut in the house.

6 Anxiety among staff

Unsurprisingly, the pandemic was generating extreme anxiety among staff. This was repeated across numerous comments from workers, for example:

Working within the Disability Sector during the Health Crisis has caused a lot of employees to become stressed and anxious for their own personal safety.

What happens if the clients get the Covid-19? What happens to me if I get the virus from the clients?

Very stressful right now with all the uncertainty of secondment, transition to NDIS processes and now the Covid-19 virus.

Many explained feeling very concerned about the risks for their health:

Clients are not being forthcoming when they feel unwell, as they will lose the service for the day. In that instance they put me as a worker at risk as well. I have clients in the car and attend medical appointments with them. It makes me very uncomfortable and very paranoid about my own health.

These anxieties were exacerbated by staffing practices that generated unreasonable workloads. One commented that providing supports was:

…even more so difficult with the staffing shortage, as they have not got any new casuals hardly in the past 12 months. Staff are not allowed to come to work if they feel slightly unwell, so we are shorter still. It is putting even more pressure on the same few staffing group. And we don't seem to be getting any further with anything at present.

A lot of friends and co-workers have simply lost shifts/jobs with the virus and people (like me) who are on full time contracts or permanent positions are picking up the slack.

7 Job and income security in the context of pandemic

The comments also capture other impacts on workers, many of which were substantial and resulted in loss of employment and income. Some had lost hours as their work ceased or reduced, for example:

I have lost my day centre employment because of this virus.

Some work lost due to house lock downs, due to Covid-19.

I was happy to work 24 hours in a week but since the hub shut down for a while due to Coronavirus, I am not sure where I can work from next week.

Many workers also had additional family care responsibilities in the context of the virus or had lost income as they needed to self-isolate.

I had to drop some hours to look after my family but I have lost income and fallen behind my mortgage repayments.

Since this incident, I have to keep myself quarantined, same as my husband because he landed in Australia after 15/3/2020. So, I have to use my annual leave and sick leave to cover my day off.

Staff are not being paid for self-isolation when returning from overseas.

I got stood down as I'd been overseas before the government had put people into the 2 week isolation.

Other impacts were less severe, including dealing with the additional work of complying with employers' leave policies to enable quarantine, for example:

Following up enforced Covid-19 leave procedures and chasing medical results to satisfy my employer policy and be able to return to work without limitations of working remotely and suffering unpaid sick leave when I was told I must be tested and quarantined.

Several pointed to the failure of employer and government policies to remove disincentives and penalties for those needing to self-isolate.

All things considered, my employer treats its workers well. It does not deliberately victimise us or exploit us. But the system within which we work means we do not receive fair compensation or reasonable job security. In the context of COVID-19, you can imagine that workers in our industry will be reluctant to self-report and self-isolate when it means that they will lose wages. That puts vulnerable people at risk. But I don't blame the workers, I blame the government for not ensuring that we are not penalised.

Another pointed out how loss of jobs and hours reflect the lack of funding security for services, under a fragmented fee for service model of the NDIS (see quote below). This worker explained how operational funding offered better continuity and certainty following pandemic.

A perspective on COVID in the context of the NDIS

These are scary times, especially when we are working with such vulnerable people. While I fully support Social Distancing as a means of protecting clients, families and workers alike, I fear the pay-for-service model has created a situation where a lot of services may not pull through this crisis. The lack of security in funding has sounded warning bells thanks to COVID-19. With clients staying home in unprecedented numbers the viability of service providers is under threat. From my understanding the benefit of the previous block funding method was that services would be stay operational for the year regardless of absences. This would more or less guarantee that there would be services to return to once the crisis had passed. At the moment, I feel unless we change this way of operating, we may lose a lot of essential services for our clients. I think the government should reassess the funding model in understanding that precious industry experience has been lost and more will go the more we create a climate of uncertainty. We need a more collaborative approach between services as we all should have our client's best interests at heart. Sadly, it feels like they are becoming more of a commodity in the corporate agenda.

(Worker in a not-for-profit community setting, Tasmania)

Workers were particularly concerned about their financial future. Some expressed relief they could continue to provide for their families, while others anticipated loss of hours and pay:

I'm so relieved I have an ongoing line - at least someone in my family has a guaranteed income.

I have very uncertain future for day programme and expect to lose about 20 hours a fortnight work at least which will cause a lot of financial pressure on my already restricted situation.

Covid 19 is affecting my work hours and now not sure how my future I have taking 2 months off and not paid as I am casual.

I have been in this industry for 12 years, I suffer from [a complex health conditions]. I have two children. Due to my condition and no one to look after the kids at home, I have to stay home and don't have any sick or recreation leave. My wife works in aged care as a service assistant. How as a family we can possibly pay our mortgage, utilities, foods etc with a revenue of $800 weekly? The bank is offering hold for six months but still charging interest for the six months, which means putting workers more in debt.

In summing up their circumstances, some workers called for hazard pay, or another pay incentive, for those who remained employed, in recognition of increased risk:

Putting clients at risk with expectations of continuing day placements at the start of the outbreak makes clients extremely vulnerable, and no thought about staff working to keep the clients safe it's a worry especially when I have a young child at home not knowing if I

am passing something on. There should be a danger wage increase during this awful time.

Day programs not closing earlier putting vulnerable clients more at risk. Also no support or concerns for staff that could catch Covid 19 that have children to look after at home. There should be a pay incentive for working around the increased risk.

8 Conclusions

The circumstances disability workers describe show the way COVID-19 has massively increased the risk of working in disability services, and the health and wellbeing costs incurred by disability workers. Decent pay and working conditions are essential elements of effective responses to the virus and will build capacity to sustain services and supports through the coming period of recovery.

Key issues relate to the supply of protective equipment to disability workers; provider organisations' capacity to develop and enact health and safety plans and protocols; arrangements to minimise movement of staff between workplaces; additional resources to ensure time for hygiene related tasks and to support people with disability in the context of social distancing (including people with intellectual disability); additional incentives to sustain labour supply in the context of additional demands and risks; operational funding to sustain service supply; and resources to support workers to self-isolate (e.g. sick leave).

While the survey provided an unanticipated, incidental opportunity to collect research evidence about the disability workers' initial experiences of COVID-19 and its impacts on their work and working lives, further research is needed to understand workers' experiences over the longer term, and to assess the impacts of government policies on this group of essential workers.