



PERSONAL PROTECTIVE EQUIPMENT NEEDS OF NDIS PARTICIPANTS DURING COVID-19: PRELIMINARY RESULTS

May 2020

The Summer Foundation is a not-for-profit organisation, established in 2006, that aims to change human service policy and practice related to young people in nursing homes. Our mission is to create, lead and demonstrate long-term sustainable changes that stop young people from being forced to live in nursing homes because there is nowhere else for them.

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EXECUTIVE SUMMARY

Concerns regarding the vulnerability of people with disability during the COVID-19 pandemic have been raised by the disability sector in Australia consistently over the last two months. People with disability, especially those with underlying medical conditions, are disproportionately vulnerable during COVID-19.

A national survey conducted in April 2020 obtained the perspective of 351 National Disability Insurance Scheme (NDIS) participants on their personal protective equipment (PPE) needs. The 30 question survey was designed to inform a national strategy to source PPE and provide an accessible distribution pathway to NDIS participants. Central to this strategy is a collaborative initiative between the Summer Foundation and 2 of Australia's largest providers of PPE, RSEA Safety and Blackwoods. The initiative involves the launch of 2 online stores offering PPE for NDIS participants.

The current guidelines promoted by the Australian Government to control the spread of COVID-19 are primarily focused on hygiene and social distancing. However, these are not always options for people with disability. The recent survey of NDIS participants found that 58% of respondents require support in close proximity which prevents social distancing. A further 8% of survey respondents require support for respiration, which involves disability support workers performing aerosol-generating procedures with the risk of exposure to droplets.

There is a chronic global shortage of PPE. Some people with disability who were regular users of PPE prior to COVID-19 can no longer source the protective equipment essential for personal care. The survey results show that prior to COVID-19, 14% of disability support workers working with NDIS participants wore PPE most of the time and a further 30% wore PPE some of the time.

People with disability and those who support them have a critical need for clear, concise and consistent information about PPE and its use. One respondent reported: "I'm rather lost with PPE. I'd like to be able to access supplies but I don't know what I need or where to get it."

While over half (61%) of respondents knew what PPE they required for COVID-19, almost a third (30%) were not sure and some (9%) did not know. When asked about specific PPE concerns, survey respondents were most concerned about where to get PPE (76%), the cost of PPE (48%) and how to use PPE (19%). Affordability was frequently cited as a barrier to PPE, with one respondent commenting that they "cannot get PPE or sanitizer unless it is at a ridiculous cost".

Many survey respondents felt vulnerable, with some expressing associated anxiety and depression. One respondent reported: “I cannot survive without [support workers], but without PPE I can no longer feel safe in my own home. It is a very vulnerable and horrible position to be in...”.

Respondents expressed anger at seemingly being “left out” and “forgotten” in the community’s response to the pandemic. One respondent said: “I am pretty sure we are all going to die. And they will write our disability on the death certificate, not what we died of.” Another said: “We are utterly voiceless and invisible in this crisis. It is not ok.”

PPE for people with disability is also critical for preventing infections and hospital admissions. The survey found that very few (only 7%) NDIS participants had access to all the PPE they needed. The timely provision of PPE to people with disability during COVID-19 will be more cost effective and result in better outcomes for all involved. Access to PPE during COVID-19 is essential for people with disability and support workers.

There are four clear recommendations stemming from this PPE survey:

Information: NDIS participants and support workers urgently need clear, consistent and accessible information about PPE - when to wear it, how to wear it and how to dispose of it.

Additional NDIS funding for PPE: There is an urgent need for the NDIS to provide reasonable and necessary funding for the additional PPE that some NDIS participants urgently need during COVID-19.

Funding PPE prior to NDIS participants getting sick: The National Disability Insurance Agency (NDIA) should consider proactively funding PPE for all NDIS participants who rely on disability support workers for essential and basic daily tasks. Some NDIS participants need to have PPE on hand when they get any cold or flu symptoms.

Infection control strategies and resources specific to people with disability: Health and disability experts need to explore and develop options, strategies and resources specifically for people with disability who have a suspected case or confirmed diagnosis of COVID-19 and are not able to comply with infection control measures developed for the general population.

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ABBREVIATIONS & DEFINITIONS

TERM	DEFINITION
COVID-19	The disease caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) virus
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NMS	National Medical Stockpile
P2/N95 mask	Disposable P2/N95 face masks (also known as P2/N95 respirators) are able to filter out very fine particles from the air when worn correctly
PPE	Personal protective equipment

1. INTRODUCTION

1.1 BACKGROUND

One billion people, equivalent to 15% of the world's population, experience some type of disability (World Health Organization, 2011). Unfortunately, this population is at increased risk of developing further health complications, and the COVID-19 pandemic is no exception. People with disability, especially those with underlying medical conditions, are disproportionately vulnerable during COVID-19 (Centers for Disease Control and Prevention, 2020), the disease caused by the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) virus (World Health Organization, 2020b).

Concerns regarding vulnerability to COVID-19 have been raised by the disability community (Stillman et al., 2020). A number of barriers, both new and existing, will heighten the risk of people with disability developing COVID-19. Individuals often experience higher health needs, worse outcomes and face discriminatory laws and stigma, yet are less likely to access health care (Nguyen et al., 2020; United Nations, 2020). Such barriers may be exacerbated during COVID-19, including disrupted care or the introduction of the virus by disability support workers. For individuals who reside in congregate settings such as group homes, hostels or aged care facilities, the risk is also heightened due to proximate living arrangements. A lack of care, with the possibility of denied care when health care providers determine who will receive limited resources (Bagenstos, 2020), will likely increase morbidity and mortality within this population (Armitage & Nellums, 2020). Preventing infections and hospital admissions will be cost effective and result in better outcomes for all involved.

The current guidelines promoted by the government to control the spread of COVID-19 are primarily focused on hygiene and social distancing. However, these are not always options for people with disability. For example, maintaining the recommended social distancing of 1.5 metres is largely impossible for individuals with complex support needs. In 2018, approximately 2.5 million Australians with disability required assistance with at least one activity of daily life (Australian Bureau of Statistics, 2018). Consistent with other public health emergencies (Wingate et al., 2007; World Health Organization, 2013) guidelines have not clearly considered the specific needs of people with disability, prompting scholars to recommend that COVID-19 preparedness and response planning requires a disability-inclusive perspective (Armitage & Nellums, 2020; O'Connell et al., 2020). Given the increased risk among people with disability, special considerations to address safety and care are required (Vieira et al., 2020).

The National Disability Insurance Scheme (NDIS) is Australia's first national scheme for people with disability (NDIS, 2020). There are around 4.4 million Australians who have a disability (Australian Bureau of Statistics, 2018). Within the next five years the NDIS will provide an estimated 500,000 Australians, aged under 65 years, who have permanent and significant disability with funding for support and services. The NDIS provides support to eligible people with intellectual, physical, sensory, cognitive and psychosocial disability. Current guidelines for disability providers and self-managed NDIS participants state that, outside of usual clinical care requirements, there is no requirement for workers supporting NDIS participants to wear surgical masks or other items of personal protective equipment (PPE) unless they are working with people who have suspected or confirmed COVID-19 (NDIS Quality and Safeguards Commission, 2020). NDIS participants who use PPE as a usual part of their support arrangements have been advised to continue to access PPE through their usual means. Where this is no longer possible, they have been advised to approach the National Medical Stockpile (NMS) for their PPE requirements.

The Australian Government Department of Health guidelines state that PPE should be worn when caring for someone with a confirmed or suspected case of COVID-19 (Australian Government Department of Health, 2020b). Recommended PPE for working with someone with confirmed or suspected COVID-19 includes wearing a gown, P2/N95 mask, protective eyewear and gloves. Guidelines state that PPE should be removed before exiting the room or the person's home, and hands should be washed or sanitised immediately after removing PPE. The Department of Health states that as PPE is a limited resource, the Australian Government's highest priority is to ensure access to masks and other PPE for frontline acute health service and primary care staff (Australian Government Department of Health, 2020b).

In the COVID-19 Management and Operational Plan for People with Disability, the Department of Health (2020c) identifies a range of possible actions related to PPE for people with disability including:

1. Mobilising the resources of the NMS to support the appropriate provision of PPE to people with disability and carers with an emphasis on:
 - a. Supporting carers and workers providing support to people with disability who have a suspected case or confirmed diagnosis of COVID-19;
 - b. Supporting continuity of service, where PPE is a usual and essential requirement for the delivery of particular support activities;
 - c. Enabling access to PPE for people who receive supports which involve significant and close physical contact.
2. Developing clear guidance for people with disability and support workers on circumstances where PPE should be used and the appropriate use of PPE.

3. Developing guidelines for the best use of the limited supply of PPE.
4. Considering options for additional supports or variation to supports where people with disability, who are confirmed with or suspected to have COVID-19, cannot wear PPE or comply with requirements to wear PPE.

Research suggests that PPE can reduce rates of COVID-19 transmission and protect health workers and clients in the health care setting (Cook, 2020). As the pandemic intensifies and the demand for resources increases, concern regarding access to PPE rises globally (Dargaville et al., 2020; Ranney et al., 2020). In Australia, NDIS providers and self-managing participants are being encouraged to source PPE independently, if they are able to (Victoria State Government Department of Health and Human Services, 2020). The World Health Organization (2020d) recently stated that: “the chronic global shortage of PPE is now one of the most urgent threats to our collective ability to save lives”. Availability of PPE is especially concerning given its association with compliance to standard precaution practices (Beyamo et al., 2019). Haile, Engeda, and Abdo (2017) reported that those who had PPE readily accessible were 2.87 times more likely to always be compliant than those who did not have PPE readily accessible. Consequently, inadequate PPE may lead to increased risk for people with disability and disability support workers. Although no empirical research is available for the use of PPE during COVID-19, previous international reviews into infection control precautions, such as PPE, have found that compliance was suboptimal (Gammon et al., 2008; Mitchell et al., 2012).

