Navigating Complexity in a Global Pandemic: The Effects of COVID-19 on Children and Young People with Disability and Their Families in Australia

Abstract: While Coronavirus Disease 2019 (COVID-19) does not discriminate against particular groups, our social structures and systems mean some people are more at risk in a pandemic context—from both the disease and the social and policy responses to the pandemic. This is particularly so for people with disability, in part because they often have poorer health outcomes from underlying conditions but also due to discrimination and social exclusion. Here, we draw from a survey about the impacts of the COVID-19 pandemic on Australian children and young people with disability and their families. Respondents faced a range of inequities prior to the pandemic, and COVID-19 has further exposed and often exacerbated them. We conclude that recent developments in the Australian disability context to personalize services have arguably made people with disability and their families less safe within a pandemic context, and we outline some ways in which these issues might be addressed.

The Coronavirus Disease 2019 (COVID-19) pandemic has killed many people globally and has radically changed the ways of life for many others. While politicians frequently comment that COVID-19 does not discriminate, our underlying social structures and systems mean some groups are more at risk in a pandemic context and are therefore more affected than others. This is particularly the case for people with disability, in part because they often have poorer health outcomes relating to underlying conditions, but more significantly due to discriminatory issues such as difficulties in accessing health and other services and typically faring worse within the health care system (Emerson et al. 2011; Kavanagh et al. 2013; Sabatello, Landes, and McDonald 2020). Evidence from previous pandemics shows that health inequities worsen during epidemics as more marginalized communities have fewer resources (financial and social) and struggle to access necessary supplies and services (Quinn and Kumar 2014). More broadly, research has shown that people with disability are frequently overlooked in crisis and emergency response, leading to unequal outcomes when universal or generalized supports are applied to the affected population—despite the fact that people with disability can make important contributions to risk reduction and disaster response (Alexander, Gaillard, and Wisner 2012; Ronoh, Gaillard, and Marlowe 2015; Stough and Kelman 2018).

In this article, we draw from the results of a nationwide survey conducted on the early impacts of the COVID-19 pandemic on Australian children and young people with disability and their families (Dickinson and Yates 2020). We present some key messages from the data and go beyond this, drawing on the disability policy literature and referencing recent policy and administrative changes to explore why individuals and families may have experienced challenges during the COVID-19 response.

While the overall Australian COVID-19 response has been successful in relation to many comparable countries (Moloney and Moloney 2020), data presented in this article show that the COVID-19 pandemic has exposed and exacerbated social inequities. Children and young people and their families faced a range of inequities prior to the pandemic, and this experience only served to illuminate and, in some cases, worsen them. We demonstrate this by first illustrating how children and young people with disabilities and their families did not receive sufficient targeted information. This is problematic as families often rely on complex networks of systems and support services, and we outline the impact the pandemic and associated lockdown has had on these supports. Furthermore, people with disability were not considered in Australia’s key pandemic planning and response documents (e.g., the Australian Health Management Plan for Pandemic Influenza and the Commonwealth Department of Health’s first COVID-19 emergency response plan) until well after the COVID-19 pandemic was declared. Finally, we argue that recent developments in the Australian disability context to
personalize services have arguably made people with disability and their families less safe within a pandemic context and set out some potential actions to address these issues.

**Methods**

The survey was designed and distributed online by Children and Young People with Disability Australia (CYDA), a national organization representing children and young people with disability aged 0–25 years. CYDA promoted the survey to its membership of over 5,000 people, as well as sharing it on social media. The survey was conducted from 16 March to 23 April 2020 and had 697 responses, 425 of which were received in the first week. Questions were mostly multiple choice, with a number of free-text boxes for additional contextual information. Most participants (93%) were family members of children and young people with disability, with the remainder being children and adults with disability (4%) or unspecified (3%). Respondents came from all states and territories, with the majority being in Victoria, Queensland, and New South Wales. For more details on survey methodology, see Dickinson and Yates (2020). We now draw on survey findings to describe the impacts of the pandemic on children and young people with disability and their families, particularly impacts relating to information provision and service complexity.

