

More than isolated: The experience of children and young people with disability and their families during the COVID-19 pandemic

Report on *CYDA's 2020 COVID-19 (Coronavirus) and children and young people with disability survey*
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Executive Summary

The COVID-19 global pandemic has had a significant impact on all Australians, but there are very good reasons why the impact might be more keenly felt by people with disability and their carers.

Children and Young People with Disability Australia (CYDA), the national representative organisation for children and young people with disability, identified that Australia lacked a coherent national response for children and young people with disability in the context of the COVID-19 pandemic. They devised a survey to capture the impact of COVID-19 on children and young people and their families and identify unmet needs for resources and information.

Such a process was designed to capture issues relating to COVID-19 specifically, but also to help plan for future emergency scenarios (e.g. pandemics, bushfires, floods).

This report sets out the key findings of the survey, identifying areas requiring responses and future research priorities.

The survey was launched just five days after the World Health Organization declared the pandemic on 11 March and remained open for five and a half weeks, attracting just under 700 responses – predominantly from family members of children and young people with disability.

Respondents identified a broad range of impacts, including the inability to access essential products and services and the cancellation of supports and educational programs, all of which generated additional caring responsibilities. Households reported feeling scared, uncertain about the best ways to act, and that this was having an impact on the mental health of all family members.

Summary of key findings:

- Survey responses clearly demonstrated that people felt like there was a general lack of information about the coronavirus targeted to children and young people with disability and their families, with 82% stating they lacked information. Moreover, lack of information targeted to the particular needs of households exacerbated distress and uncertainty.
- Uncertainty about education was a prominent theme, including school closures and challenges with learning from home, and that progress gained by children and young people with disability would be lost during this period.



There is a richness in diversity and human experience and this needs to be valued and planned for. During this period of the COVID-19 pandemic this seemed to be missing as all people were treated the same, not recognising that some groups might require more support and consideration so that they can be viewed as equally valued members of society.

- Half of survey respondents experienced a decline in their mental health either for themselves or for the child or young person with disability. This increased over the period of the survey.
- The majority of respondents were unable to buy essential supplies, e.g. groceries, special dietary products, hygiene products, which peaked at the commencement of the pandemic period. Many of these essential goods were necessary for the children and young people with disability because of their conditions.
- One in three respondents experienced cancellation of support workers (either by self or service) and NDIS services.
- There was significant concern in survey responses that people might lose work or be required to give up work due to the COVID-19 pandemic, and this would have an impact on household income.
- There were a range of health issues including inability to access COVID-19 testing, telehealth being inaccessible and fear of engaging with health services.
- Information about COVID-19 was not appropriately targeted to the needs of children and young people with disability and their families.

The findings of this survey represent a snapshot in time during a period where there was national and international apprehension and fear about the COVID-19 pandemic and how this would play out in local communities, some of whom had only recently emerged from a bushfire crisis.

People across Australia have experienced work and income disruption, supply shortages and educational difficulties. However, all of these disruptions are exacerbated for children and young people with disability and their families.

Many of those who care for children and young people with disability are constantly beset by difficult decisions and precariously balancing work, play, care and education to provide the best possible lives for those under their care. Many people can only manage these things when the world is operating as it normally does – but this global pandemic (especially when immediately preceded by bushfires) has thrown these precariously balanced routines off to such a degree that families are struggling to cope.

The lives of children and young people were thrown into turmoil throughout the period. This group already face multiple barriers and difficulties in accessing inclusive education, support for reasonable adjustments and the same curriculum as their non-disabled peers, placing enormous pressure on them and their families during this time.

There is a richness in diversity and human experience and this needs to be valued and planned for. During this period of the COVID-19 pandemic this seemed to be missing as all people were treated the same, not recognising that some groups might require more support and consideration so that they can be viewed as equally valued members of society.

The lives of children and young people were thrown into turmoil throughout the period. This group already face multiple barriers and difficulties in accessing inclusive education, support for reasonable adjustments and the same curriculum as their non-disabled peers, placing enormous pressure on them and their families during this time. CYDA will explore these issues in depth through their 2020 Education Survey Learning in a time of crisis COVID-19 (Coronavirus).

However, these issues will not simply be solved by providing more evidence or better targeted evidence. The main message of this report is that urgent action is needed to attend to the many inequities that people with disability and their families and carers face on a daily basis. Without movement on these issues, any future widespread emergencies will again produce substantial destabilisation for these households, with similarly detrimental impacts.

Introduction

People with disability are an ‘at-risk’ population in the COVID-19 pandemic. This is not because of their impairment, but because of the discrimination people with disability face in our society.