People with disability and their support workers need access to PPE during COVID-19. The situation is causing considerable concern for people with disability. An example is provided by the following quote from Sam Petersen. Sam is an NDIS participant and stroke survivor:

“I have a problem that nobody seems to have the answer for. I can not live without physical support. Therefore, I’m worried about getting COVID-19 because the support workers don’t have the Personal Protective Equipment to support me, and if I got it I will automatically go to hospital because they don’t have the Personal Protective Equipment to support me at home. It would be like I couldn’t live in my home again. I have spent 5 years in an institution setting. Often, I have found they will do stuff to me without my consent, and or, do something wrong and I can’t quickly say, “no, do it this way”...We have hardly any mention in the media. I need help. We all need help.” Sam Petersen¹

¹ Sam Petersen, 2020, personal communication via <http://genyusnetwork.com/summer-ppe-and-me/>

In line with the World Health Organization's recommendations (World Health Organization, 2020a), the Department of Health (2020c) have outlined that access to PPE will be prioritised to those who deliver supports to people with disability which involve significant and close physical contact. Despite this, and given that the COVID-19 literature is emerging, no research has yet examined the PPE needs of people with disability or the availability of PPE to them.

In late March 2020, NOVEL-19 were working with state governments to estimate and procure the quantity of ventilators and PPE needed for hospitals across Australia in preparation for COVID-19. NOVEL-19 is a private sector group of business leaders and philanthropists bringing an agile entrepreneurial response to COVID-19. The group has strong links with the federal and state governments, medical research institutes and industry, and is working with a McKinsey team, financially supported by the Commonwealth Bank. They are aligned with the government, aiming to accelerate initiatives to support the government's response to COVID-19. Given the global shortage and highly competitive international market for medical supplies such as ventilators and PPE, the normal government processes were initially ineffective in procuring the COVID-19 related supplies for Australia. NOVEL-19 was able to set up international procurement operations to source ventilators and PPE, with the resulting products being supplied largely to state health departments.

The Summer Foundation started to work with NOVEL-19 in late March 2020 to develop a demand model to estimate the quantity of PPE needed for NDIS participants and develop a strategy for procuring and distributing PPE. The initial model to estimate demand utilised NDIS data (provided by personal communication to Di Winkler, Summer Foundation, from the NDIA) grouped 353,203 NDIS participants into four segments:

- (i) No respiratory symptoms: supervision/limited proximity care required.
- (ii) No respiratory symptoms: personal care required with close proximity.
- (iii) No respiratory symptoms: proximate care with potential direct contact with respiratory droplets (e.g. tracheostomy management).
- (iv) Any participants with symptoms (cold/flu-like included).

NDIS participants were allocated to the first three segments based on the following data:

- Living situation
- Number of hours of core support for daily activities
- Additional supports such as critical respiratory or home enteral nutrition support

It was also assumed that:

- 10% of people have cold/flu-like symptoms on any given day
- On average, gloves need to be replaced every hour and other PPE (e.g. masks, gowns and face shields) need to be replaced every 4 hours

While the estimate of PPE demand based on population data was a valuable starting point, some of the assumptions needed to be tested. Tapping into the expert knowledge of people with disability was a logical next step to developing a strategy to make PPE more readily available to NDIS participants.

A survey of NDIS participants was designed to harness this expert knowledge and test some of the assumptions in the demand model based on population data. Together the demand model and the PPE survey results provide a timely and rigorous evidence base to inform a national strategy to source and distribute PPE to NDIS participants in Australia.

1.2 AIMS

This project aimed to understand the personal protective equipment (PPE) needs of NDIS participants and support workers during the COVID-19 pandemic. There were three specific aims:

1. To obtain the perspective of NDIS participants on PPE needs
2. To provide an evidence base to inform models to estimate the quantity of PPE required for NDIS participants
3. To inform strategies to distribute PPE to NDIS participants

1.3 METHOD

A 30-question survey was developed by the Summer Foundation Research Unit to assess the PPE needs of people with disability who are NDIS participants. The survey was administered via the Qualtrics platform as an online survey and participants were recruited via social media on the Summer Foundation platforms.

The survey ran from 11-22 April 2020 and was targeted towards NDIS participants. If NDIS participants were unable to complete the survey themselves, it could be completed on their behalf by friends, family, support workers or support coordinators. The survey collected categorised information about participant background, including demographics, NDIS related information, and the type and frequency of assistance received from support workers or other informal supports. Information was collected about the need for different types of PPE and current concerns over PPE during COVID-19. Participants were also asked about whether they had chronic health conditions that were known to be risk factors for COVID-19 complications.

Answers to the final question of the survey, “Is there anything else you’d like to tell us?” were analysed using the Framework Method for qualitative data analysis (Gale et al., 2013) as described in Section 3.

1.4 INITIAL PRESENTATION OF QUANTITATIVE RESULTS

To facilitate the timely use of data obtained from the survey, this report presents a preliminary analysis of the respondents’ demographics and survey responses. A Business Intelligence tool was used to conduct this initial data review. The data presented in the tables and graphs shows the counts, proportions and means (average) associated with the survey responses to each question, unless otherwise indicated. Subsequent publications will be prepared with a more comprehensive analysis of the data with the aim to better estimate the PPE needs for NDIS participants across Australia.

2. QUANTITATIVE RESULTS

2.1 SURVEY PARTICIPATION

A total of 439 individuals accessed the survey. Of these, 351 (80%) answered some of the key first questions that were necessary to understand an individual's background and experience. These included general descriptors of who they were, how their NDIS plan was managed and the proximity of support received. It should be noted that some questions were not asked of all participants. If a participant was not expected to have an answer based on their previous responses, they were not asked follow-up questions. The reported results are based on the proportion that answered each question.

The survey participants took an average of 7.7 minutes to complete the survey, with variation between groups. NDIS participants took an average of 9.3 minutes, while family or friends took 6.3 minutes, support workers took 3.6 minutes and support coordinators took 5.3 minutes.

2.2 PARTICIPANT DEMOGRAPHICS

As shown in Table 2.1 below, most survey participants (89%) were either NDIS participants themselves or a friend or family member of an NDIS participant.

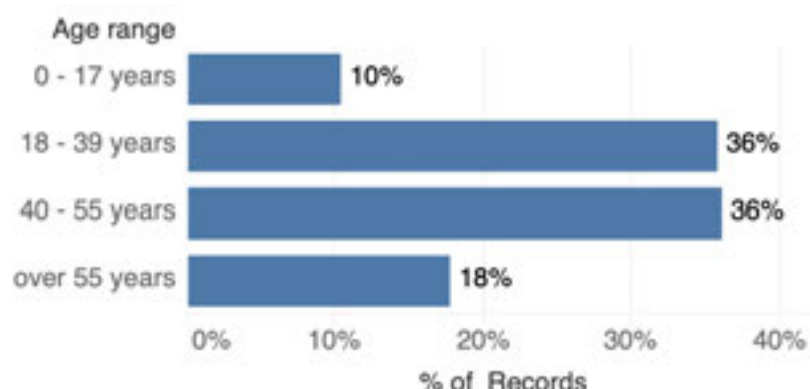
Table 2.1. Number of survey respondents based on their relationship to an NDIS participant (n=351).

Who are you?	Number of Records	% of Records
NDIS participant	168	48%
Friend or family member completing survey on behalf of NDIS participant	145	41%
Worker completing survey on behalf of NDIS participant	17	5%
Other, please specify	13	4%
Support coordinator completing survey on behalf of NDIS participants	8	2%

Participants were asked about their age within age ranges as shown in Figure 2.1.

The age of survey participants fell within the full scope of NDIS participant eligibility, with the majority being between 18 and 55 years of age.

Figure 2.1. Age range of NDIS participants surveyed (n=351).



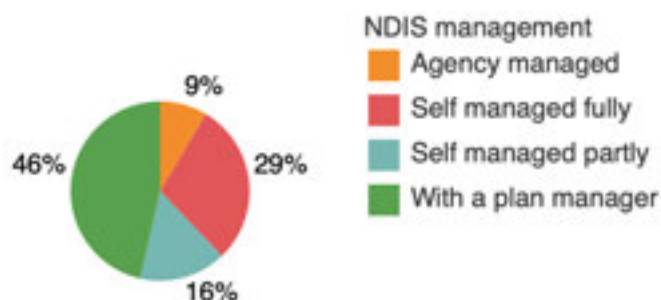
Half of the survey participants lived in their own home and one-quarter lived with their parents. The remainder lived in group homes with shared support or in residential aged care facilities. See Table 2.2.

Table 2.2. Number and percentage of NDIS participants surveyed with each type of living arrangement (n=310).

Where do you live?	Number of Records	% of Records
In own home (e.g. private, social or public housing)	176	50%
With parents	90	26%
Other, please describe	14	4%
Group home	14	4%
Apartment, townhouse or villa with shared support	12	3%
Residential aged care	4	1%

Almost half of the survey participants (46%) used a plan manager to manage their NDIS funds. This was similar to the proportion of survey participants (45%) who self-managed their NDIS funds either partly or fully. In contrast, less than 9% of survey participants had NDIS funding that was fully agency managed. See Figure 2.2.

Figure 2.2. Proportion of surveyed participants within each type of NDIS plan management (n=351).



2.3 SUPPORT NEEDS

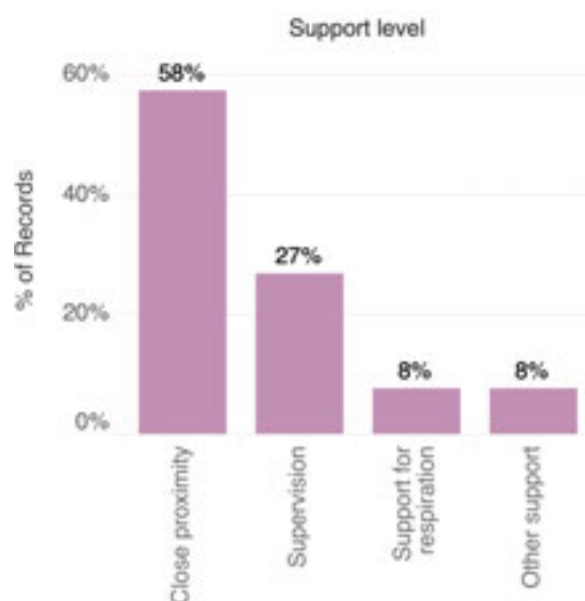
To get an understanding of the risk of COVID-19 virus transmission, survey participants were asked about the proximity of support they received, based on the categories described in the introduction, where they had the opportunity to select one of four responses:

- (i) Supervision - disability support workers mostly provide supervision with limited physical contact. Workers do not work in close proximity and provide limited personal care
- (ii) Close proximity - disability support workers provide personal care and work in close proximity
- (iii) Support for respiration - disability support workers provide support that has a higher risk of direct contact with respiratory droplets e.g. suctioning or trache management
- (iv) Other, please describe

Figure 2.3 shows that 27% of survey participants require supervision from support workers with limited physical contact. In contrast, 58% require close proximity support that would prevent social distancing. Almost 8% of survey participants require support for respiration, which creates considerable risk of direct contact with respiratory droplets.