**Information Provision Is Important**

When asked “Do you feel that there is enough information targeted at families or children and young people with disability about COVID-19”, 82 percent of respondents said no. This lack of information specifically targeted to the particular needs of households was explained to exacerbate distress and uncertainty:

> I don't think immune suppressed children have been taken into account for the algorithms to decide when to shut schools. I don't know how vulnerable my child is and it worries me but if I choose to pull him out without a medical letter my employer will not accept my leave. My employer will continue to pay wages for self-isolation if a practitioner agrees. The problem is my GP doesn't even know if my child is at risk.

There was significant uncertainty concerning how the virus would affect children and young people with disability, whether and when to keep students with disability home from school, if it was safe to let support workers into homes, how much personal protective equipment (PPE) was required (including how to source such equipment given national shortages at the time), what would happen to children if their parents and carers became sick, and whether disability funding packages could be adjusted to support any changes required.

While knowledge of COVID-19 was generally low at the time of the survey, people with disability felt there had been little effort from governments and the media to consider or meet their specific needs based on the information that was available. Families expressed a sentiment that, although there had been attention paid to the provision of information about the risks to older people, people with disability had been overlooked. There was a general feeling within respondent comments that people with disability are a low priority in public responses to crises, a sentiment borne out by the federal government’s demonstrable lack of attention to the intersection of disability and pandemic planning. As mentioned above, Australia’s first COVID-19 health response plan did not include or even mention people with disability, and a disability-specific COVID-19 plan was not implemented in Australia until April, before which “people with disabilities had little or no targeted accessible information” (OHCHR 2020). This is consistent with research showing that people with disabilities are often overlooked in emergency planning (Alexander, Gaillard, and Wisner 2012).

In particular, government messaging indicated that children and young people were at a lower risk, but at the same time, evidence from coronavirus hotspots overseas indicated that people with disability and comorbidities were at higher risk (Ryan 2020). Furthermore, there was insufficient information on how immunocompromised people and their carers could best protect themselves. There were also accessibility failures: important public health information was often not provided in an accessible format. Many respondents noted a lack of resources to help explain coronavirus to children and young people with disability, such as social stories and videos that could help children practice better hygiene and understand why they could not participate in their usual activities.

There was also inconsistency of messaging about schooling and risk from state and federal levels of government, with schools in different states closing and then reopening at different times. In line with the Australian Health Management Plan for Pandemic Influenza, which does not recommend school closures unless there is evidence of clinical severity and/or high transmissibility in children, the federal government recommended that schools stay open during the early weeks of the pandemic. However, several state premiers took matters into their own hands and shut down schools against federal advice (Leask and Hooker 2020; Moloney and Moloney 2020). A public debate raged about whether it was safe to send children to school. While this uncertainty was potentially confusing and distressing for all families, it was more intensely felt by parents and carers of this potentially more high-risk group, who often need greater levels of personal care and may be less able to physically distance and practice strict hygiene measures (Goggin and Ellis 2020). As one respondent explained:

> [We need] clear consistent messaging about how big the risk is for him as someone considered vulnerable if he is to contract it. Should we be waiting for school to close or should we keep him at home? Should we keep our other kids home from school to protect him? How serious is this?

Another family member commented:

> Nothing in the media regarding people or young people with a disability being an at risk group. Our son is in a mainstream [state] secondary school in a special unit. Much has been said about schools continuing, but kids in special units do not have the skills in areas such as personal hygiene or social distancing to lower their risk of contracting COVID-19. They also may not be immunocompromised but may have lower physical respiratory strength to deal with the virus or cope with medication or hospitalisation.

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A lack of information and inaccessibility of information combined with inconsistency of messaging left many families uncertain of what to do, particularly in the early days of the pandemic. This caused difficulties for many families as they typically exist surrounded by complex systems of services and supports.

**Navigating Daily Complexity**

In Australia, as in many other parts of the world, people with disability and their families are surrounded by complex webs of services, provided by a combination of professionals, friends, and family members and funded by a blend of private, state, and not-for-profit sources. These include educational supports, personal support workers for daily care, physical and cognitive therapies, medical services, and specialized equipment and food supplies, to name just a few. Not only are these services necessary for the welfare of the children and young people, but parents and carers often rely on them in order to participate in the workforce, support siblings, and maintain their own health and well-being.