Across the world research shows that people with disability are more likely face poverty, are less likely to be in work, and more likely to be socially isolated (Kavanagh et al. 2013, Milner et al. 2014, Kmjacki et al. 2016), which also makes them more likely to experience poor health outcomes within a pandemic. This compounds the reality that a high proportion of people with disability have underlying health conditions such as diabetes, autoimmune and respiratory problems (World Health Organization 2018). Yet for too many people with disability, health services remain difficult to access and a place where discrimination is often experienced (Temple, Kelaher, and Williams 2018). Evidence from previous pandemics shows that health inequities worsen during epidemics (Quinn and Kumar 2014). This means that without proactive policies to protect people with disability, we are likely to see a growing gap in socio-economic and health outcomes between people with and without disability.

Children and Young People with Disability Australia (CYDA) is the national peak body that represents children and young people (aged 0–25) with disability. CYDA is a not-for-profit community organisation that provides a link from the direct experiences of children and young people with disability and their families to federal government and other key stakeholders.

CYDA identified that Australia lacked a coherent national response for children and young people with disability in the context of the COVID-19 pandemic. While swift responses were formulated in relation to some ‘vulnerable’ groups, for example aged care, there was a gap in relation to children and young people and their families. In order to effectively advocate on behalf of this group, CYDA quickly developed a survey to capture the impact of COVID-19 on children and young people and their families and identify needs. Such a process was designed to capture issues relating to COVID-19 specifically, but also to help plan for future emergency scenarios (e.g. pandemics, bushfires, floods).

This report sets out the key findings of the survey, identifying areas requiring responses, issues that will require quicker responses during future emergencies, and identifying future research priorities. We find that the families of children and young people with disability have been affected in ways very similar to the rest of the population (e.g. supermarket shortages, school closures and income loss), but that these disruptions and

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difficulties have been heightened by the precarious circumstances of many of these families. There are also additional impacts and disruptions felt by these families such as support worker and therapy cancellations, plus an unmet need for disability-specific information about COVID-19. These challenges will not be news to those in the disability community and the pandemic has thrown the various daily inequities that people with disability and their families and carers face into sharp relief. Our main message of this report is that urgent action is needed to attend to the many inequities that people with disability and their families and carers face on a daily basis. Without movement on these issues, any future emergencies will likely produce significant destabilisation for these households, with significant detrimental impacts.

The report begins by describing the approach taken to the development of the survey and analysis of data, and reporting the demographics of the sample. Then we outline the main impacts of the pandemic as described by respondents, focusing on areas such as education, employment, health and service access, as well as ways these impacts are interconnected. Finally, we report on the additional support and information respondents said they needed, and consider what further research is needed to understand and support the families of children and young people with disability in times of crisis.

Research design and analysis

Early in the progress of the COVID-19 pandemic, CYDA identified an urgent need for more information on how the families of children and young people with disability were being affected and the steps needed to fill any emerging gaps.

Based on conversations with members identifying potential impacts and needs, CYDA staff quickly developed a survey to capture the perspectives of households. They launched the survey on 16 March 2020, just 5 days after the World Health Organization declared the pandemic on 11 March, and closed it on 23 April (a total of 5.5 weeks). This survey therefore provides vital information on respondents' experiences in the early weeks of the pandemic.

CYDA sought the assistance of researchers from the Public Service Research Group, UNSW Canberra to analyse the data and prepare this report. They received ethics approval from the UNSW Human Research Ethics Advisory Panel, reference HC200281.

CYDA shared the survey to its membership of over 5,000 people, and was promoted via social media by a number of other disability advocacy organisations. The survey received a very strong early response – over 400 respondents in the first three days. As CYDA reviewed initial survey data, it became apparent there were some gaps in questions asked, and small changes were made to the questions as a result. The full survey and a summary of changes can be found at Appendix 1. These changes have implications for how data have been analysed. Where items were added after the initial launch of the survey, we calculated descriptive statistics based on the number of respondents who had been exposed to those items, and this is indicated throughout the report.

The section on additional information and support required was originally limited to an open-ended question about information and support needs. This was expanded after four days to include a list of options (such as health information and support or education information and support) as well as an open-ended question. At this point 425 respondents – more than half the total who responded overall – had already completed the survey. To create some consistency for the full data collection period, we reviewed open-ended responses from the original four days of data collection and coded them into the six categories subsequently added. However, the numbers in each category would likely have been higher if a list of options had been included from the initial launch of the survey.

We coded the qualitative data using thematic analysis in NVivo 12. Codes were created using broad themes such as health, employment and income, education, and support workers. These areas were then refined into sub-themes and checked for consistency. Participation was anonymous and we have removed any potentially identifying information from quotes used in this report.