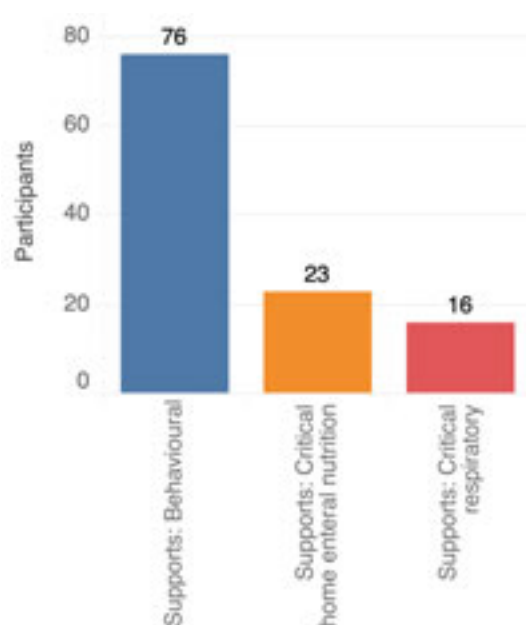
Approximately 8% (27) of respondents identified that they receive 'other support' funded by the NDIS. For some, this included activities supporting the household such as cleaning, shopping, cooking and transport (8 survey participants). Seven survey participants also indicated that their previous or intended support was halted or never began because of COVID-19. Others indicated no disability supports (4) or nursing home care (1). The final comments were more specific to their circumstances such as parental responsibilities (1) or adding detail to their support worker experience.

Figure 2.3. Proportion of NDIS participants surveyed who receive support from disability support workers at varying proximities (n=351).



To get a further understanding of risk of COVID-19 virus transmission, survey participants were asked to identify specific support needs that could put them or their support worker at additional risk, including behavioural supports, critical home enteral nutrition support, or critical respiratory supports. Only 33% of participants identified that they receive these supports, with approximately one in five survey participants specifying that they had behavioural support needs. See Figure 2.4.

Figure 2.4. Number of NDIS participants surveyed who receive specific types of supports (n=147).

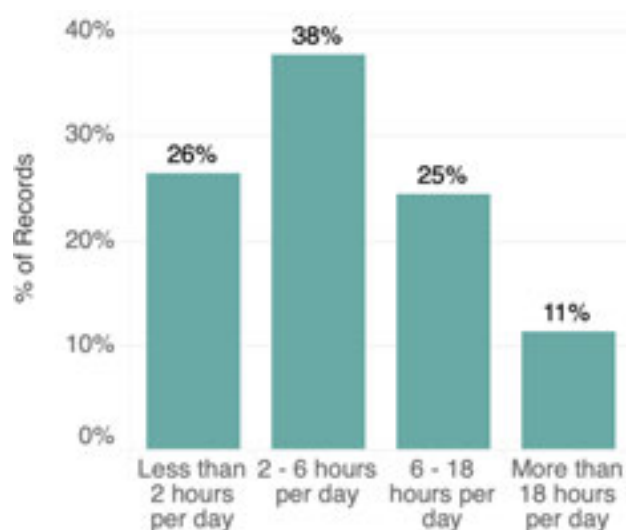


It is important to note that 51 people indicated 'other' for this question. An exploration of these findings showed that the most frequently mentioned 'other support' included personal care activities (23) including activities such as showering, nursing care, catheter and bowel care, trache management and PEG feeding. Other responses identified a range of supports including transport, allied health, mental health, household management and education.

The average number of core support hours provided to survey participants per day varied considerably, with over half receiving 6 or less hours (Figure 2.5).

Approximately 12% of survey participants did not indicate whether they receive core supports.

Figure 2.5. Average hours of core support received by surveyed participants each day (n=310).



2.4 PARTICIPANT CHRONIC CONDITIONS

Survey participants were asked to indicate if they had any of the six conditions that are known to increase the susceptibility of individuals to COVID-19 related complications. The chronic health issues that participants could choose from were:

- Asthma
- Reduced lung capacity
- Smoker
- Immunocompromised e.g. cancer treatment or other immune weakening medication, immune deficiencies, HIV or AIDs
- Diabetes
- Severe obesity

Participants could also choose 'other, please specify' or 'none of the above'. A total of 239 participants identified that they have one or more chronic conditions, representing 68% of the survey population.

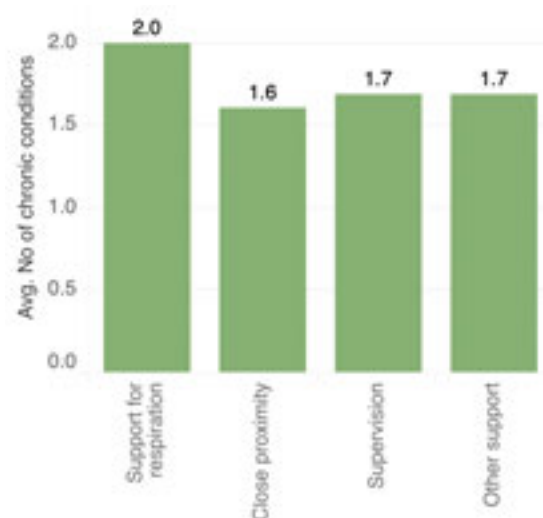
Table 2.3. Counts and proportions of key chronic conditions for survey participants (n=239).

Conditions	Count	Proportion
<i>Asthma</i>	78	22%
<i>Reduced lung capacity</i>	87	25%
<i>Smoker</i>	21	6%
<i>Immunocompromised</i>	84	23%
<i>Diabetes</i>	28	8%
<i>Severe obesity</i>	42	12%
<i>Other</i>	81	23%

An exploration of the other chronic conditions people experienced showed that cardiovascular related conditions were most common (15), along with epilepsy, (11), sleep apnoea (4), kidney disease (4) and multiple sclerosis (3). A number of less common conditions such as fibromyalgia (2) cauda equina syndrome (1), factor V Leiden (1) and intellectual disability (1) were also identified. Some respondents were less specific with their descriptions such as 'auto immune' conditions or descriptions such as bedridden, wheelchair dependant or legally blind.

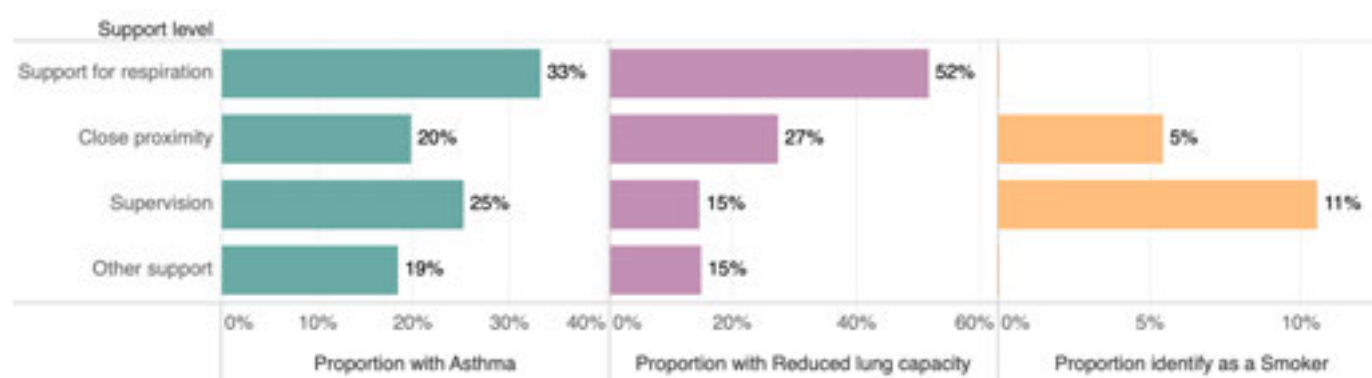
In terms of the average number of the 6 key conditions identified, most support level groups were within the range of 1.6-2.0 conditions per person.

Figure 2.6. Average number of six key chronic conditions across proximity support levels (n=204).



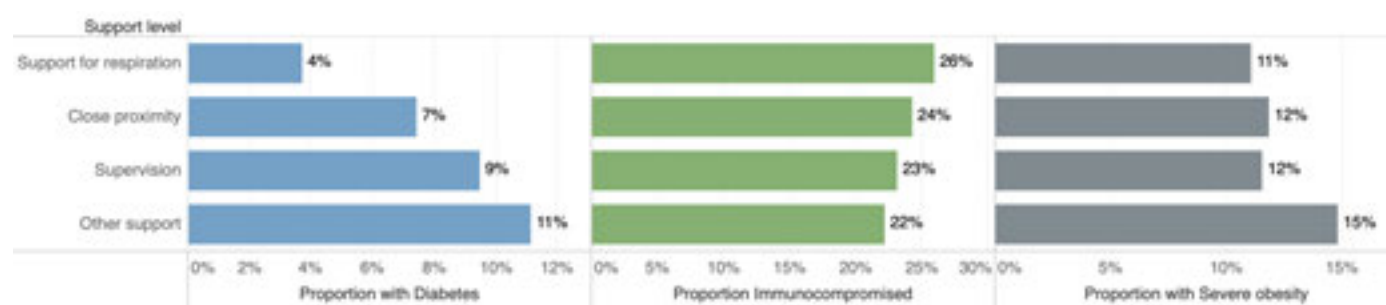
Further exploration of the key chronic health issues found that survey participants who receive support for respiration from support workers were more likely to have asthma or reduced lung capacity, however, no people within this group identified as smokers (see Figure 2.7). Of the survey participants that did identify as smokers, most receive supervision from support workers, while a smaller amount receive close proximity support. Overall, there is a high number of participants with chronic respiratory conditions placing them at higher risk of complications if they contract COVID-19.

Figure 2.7. Proportions of survey participants identifying they have any one of the key respiratory chronic conditions related to higher COVID-19 risk (n=239).