The COVID-19 pandemic has led many of us to experience work and income disruption, supply shortages, and difficulties in accessing services. However, our research found that these disruptions were exacerbated for families of children and young people with disability. Family responses painted an overall picture of a group of people constantly beset by difficult decisions and precariously balancing work, play, care, and education to provide the best possible lives for their children. For example:

> The biggest issue for me is schools closing. I have 3 children on the autism spectrum (with other learning needs) and am a sole parent, luckily their dad will help. It will be extremely difficult getting through/surviving each day due to behaviours & I hope we can achieve some productive schooling? So hard, and usual challenges compounded as I have lost my/our usual support of community sports and activities, grandparent help & I have had to cancel NDIS [National Disability Insurance Scheme] support workers coming into the home (due to health vulnerability) and I won't have my regular carer/health activities. I have difficulties and am under extreme stress at the best of times, let alone now.

Many families can only manage these complex arrangements when the world is operating as it normally does—however, this global pandemic (especially when immediately preceded by an extreme bushfire season) has thrown these precariously balanced routines off to such a degree that families struggled to cope.

Many of the impacts of the pandemic are felt in interconnected ways. For example, immunosuppression and increased vulnerability to coronavirus leads to disability services canceling for fear of contracting or spreading this disease. Service cancellation means that parents are unable to work as they are required to care for their children, which for some might mean that their employment and income are disrupted. Having less income makes it harder to afford scarce supplies at a time when prices have increased due to demand (‘panic buying’ was a significant problem at the time in many parts of Australia). Inaccessibility of food supplies exacerbates challenging behavior in some children and young people, and all of these things put extra pressure on children and young people with disability and their families. Unable to access basic necessities for everyday care; unable to access support networks such as extended family, support workers, and schools; and unsure of what would happen in the days and weeks ahead, many families expressed extreme distress and worry. In fact, half of survey respondents noted a decline in their mental health status or that of the child or young person. This increased over the period of the survey as the effects of the pandemic compounded. As one respondent explained at the end of March:

> I’m mentally drained, depressed and feel so alone. I have no family or friends for support and limited NDIS funding that’s not supportive of our immediate needs. No one at this time is willing to help. I’m scared as a parent, I’m scared of failing my child, and I’m scared about the mental health impacts on me as a parent with absolutely no support. Can I take care of my child long term in this situation? Not for much longer.

**Recent Reform Agendas May Make People Less Safe**

Australia has followed the trends seen in disability services in many other areas of the world (e.g., Canada, United States, Northern Europe) in seeking to individualize disability services. It is argued that a one-size-fits-all approach to service delivery cannot effectively meet the needs and desires of the broad range of people with disability and is an inefficient use of funding (Dickinson 2017). In line with a New Public Management philosophy (Ferlie et al. 1996), externalizing disability services from the state to a range of private and not-for-profit service providers has been seen as a way to promote diversity and enable better choice and control. This reform theme has been expressed most recently in Australia through the creation of the National Disability Insurance Scheme (NDIS). Disability services had previously been determined and delivered through state or territory governments, and the various systems across the country were complex, underfunded, and fragmented, with splits between state/territory and federal responsibilities. Under the NDIS, services for those with high support needs have been harmonized under a national system where individuals are allocated care budgets they have a role in directing. This has involved a shift from block contracting arrangements with providers to spot contracting arrangements (i.e. contracting for singular services) according to the preferences of individuals (Fisher, Baines, and Rayner 2012).

Dickinson, Carey, and Kavanagh (2020) argue that a shift to personalized service systems has the potential to make it more difficult for governments to respond to public health events and can even place people with disability at greater risk. Within the previous system, governments had a degree of control over the workforce and levered to mobilize this control to do things differently. However, these are lacking within a personalized system. It is difficult to identify who the workforce is precisely and to train them in infection control, to mobilize supplies to all who need them, and to upscale the workforce in the face of care worker shortages. With personalized systems, there are fewer options for control or even the intelligence required to understand what actions to take in a pandemic context.

What this means is that some people will go without care where providers are not able to deliver, and there is no backup option.