Respondents identified conditions that have been cited as possible concerns for those contracting COVID-19 (Australian Government Department of Health, 2020c; Kass, Duggal & Cingolani, 2020) including diabetes, being immunocompromised, and severe obesity (Figure 2.8). Almost 1 in 5 participants had immunocompromised systems through cancer treatment or other immune weakening medication, immune deficiencies, HIV or AIDs, and were present across all support groups. Diabetes was more common in NDIS participants who require supervision or other support when compared to participants who require close proximity or respiration support. Severe obesity was present at 11-12% for all support groups, apart from the 'other support' group which approached 15%.

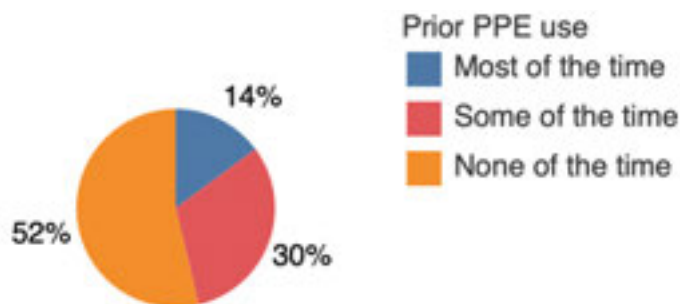
Figure 2.8. Proportions of survey participants identifying they have any one of the other key chronic conditions related to higher COVID-19 risk (n=239).



2.5 PPE EXPERIENCE, KNOWLEDGE AND CONCERNS

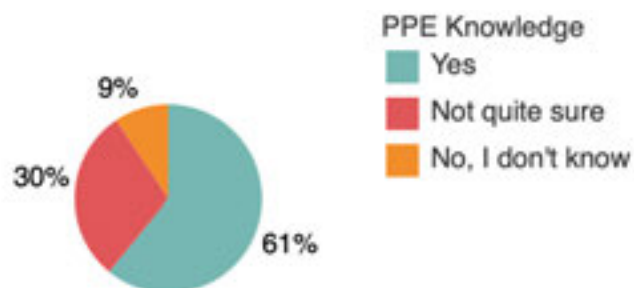
Survey participants were asked a range of questions about PPE to understand their needs. Figure 2.9 shows that almost half (44%) of participants indicated that their disability support workers wore PPE prior to COVID-19, with 14% using PPE most of the time.

Figure 2.9. Proportion of survey participants whose disability support workers wore PPE prior to COVID-19 (n=337).



While over half (61%) of respondents knew what PPE they required for COVID-19, almost a third were not sure (30%) and some (9%) did not know. See Figure 2.10.

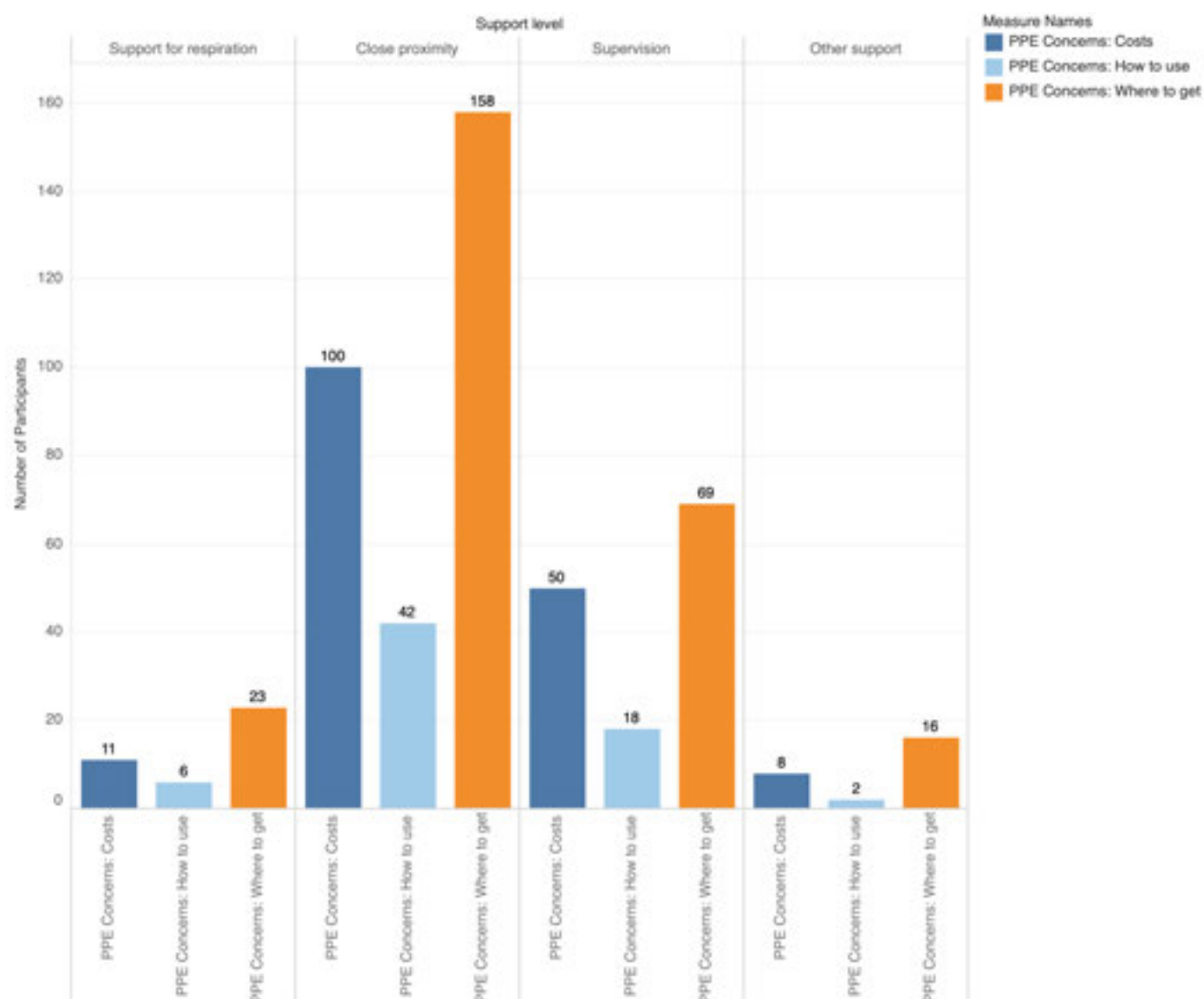
Figure 2.10. Proportion of survey participants who knew or did not know exactly what type of PPE they would need during COVID-19 (n=330).



When asked about specific PPE concerns, survey participants identified issues related to where to get PPE (76%), the cost of PPE (48%) and how to use PPE (19%). Another 48 survey participants identified other concerns that included the lack of PPE training for disability workers, NDIS funding for PPE, when to use PPE, variability in which organisations provide it to their support workers and correct disposal of PPE.

Further examination of the specific concerns of respondents over PPE showed that regardless of the proximity of support received, the highest concern was where to get PPE, followed by the cost of PPE and how to use PPE. See Figure 2.11.

Figure 2.11. Concerns about PPE based on the proximity of support received by survey participants (n=328).



It is particularly noteworthy that only 7% of NDIS participants had access to all of the PPE they needed. Almost three quarters of the sample reported that they did not have access to all of the PPE that they needed.

Figure 2.12. Access to PPE (n= 338).



For those who currently had access to all or some of the PPE they needed (23% of all respondents), there were a variety of places they were accessing it from as shown in Table 2.4.

Table 2.4. Source of PPE that was currently being used by survey participants (n=69).

Current PPE coming from	Number of Records	%
Online purchase of PPE	25	36%
Provided by my disability support provider	15	22%
Other, please describe	29	42%

Those who identified 'other' sources often cited supermarkets, provision by families and nursing homes, or utilising their own. One respondent noted that due to the shortage and the lack of availability from the normal consumable providers they were constantly looking through eBay and had their workers searching all the local supermarkets trying to find PPE items.

2.6 AVERAGE ESTIMATED NUMBER OF PPE ITEMS NEEDED

Survey participants were asked whether they knew how much PPE they needed on a weekly basis. If they indicated that they did know (35% of respondents), they were then asked to estimate the number of items of PPE they required within a specific time period. These items and their respective time periods were:

- Gloves (weekly)
- Disinfectant wipes (weekly)
- Gowns (weekly)
- Eye protection glasses (weekly)
- Surgical masks (weekly)
- ISO compliant masks – P2/N95 (weekly), where P2/N95 masks are relevant where the person with disability has any cold/flu like symptoms or a worker may be exposed to respiratory droplets
- 100ml alcohol-based hand sanitiser (monthly)

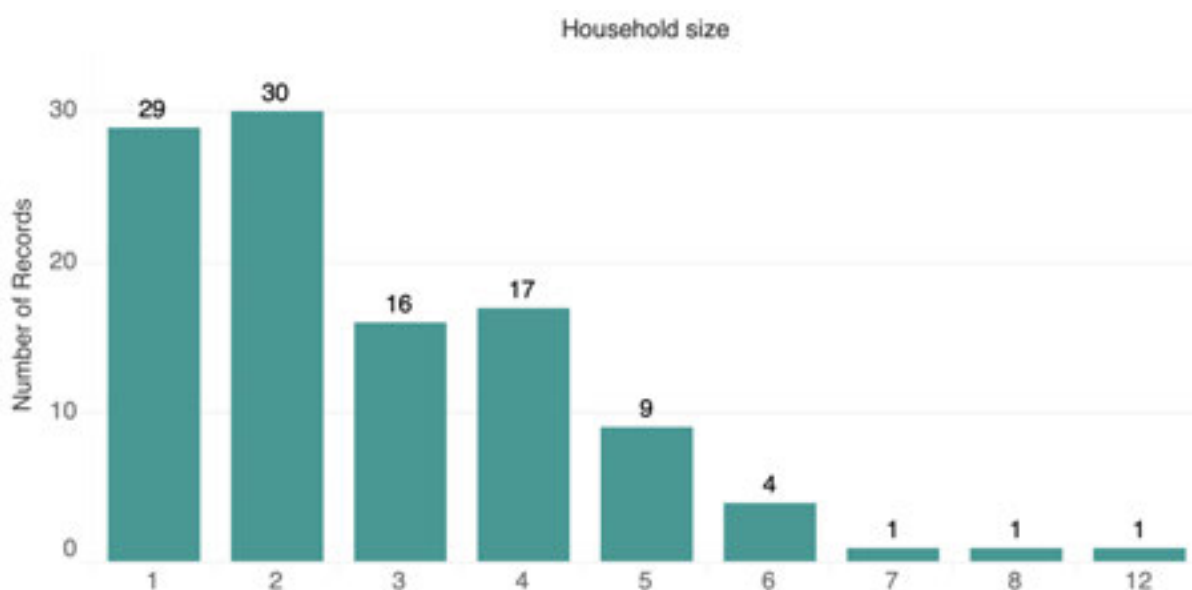
Given this group felt confident in estimating their PPE needs, the survey asked them additional questions to help estimate potential PPE needs across the four proximity support levels.

This included understanding:

- Their household size
- How many support shifts they had per week
- Whether they shared support with other NDIS participants
- The unpaid support provided by friends and family

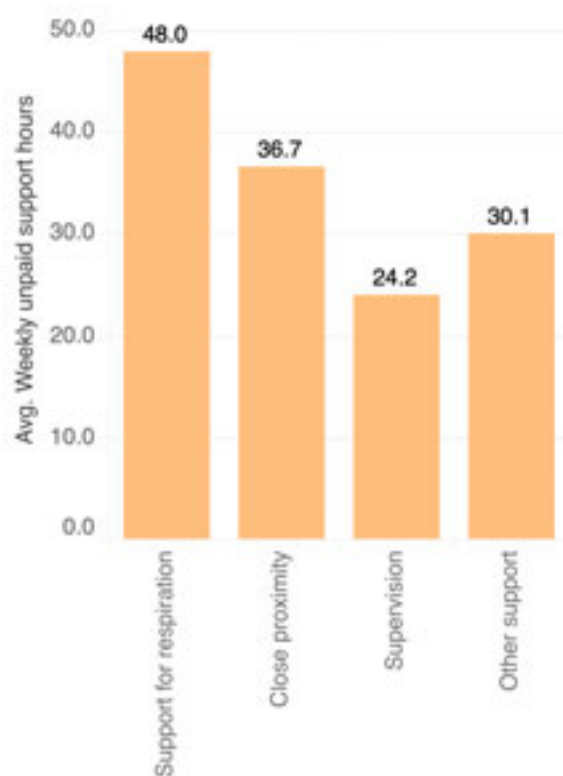
Of the 108 respondents outlining household size, 55% lived on their own or with one other person, 39% lived in a household of 3-5 people, and 7% lived in a household of 6 or more people. See Figure 2.13.

Figure 2.13. Number of people who lived in the households of the NDIS participants (n=108).



In Figure 2.14 we can also see that family and friends spent significant amounts of time supporting NDIS participants in addition to their paid supports. This illustrates that the PPE needed was not just for the disability support workers, but also for family and friends who on average provide 24 hours or more support over a week.

Figure 2.14. Average unpaid weekly hours of support provided by friends and family by proximity support level (n=108).



As shown below in Table 2.5, there was considerable variation in the estimates of PPE needed from different participants as evidenced by the difference between some averages and the median values. This will be further explored across the different proximity support levels below.

Table 2.5. Estimation of PPE requirements for survey respondents who knew how much PPE they required.

Item	n	Range	Average	Median
Gloves (weekly)	105	0-200	39.9	30
Disinfectant wipes (weekly)	97	0-400	75.1	50
Gowns (weekly)	103	0-60	7.8	3
Eye protection glasses (weekly)	101	0-32	4.7	1
Surgical masks (weekly)	100	0-56	15.7	14
ISO compliant masks – P2N95 (weekly)	96	0-50	9.2	5
100ml alcohol-based hand sanitiser (monthly)	103	0.5-42	7.1	5

In an effort to better understand the variations in needs across support levels, the averages were calculated across the different groups for all the items (see Figures 2.15 and 2.16). Not unexpectedly, the average need for most PPE items was generally greater for the close proximity and support for respiration groups.

In contrast, disinfectant wipes were the only PPE item needed in a higher quantity for the supervision group than the support for respiration group. This quantity may be related to an aspect of mobility for this group where those supervising need to wipe down more surfaces of more mobile people with a disability.

Figure 2.15. Average weekly requirement for gloves, disinfectant wipes, gowns, eye protection glasses, ISO compliant masks and surgical masks, based on support needs, for survey participants who were confident of their PPE requirements.

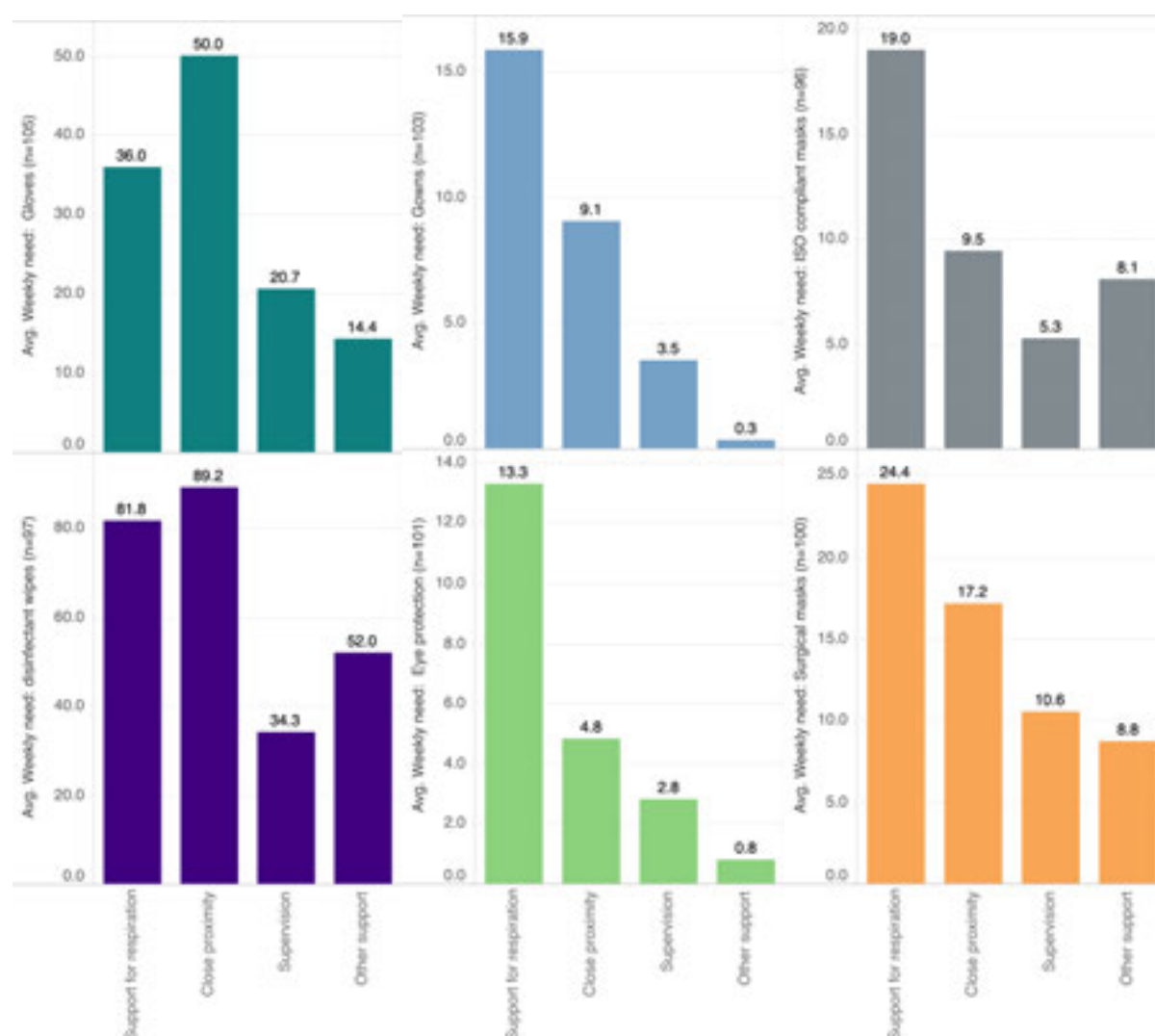
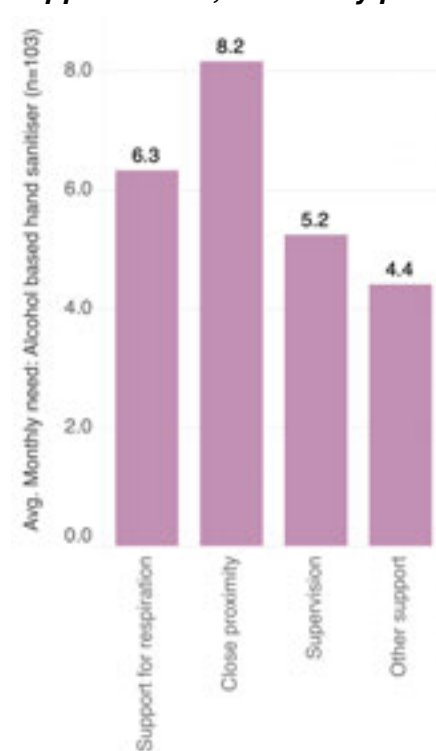


Figure 2.16. Average monthly requirement for alcohol-based hand sanitiser, based on support needs, for survey participants who were confident of their PPE requirements.



2.7 PREFERRED METHOD FOR PURCHASING PPE

Survey respondents who knew how much PPE they needed on a weekly basis were asked whether they would be happy to purchase a PPE starter kit based on the answers to a few questions, which would be used to help tailor the kit to their needs.

Of the 116 who answered this question (33% of total survey respondents), most (53%) agreed or strongly agreed, with 33% being unsure. In contrast, only 13% disagreed or strongly disagreed. See Table 2.6.

These same 116 survey respondents answered the next question about whether they would like to purchase individual PPE items in the quantities that they need. Out of those who answered, the vast majority (90.8%) agreed or strongly agreed. See Table 2.7. These results show that although people would consider PPE starter kits, there was a greater preference for being able to purchase individual PPE as needed.

Table 2.6. Willingness of survey participants to purchase their PPE as a starter kit (n=116).