The shift to a personalized model of service delivery has created a gig economy within disability services. Care roles are already low paid compared to many industries, but this shift means a greater
number of disability support workers are employed on a casual basis and paid per service. What this means is that if they do not go to work, they are not paid. There are many criticisms that can be made of the gig economy (Gandini 2019), but these are more worrying in a pandemic context. Such a system can incentivize individuals who desperately need income to take risks with their own health and that of the people with disability they are supporting, for example, turning up to work when they are unwell. In fact, the ‘second wave’ of coronavirus occurring in Victoria from June 2020 was identified as being driven by a casualized workforce, particularly low-paid aged care staff working across multiple facilities with no access to sick leave (Teicher and Van Gramberg 2020).

For those who hire workers directly rather than through a large provider, they have no guarantee that the worker will turn up for their shift, and if not, there may not be another worker deployed. As care workers become sick or are required to care for family members who are ill or forced to isolate, there is a question of who identifies a standby workforce and how this is mobilized. As governments no longer have control over the workforce, they have little ability to create surge capacity in a coordinated manner. The system is essentially reliant on a range of providers, some of whom are quite small and may not have the ability to scale up. Some may simply close down. This was certainly a concern for respondents to the survey, as one individual described:

> We are seriously concerned for some of our support workers who are sole traders and unable to deliver their support during COVID_19 and because our family need to self-isolate due to 2 elderly parents and a son with weakened immune system so we cannot risk having anyone else in the house.

Due to worldwide shortages of protective gear at the time and the prioritization of frontline health care staff, many disability support workers did not have access to PPE (Kavanagh et al. 2020). Even rather mundane supplies such as hand sanitizer were difficult to access, raising real issues for some families. One survey respondent reported: “I need to have hand sanitizer available for support workers. I can’t buy any.” Even without international shortages, it is unclear who should provide protective equipment and other resources needed in a pandemic to disability workers (i.e., those who are supporting activities of daily living like feeding, bathing, teeth brushing). In Australia, employers are responsible for providing protective equipment to workers. In the case of larger providers, this may be possible, but it is important to remember that, where people with disability are employing their own workers directly, we are asking them to go out and acquire protective equipment for their support workers. In August 2020, the NDIS announced that scheme participants could purchase PPE from their scheme funds, but only for a limited time, for participants in certain high-risk areas—and after participants had been buying their own PPE for 5 months. This also raises the question about who should be responsible for training workers in infection control.

Where Next in Supporting Children and Young People with Disability and Their Families?

Our findings suggest that people with disability and their families face significant challenges during COVID-19 (see also Goggin and Ellis 2020; Sabatello, Landes, and McDonald 2020; Wilson 2020). To some degree this is unsurprising as, prior to the pandemic, the evidence indicated that this group is one of the more marginalized within Australian society and faces a significant range of inequities on a daily basis. Previous pandemics have shown that health inequities worsen during epidemics (Quinn and Kumar 2014), and our evidence suggests that a range of other inequities are also intensified by such events. To this extent, our findings reiterate observations made by Dzigbede, Gehl, and Willoughby (2020), who found that the COVID-19 epidemic is exposing social inequities that are exacerbated as the virus spreads.

In addition, the recent policy trajectory of personalization has made many children and families more exposed and at risk. The individualization of services has left families and workers less supported in the face of a crisis situation such as this. This does not necessarily need to be an inherent feature of such systems but has been a byproduct of the way in which Australia has chosen to design its disability support system.

Although Australia did well in keeping the numbers of infection down initially, there was a second wave in the state of Victoria during July–September. This led to the reintroduction of a number of restrictions (including a curfew) and a return to remote learning for most students. Since then a number of short lockdowns have continued to disrupt lives and services in some locations. Our data suggest some key actions that Australian governments could take at this time, including:

- Provision of information in an accessible format with consistent measures relating to where families might access advice and support;
- Ensuring the provision of PPE and training in infection control to disability support workers;
- Provision of paid pandemic leave for those support workers on ‘gig’ contracts so that individuals who are sick do not need to attend work and risk infecting others;
- Establishment of a team of disability support workers who can be called to give support where families have services cancel workers due to sickness.

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