Purchase PPE starter kit	Number of Records	%
Strongly agree	35	30%
Agree	27	23%
Neither agree or disagree	38	33%
Disagree	12	10%
Strongly disagree	4	3%

Table 2.7. Willingness of survey participants to purchase their PPE as individual items (n=116).

Purchase individual PPE items	Number of Records	%
Strongly agree	56	48%
Agree	49	42%
Neither agree or disagree	8	7%
Disagree	2	2%
Strongly disagree	1	1%

2.8 REPRESENTATIVENESS OF THE SURVEY POPULATION

The survey respondents and NDIS population were similar in their living situations.

However, the respondents in the current survey differed from the NDIS participant population (see Table 2.8) in the following ways:

- Survey respondents were older than the NDIS population
- More survey respondents self managed their plans or had a plan manager compared with the NDIS population
- Survey respondents had more hours of core support funded for daily activities than the NDIS population

Table 2.8 Comparison of survey respondents to NDIS population.

	Survey Respondents	NDIS Participants*
Age		
0-17 years	10%	53%
18-55 years	72%	35%
Over 55 years	18%	13%
Living situation		
Group home	4%	8%
Aged care	1%	2%
Other housing	95%	80%
Plan management†		
Self managed - fully	29%	18%
Self managed - partly	16%	12%
With a plan manager	46%	35%
Agency managed	9%	35%
Funded hours of core support for daily activities per day		
Less than 2 hours	26%	86%
2-6 hours	38%	10%
6-18 hours	25%	4%
More than 18 hours	11%	1%

* Data provided by the NDIA 7th April 2020 specific to NDIS participants in receipt of funding for core daily activities (personal communication to Di Winkler, Summer Foundation)

† Plan management data from all NDIS participants from December 2019 COAG Disability Reform Council Quarterly Report

The age distribution difference between the survey respondents and the NDIS population is unsurprising, given the survey was shared via traditional social media more typically used by adults (Facebook or Twitter). Similarly, the comparatively higher proportion of fully or partly self-managed respondents was expected. Self-management of NDIS funding requires that the NDIS participant (or someone who supports them) has sufficient cognitive capacity for routine financial management. In turn, people with this capacity would be more likely to participate on social media platforms where the survey was shared. Further, self-managed NDIS participants requiring a large number of core support hours are more likely to be aware of their need for PPE, see it as an issue relevant to them and be interested in and motivated to complete the survey.

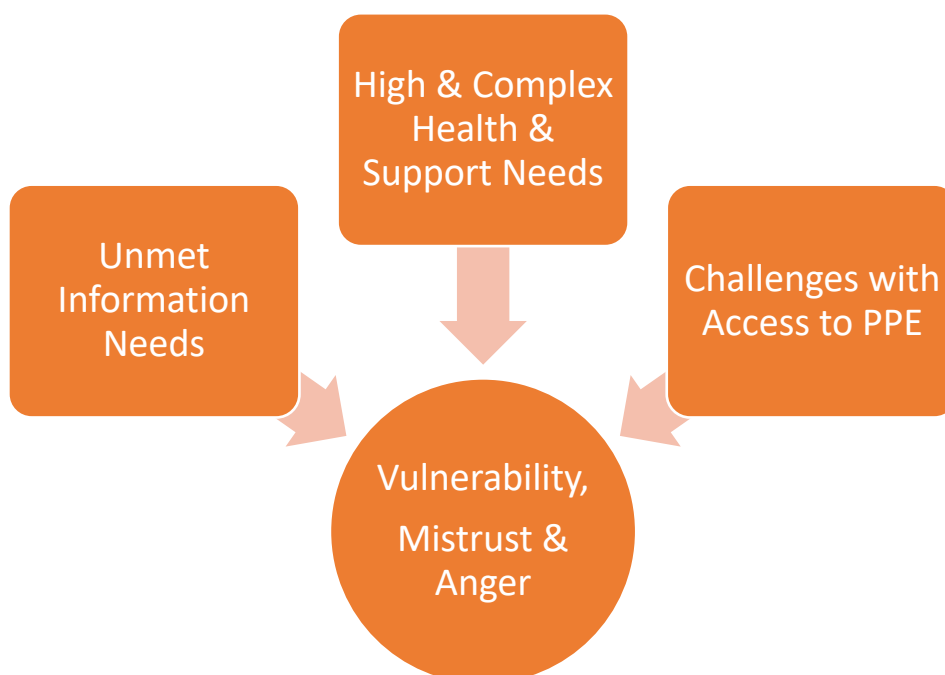
The aim of the survey was to glean the expert knowledge of NDIS participants about PPE. We were not aiming for a representative sample of all NDIS participants. Indeed part of the purpose of this survey was to inform the development of online PPE stores specifically for NDIS participants. The primary users of such stores are most likely to be self-managed NDIS participants.

3. QUALITATIVE RESULTS

Answers to the final question of the survey “Is there anything else you’d like to tell us?”, were analysed using the Framework Method for qualitative data analysis (Gale et al., 2013). Of the 439 complete survey responses received, 90 respondents (21%) chose to provide more information and answer this question (question 29). The responses reflected a range of perspectives: 56 respondents were NDIS participants; 30 were friends or family members of NDIS participants; 2 were support coordinators; 1 identified as a worker; and 1 identified themselves as a carer. More than 30% (n=26) fully self-managed their NDIS plans and 20% (n=17) partially self-managed their NDIS plans, while 43% (n=37) had a plan manager and 7% (n=6) had their plans agency managed.

Data were coded by two researchers with experience in qualitative data analysis. Following initial independent coding, the researchers met to compare assigned codes, and reached agreement by consensus on the key themes identified within the data. Four themes were strongly reflected in the experiences people shared: (i) Unmet Information Needs; (ii) High and Complex Health and Support Needs; (iii) Challenges with Access to PPE; and (iv) a Sense of Vulnerability, Mistrust and Anger. The first three themes together contributed to respondents’ sense of vulnerability, mistrust and anger, as shown in Figure 3.1.

Figure 3.1 Is there anything else you would like to tell us? The qualitative analysis.



These four key themes and associated subthemes represented in people's experiences are outlined below. Quotes from respondents are included below to exemplify the experiences shared in the survey.

3.1 UNMET INFORMATION NEEDS

Analysis of responses to the open-ended question of the survey quickly revealed that respondents had experienced a lack of information regarding PPE. This lack of information was expressed in four ways: inadequate communication, a lack of transparent information, a lack of consistent information, and a lack of accessible information.

3.1.1 INADEQUATE COMMUNICATION

Respondents described receiving little or no communication from their support providers, and others within the sector, regarding both PPE, and other measures that should be taken to protect themselves and their support workers from COVID-19.

"... There has been inadequate communication dispersed to families who have support workers visit houses in support of a family member in regards to physical distancing etc." Respondent 64

"My support worker needs to take me out in her car. She has other clients she takes out too. What does the provider need to do to support her to clean the car?" Respondent 8

"My SW (support worker) works for a registered provider and neither her or myself have heard from them regarding ppe or covid restrictions." Respondent 56

"There has been zero direction / assistance from the NDIS or my Support Coordinator in relation to sourcing PPE during this pandemic." Respondent 59

3.1.2 LACK OF TRANSPARENT INFORMATION

A lack of clear information meant that some respondents were unsure about how PPE should be used, how it could be accessed, and who was responsible for PPE supply.

"I want to know if masks are to be used at the moment. There is no clear definition and who should be supplying them to support workers." Respondent 3

"Should I provide the masks..?" Respondent 69

"What should my worker be using for PPE?" Respondent 9

"... I have tried to find out if I am allowed to purchase PPE using my NDIS funding and have not been able to get a clear answer..." Respondent 67

Respondents identified that a lack of transparent information was associated with anxiety for people with disability and complex needs.

“We really need transparency from the government regarding their planning inc. exactly who they deem a priority, the shortage estimates, how they will reduce shortages & how PPE will be disseminated. The lack of transparency is causing avoidable anxiety and difficulty with personal planning.” Respondent 47

3.1.3 LACK OF CONSISTENT INFORMATION

Respondents also indicated that information received had lacked consistency.

“People (are) saying different things about masks.” Respondent 63

3.1.4 LACK OF ACCESSIBLE INFORMATION

Respondents commented that information should be made available in accessible formats, to meet the needs of people with a range of disabilities.

“... People everywhere are confused, but those with intellectual disability even more so...” Respondent 71

“Information needs to be available in Easy English as well as audio formats (including picture descriptions)” Respondent 34

3.2 HIGH AND COMPLEX HEALTH, CARE AND SUPPORT NEEDS

Over one third of respondents (n=33) used this open-ended survey question to report that they, or a member of their household, experienced complex health or support needs. Many indicated that they had experienced, or were currently experiencing, respiratory conditions that placed them at higher risk of complications resulting from COVID-19, including COPD, emphysema, chronic bronchitis, respiratory failure and ventilator dependence.

Others reported that their immunocompromised status placed them at greater risk of infection. In two instances, respondents were forgoing their usual supports due to their immunocompromised status, and lack of access to PPE.

“I live with my husband and he is also on the NDIS due to an autoimmune disease... He also has (a range of other health conditions). He is also physically disabled... Because we’re both at risk but him especially so we both have to be extremely careful. We currently have no PPE and nor did our support workers, cleaners and gardener. Due this reason we have had to stop all support that requires close contact within our home and also all allied health supports... This has made mine and my husband’s life extremely difficult...” Respondent 67

We just can't take the chance that the carer is not going to get us COVID
19. What are we meant to do(?)” Respondent 73

Other respondents identified that an individual's unique disability and support needs present implications for the use of PPE.

“... any form of dementia or brain related injury really increases fear. Gowned and masked people are scary. Mental health issues compound physical health challenges.” Respondent 48

“... Autistic people who touch everything may need disposable gloves as much as support workers providing personal care...” Respondent 71

3.3 CHALLENGES WITH ACCESS TO PPE

Challenges with access to PPE were commonly cited by survey respondents. These challenges manifested in a number of ways: not knowing where or how to access PPE, affordability of PPE, and actual or anticipated PPE shortages.

3.3.1 NOT KNOWING WHERE OR HOW TO ACCESS PPE

Participants indicated that they were unsure of what types of PPE they would need, or how to access these.

“I'm rather lost with PPE. I'd like to be able to access supplies but I don't know what I need or where to get it.” Respondent 45

“I am having to try to do my own research, including emailing the national stockpile and registering with businesses diversifying into sanitiser production. No idea where to get appropriate masks.” Respondent 59

3.3.2 AFFORDABILITY

Affordability was frequently cited as a reason why respondents were unable to access PPE themselves.

“Cannot get PPE or sanitizer unless it is at a ridiculous cost and the DSP is under \$450 per fortnight for under 21 making everything unaffordable.” Respondent 71

“Should I provide the masks, but (they) are very expensive and I won't be able to afford given (sic) it to them? The same as hand sanitiser. I don't have any at home nor I can afford to provide.” Respondent 69

“Accessing these things is getting harder and more expensive beyond our budget.” Respondent 61

“It is personally costing me a fortune to keep my participants safe.”

Respondent 86 (support coordinator)

Other respondents reported that they had sourced and purchased PPE themselves, as they had been unable to access any through other support channels.

“We have had to purchase most of my daughters PPE out of her NDIS consumables and have had to purchase all wipes, masks and sanitizer ourselves. Our service provider has provided nothing at all.” Respondent 76

“I currently provide additional PPE gloves to my support workers and do not have any access to masks.” Respondent 31

3.3.3 ACTUAL OR ANTICIPATED PPE SHORTAGES

Many respondents reported shortages of PPE in their local areas.

“Finding PPE to buy at the moment is also impossible.” Respondent 67

“Can not get any PPE in our area...” Respondent 77

“Stocks are getting harder to find in local area due to high demand.”

Respondent 86

Given shortages experienced, at least one respondent was concerned that the PPE they used would become unavailable.

“I personally need/use gloves to (for continence support) daily.

I’m concerned about possible glove shortage.” Respondent 24

3.4 A SENSE OF VULNERABILITY, MISTRUST AND ANGER

Many respondents felt vulnerable, with respondents expressing associated anxiety and depression.

“I feel very alone, fatigued and overwhelmed. I have lovely neighbours who say hello. But in my home and garden I am feeling ashamed at the mess and struggling to keep hygiene when I have no support. I am prioritising, but I am so fatigued and I know I am going into/in a slump/crash due to extreme fatigue and overwhelm of having no help. It is very distressing.” Respondent 29

“I cannot survive without (support workers), but without PPE I can no longer feel safe in my own home. It is a very vulnerable and horrible position to be in...” Respondent 50

Changes to the amount and method of support received were common, with many reporting reductions in support received. One respondent indicated that they had reduced their core supports for their own safety, and another had changed the way in which they received support.

“I cut (down) my core support to the bare minimum - not because I wanted to, but because I feel safer doing so. I was getting 7 days a week, with multiple people coming on public transport, now just 3 shower shifts.” Respondent 92

“...have moved all SW online to avoid illness.” Respondent 20

Others attributed their cancellation of support to a loss of trust in their support workers, who were not demonstrating appropriate hygiene practices.

“I’ve had no support because I don’t trust workers.” Respondent 51

“I have lost all my supports, cannot trust them especially when they can’t get hand sanitiser, some could not even be bothered washing their hands either. One took my groceries into the toilet.” Respondent 11

Others conveyed a loss of trust in the authorities.

“I am pretty sure we are all going to die. And they will write our disability on the death certificate not what we died of.” Respondent 91

Many respondents also expressed anger at seemingly being “left out” and “forgotten” in the community’s response to the pandemic.

“We have been totally missed in the conversation about the pandemic. The disappointing thing is the government is relying on the medical fraternity yet they have forgotten about us.” Respondent 82

“I feel like the disability sector has been left out of any discussions around PPE. Only frontline medical workers are considered.” Respondent 88

“We are utterly voiceless and invisible in this crisis. It is not ok.”
Respondent 92

“Why are we last to get PPE it’s so wrong??” Respondent 17

“...I feel extremely upset that the government hasn’t taken quicker more effective action to protect such a vulnerable group of people. We matter. I’m disheartened to have been left behind in this crisis both without appropriate care and protection and with the covid monetary supplements offered to everyone else except the elderly and the disabled and their carers.”

Respondent 50

4. DISCUSSION

People with disability, especially those with underlying medical conditions, are disproportionately vulnerable during the COVID-19 pandemic. The survey provided a clear evidence base to support concerns raised by the disability sector in Australia over the last two months. NDIS participants and support workers do not have access to clear and consistent information about PPE. The lack of clarity about PPE use and clear guidelines is complicated by the limited availability of PPE during COVID-19. If clear guidelines are provided to support workers at a time they do not have access to PPE, some disability support workers may decide not to work without PPE.

Approximately two thirds of survey respondents require disability support workers to provide support in close proximity to the NDIS participant. This requirement prevents social distancing from being maintained and creates considerable concern in the context of official guidelines which recommend social distancing as the preferred way to limit transmission of COVID-19 (Australian Government Department of Health, 2020d). Of even more concern is the risk posed for almost 8% of respondents and their disability support workers where daily tasks involve a high risk of direct contact with respiratory droplets, such as tracheostomy management or suctioning (support for respiration). Although this situation is only a risk if the NDIS participant is infected with COVID-19, it is not always possible to know when someone has been infected and is asymptomatic. The World Health Organization suggests this situation could exist in as many as 80% of cases (World Health Organization, 2020c).

NDIS participants who have very close contact with support workers are clearly at greatest risk. However, it is important not to dismiss the needs of respondents who indicated that their proximity to disability support workers was mostly supervisory (27%) or other supports (8%). Despite less physical personal contact with these groups, COVID-19 has the ability to remain infectious on surfaces for up to 2-3 days (van Doremalen et al., 2020). This prolonged period suggests that the need for support workers to supervise or provide other supports such as household management and transport potentially creates a higher risk of COVID-19 transmission for people with disability than the general population who do not require members outside of their household to enter their home.

4.1 CHRONIC HEALTH CONDITIONS

Current indications suggest that people who have chronic health conditions, such as asthma, reduced lung capacity, diabetes, severe obesity or are immunocompromised (e.g. cancer treatment or other immune weakening medication, immune deficiencies, HIV or AIDs), are at higher risk of developing serious medical complications from COVID-19 (Australian Government Department of Health, 2020a; Kass et al., 2020). Two-thirds (68%) of survey respondents had a chronic health condition, with one quarter indicating that they had reduced lung capacity and one quarter indicating that they were immunocompromised. Indeed, people who required support for respiration reported an average of 2 chronic health conditions, while those with other support levels had an average of 1.6-1.7 chronic health conditions. This data suggests that people needing higher levels of support from disability support workers are not only potentially at higher risk for transmission of COVID-19, but also at higher risk of developing serious medical complications if they were to contract COVID-19.

4.2 BEHAVIOUR SUPPORTS

Half (52%) of survey respondents indicated that they received behaviour supports. Participants who receive this support have challenging behaviours which can put other NDIS participants and the people close to them at risk. People with behavioural supports may be incapable of maintaining social distancing because they do not understand the need for it or because their reactionary behaviours may lead to unpredictable physical contact. Further, some people with behavioural supports may not have the capacity to follow COVID-19 hygiene guidelines related to handwashing, sneezing and coughing. These behavioural tendencies have the potential to put NDIS participants and their support workers or family members at greater risk of COVID-19 transmission.

4.3 QUANTITY OF PPE NEEDED

As shown by this survey, PPE requirements can be considerable for people with disability, particularly people who have higher support requirements. While the estimated quantities of PPE varied considerably between survey respondents, a clear need for ready access to gloves, disinfectant wipes, alcohol-based hand sanitiser and surgical masks was demonstrated.

4.4 CANCELLING DISABILITY SUPPORTS DURING COVID-19

A key finding of this project is the sense of vulnerability, mistrust and anger among survey participants, which led many respondents to restrict essential disability supports in an attempt to remain safe. For some people, this issue arose because

they did not feel that they could trust support workers who were in contact with other people to maintain sufficient hygiene requirements to prevent COVID-19 transmission. Other respondents were concerned that support workers did not have access to PPE or had not been appropriately trained in the use of PPE. This survey provides a compelling evidence base about the urgent need for PPE and clear guidelines for NDIS participants and workers about PPE use.

4.5 PPE DEMAND

The primary objective of this survey was to collect evidence that would assist with the refinement of a strategy for procuring and distributing PPE to NDIS participants.

An initial model of PPE requirements conducted by the Summer Foundation and NOVEL-19 was based on data provided by the NDIA to the Summer Foundation. A model derived using administrative data describing support categories and support frequency is limited in that it makes assumptions concerning actual PPE requirements during those support worker shifts. This survey was designed to rapidly obtain an accurate understanding of the PPE requirements of NDIS participants, which could then be used to refine the model to estimate PPE needs.

The most important finding was that while NDIS participants do require PPE on a regular basis, requirements differ substantially from person to person. While some people have no regular requirements for PPE, some had requirements for gloves and disinfectant wipes in large quantities.

4.6 ACCESS TO PPE

The National Medical Stockpile (NMS) plays an essential role in providing timely PPE to NDIS participants. However, at this stage the NMS distribution of PPE to NDIS participants is limited to masks. The survey results show that there is a clear need for ready access to a range of PPE including gloves, gowns, eye protection, disinfectant wipes, alcohol-based hand sanitiser and surgical masks. Anecdotal reports also suggest that NDIS participants applying to the NMS only receive masks if they have been diagnosed with COVID-19.

The Summer Foundation is working with Australia's largest providers of PPE, RSEA Safety and Blackwoods, to launch 2 online stores offering PPE to NDIS participants. The online stores will supply gloves, gowns, surgical masks, face shields, hand sanitiser and disinfectant wipes.

5. RECOMMENDATIONS

1. Information

Clear, consistent and accessible information for NDIS participants, support workers and close others about:

- Exactly what PPE should be used when during COVID-19
- How to use PPE correctly
- How to dispose of PPE correctly
- Where to get PPE

2. Additional NDIS funding for PPE during COVID-19

The survey found that NDIS participants and families are under considerable stress trying to source and pay for PPE during COVID-19. There is an urgent need for the NDIS to provide funding for the reasonable and necessary additional PPE that NDIS participants need during COVID-19 to:

- Protect close others and workers providing support to NDIS participants who are have a suspected case or confirmed diagnosis of COVID-19
- Protect NDIS participants who receive supports which involve significant and close physical contact
- Protect close others and workers providing behavioural supports to NDIS participants who do not have the capacity to follow guidelines about social distancing, hand washing, coughing or sneezing

We welcome the policy changes implemented by NDIA to enable NDIS participants to easily access a light touch review to their plans, in order to access the additional funding that they needed as a result of COVID-19.

3. Funding PPE prior to NDIS participants getting sick

Colds are very common, with adults, including NDIS participants contracting up to 2 to 4 colds in an ordinary year (Heathdirect Australia, n.d.). NDIS participants need immediate access to PPE when they have any cold or flu-like symptoms. One potential solution is for the NDIA to fund early access to PPE for all NDIS participants who are dependent on disability support workers to assist them with essential and basic daily tasks. This should provide approximately 7 days of full PPE for NDIS participants with cold or flu-like symptoms and provide protection for support workers. This would also provide more certainty for NDIS participants that they would continue to receive the support needed to stay at home for as long as possible and either delay or avoid a hospital admission.

4. Infection control strategies and resources specific to people with disability

Dedicated resources are needed that explore and develop options specifically for people with disability who have a suspected case or confirmed diagnosis of COVID-19 and are not able to comply with guidelines developed for the general population.

People with disability may not have the capacity to comply due to a combination of mobility, physical, cognitive or behavioral limitations. Health and disability experts need to work together to develop information and resources about alternative strategies and options for supporting COVID-19 positive NDIS participants. The COVID-19 Management and Operational Plan for People with Disability addresses this need (Australian Government Department of Health, 2020c).

REFERENCES

- Armitage, R., & Nellums, L. B. (2020). The COVID-19 response must be disability inclusive. *The Lancet. Public Health*, 2667(20), 30076.
[https://doi.org/10.1016/S2468-2667\(20\)30076-1](https://doi.org/10.1016/S2468-2667(20)30076-1)
- Australian Bureau of Statistics. (2018). *4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings, 2018*.
<https://www.abs.gov.au/AUSSTATS/abs@.nsf/Latestproducts/4430.0MainFeatures52018?opendocument&tabname=Summary&prodno=4430.0&issue=2018&num=&view=>
- Australian Government Department of Health. (2020a). *Coronavirus (COVID-19) advice for people with chronic health conditions*.
<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-chronic-health-conditions>
- Australian Government Department of Health. (2020b). *Coronavirus (COVID-19) advice for the health and aged care sector*.
<https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/coronavirus-covid-19-advice-for-the-health-and-aged-care-sector#using-personal-protective-equipment-ppe>
- Australian Government Department of Health. (2020c). *Management and Operational Plan for People with Disability*.
<https://www.health.gov.au/sites/default/files/documents/2020/04/management-and-operational-plan-for-people-with-disability.pdf>
- Australian Government Department of Health. (2020d). *Social distancing for coronavirus (COVID-19)*. <https://www.health.gov.au/news/health-alerts/novel-coronavirus-2019-ncov-health-alert/how-to-protect-yourself-and-others-from-coronavirus-covid-19/social-distancing-for-coronavirus-covid-19>
- Bagenstos, S. R. (2020). May Hospitals Withhold Ventilators from COVID-19 Patients with Pre-Existing Disabilities? Notes on the Law and Ethics of Disability-Based Medical Rationing. *130 Yale Law Journal Forum.*, 1–15.
- Beyamo, A., Dodicho, T., & Facha, W. (2019). Compliance with standard precaution practices and associated factors among health care workers in Dawuro Zone, South West Ethiopia, cross sectional study. *BMC Health Services Research*, 19(1), 4–9. <https://doi.org/10.1186/s12913-019-4172-4>
- Centers for Disease Control and Prevention. (2020). *Others at Risk: People with Disabilities*. <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html>
- Cook, T. M. (2020). Personal protective equipment during the COVID-19 pandemic - a narrative review. *Anaesthesia*, 1–8. <https://doi.org/10.1111/anae.15071>
- Dargaville, T., Spann, K., & Celina, M. (2020). Opinion to address the personal protective equipment shortage in the global community during the COVID-19 outbreak. *Polymer Degradation and Stability*, 176, 109162.
<https://doi.org/10.1016/j.polymdegradstab.2020.109162>

- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*, 13(1), 117.
<https://doi.org/10.1186/1471-2288-13-117>
- Gammon, J., Morgan-Samuel, H., & Gould, D. (2008). A review of the evidence for suboptimal compliance of healthcare practitioners to standard/universal infection control precautions. *Journal of Clinical Nursing*, 17(2), 157–167.
<https://doi.org/10.1111/j.1365-2702.2006.01852.x>
- Haile, T. G., Engeda, E. H., & Abdo, A. A. (2017). Compliance with Standard Precautions and Associated Factors among Healthcare Workers in Gondar University Comprehensive Specialized Hospital, Northwest Ethiopia. *Journal of Environmental and Public Health*, 2050635.
<https://doi.org/10.1155/2017/2050635>
- Heathdirect Australia. (n.d.). *Colds*. Retrieved May 8, 2020, from <https://www.healthdirect.gov.au/colds>
- Kass, D. A., Duggal, P., & Cingolani, O. (2020). Obesity could shift severe COVID-19 disease to younger ages. *The Lancet*, in press. [https://doi.org/10.1016/S0140-6736\(20\)31024-2](https://doi.org/10.1016/S0140-6736(20)31024-2)
- Mitchell, R., Ogunremi, T., Astrakianakis, G., Bryce, E., Gervais, R., Gravel, D., Johnston, L., Leduc, S., Roth, V., Taylor, G., Vearncombe, M., & Weir, C. (2012). Impact of the 2009 influenza A (H1N1) pandemic on Canadian health care workers: A survey on vaccination, illness, absenteeism, and personal protective equipment. *American Journal of Infection Control*, 40(7), 611–616.
<https://doi.org/10.1016/j.ajic.2012.01.011>
- NDIS. (2020). *What is NDIS?* <https://www.ndis.gov.au/understanding/what-ndis>
- NDIS Quality & Safeguard Commission. (2020). *Coronavirus (COVID-19) – Information for support workers and access to Personal Protective Equipment (PPE)*. (Issue March). <https://www.ndiscommission.gov.au/document/2006>
- Nguyen, M. L., Mundkur, A., Molony, T., Nguyen, A., Ra, R., & Howley, T. (2020). *CARE AUSTRALIA Rapid Gender Analysis of COVID-19 in Australia* (Issue April). <https://www.care.org.au/rapid-gender-analysis-covid-19/>
- O’Connell, C. M., Eriks-Hoogland, I., & Middleton, J. W. (2020). Now, more than ever, our community is needed: spinal cord injury care during a global pandemic. *Spinal Cord Series and Cases*, 6(18), 1–2.
<https://doi.org/10.1038/s41394-020-0270-0>
- Ranney, M. L., Griffeth, V., & Jha, A. K. (2020). Critical Supply Shortages - The Need for Ventilators and Personal Protective Equipment during the Covid-19 Pandemic. *New England Journal of Medicine*, 382(18), e41.
<https://doi.org/10.1056/NEJMp2006141>
- Stillman, M. D., Capron, M., Alexander, M., Di Giusto, M. L., & Scivoletto, G. (2020). COVID-19 and spinal cord injury and disease: results of an international survey. *Spinal Cord Series and Cases*, 6(21), 1–4. <https://doi.org/10.1038/s41394-020-0275-8>
- United Nations. (2020, March 19). *Preventing discrimination against people with disabilities in COVID-19 response*.
<https://news.un.org/en/story/2020/03/1059762>

- van Doremalen, N., Bushmaker, T., Morris, D. H., Holbrook, M. G., Gamble, A., Williamson, B. N., Tamin, A., Harcourt, J. L., Thornburg, N. J., Gerber, S. I., Lloyd-Smith, J. O., de Wit, E., & Munster, V. J. (2020). Aerosol and Surface Stability of SARS-CoV-2 as Compared with SARS-CoV-1. *New England Journal of Medicine*, 382(16), 1564–1567. <https://doi.org/10.1056/NEJMc2004973>
- Victoria State Government Department of Health and Human Services. (2020). *Information for community services – coronavirus disease (COVID-19): COVID-19 plan for the disability services sector*. <https://www.dhhs.vic.gov.au/information-community-services-coronavirus-disease-covid-19#covid-19-plan-for-the-disability-services-sector>
- Vieira, C. M., Franco, O. H., Restrepo, C. G., & Abel, T. (2020). COVID-19: The forgotten priorities of the pandemic. *Maturitas*, 136, 38–41. <https://doi.org/10.1016/j.maturitas.2020.04.004>
- Wingate, M. S., Perry, E. C., Campbell, P. H., David, P., & Weist, E. M. (2007). Identifying and protecting vulnerable populations in public health emergencies: addressing gaps in education and training. *Public Health Reports*, 122(3), 422–426. <https://doi.org/10.1177/003335490712200319>
- World Health Organization. (2011). *World Report on Disability*. https://www.who.int/disabilities/world_report/2011/report/en/
- World Health Organization. (2013). *Guidance Note on Disability and Emergency Risk Management for Health*. <https://www.who.int/publications-detail/guidance-note-on-disability-and-emergency-risk-management-for-health>
- World Health Organization. (2020a). *Disability considerations during the COVID-19 outbreak COVID-19*. <https://www.who.int/who-documents-detail/disability-considerations-during-the-covid-19-outbreak>
- World Health Organization. (2020b). *Naming the coronavirus disease (COVID-19) and the virus that causes it*. [https://www.who.int/emergencies/diseases/novel-coronavirus-2019/technical-guidance/naming-the-coronavirus-disease-\(covid-2019\)-and-the-virus-that-causes-it](https://www.who.int/emergencies/diseases/novel-coronavirus-2019/technical-guidance/naming-the-coronavirus-disease-(covid-2019)-and-the-virus-that-causes-it)
- World Health Organization. (2020c). *Q&A: Similarities and differences - COVID-19 and influenza*. <https://www.who.int/emergencies/diseases/novel-coronavirus-2019/question-and-answers-hub/q-a-detail/q-a-similarities-and-differences-covid-19-and-influenza>
- World Health Organization. (2020d). *WHO Director-General's opening remarks at the media briefing on COVID-19 - 27 March 2020*. <https://www.who.int/dg/speeches/detail/who-director-general-s-opening-remarks-at-the-media-briefing-on-covid-19---27-march-2020>