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Findings

We now move on to set out findings of the survey. We start by providing demographics on who responded, before exploring the impacts of COVID-19 on respondents' families, and then reporting gaps in information and support.

Findings Demographics

In this section we provide an overview of the demographic details: who responded to the survey, when they responded, and some of the characteristics of the children and young people represented in responses.

In summary, a large majority of respondents were the family members of children and young people living at home who were NDIS participants and enrolled in schools.

Just under 700 responses were received, with the majority in the first week, 16–22 March 2020 (see Table 1 and Figure 1). There was a question to capture whether respondents had completed the survey before. Only 19 respondents said they had done this, so given the low number of repeat participation and the fact that most responses were received in the first few days, we have treated this dataset largely as a cross-sectional snapshot rather than a longitudinal exercise.

Table 1: Survey responses by week

Week of the survey	Responses received	
Week 1 16–22 March	447	(64%)
Week 2 23–29 March	60	(9%)
Week 3 30 March – 5 April	103	(15%)
Week 4 6–12 April	65	(9%)
Week 5 13–19 April	15	(2%)
Week 6 20–23 April (4 days)	7	(1%)
Total	697	

Figure 1: Survey responses by week

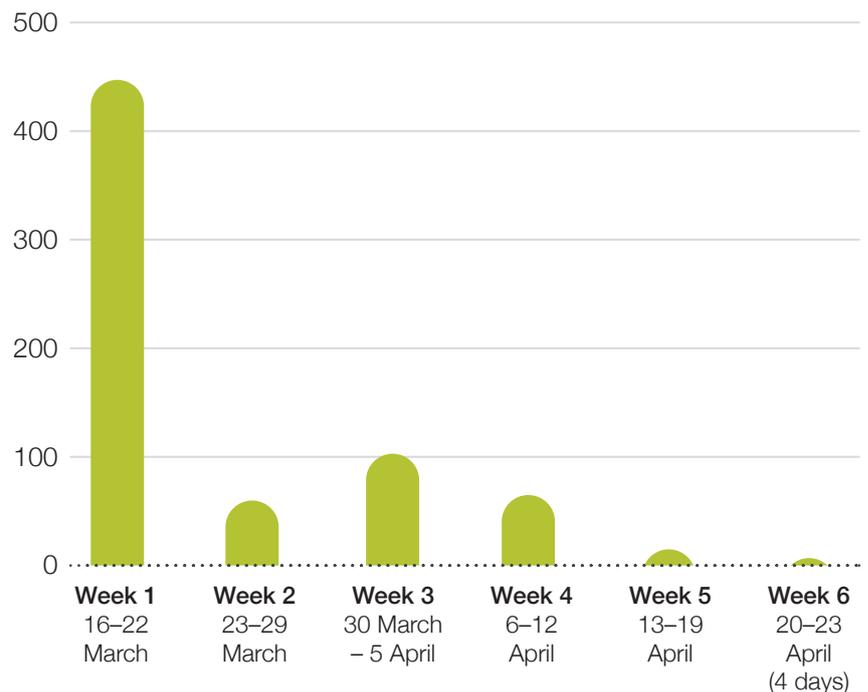
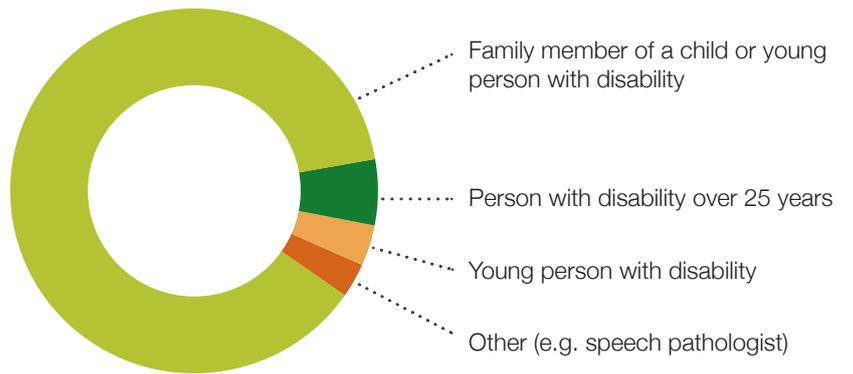


Table 2 and Figure 2 demonstrate that 93% of surveys were completed by a family member of a child or young person with disability, with far smaller proportions received from people with disability themselves (figures total over 100% because some respondents belonged to more than one category). From the free text responses, it was clear that most respondents were a parent of a child or young person with disability.

Table 2: Who completed the survey

Who completed the survey	Percentage of respondents
Family member of a child or young person with disability	93%
Person with disability over 25 years	6%
Young person with disability	4%
Other (e.g. speech pathologist)	3%

Figure 2: Who completed the survey

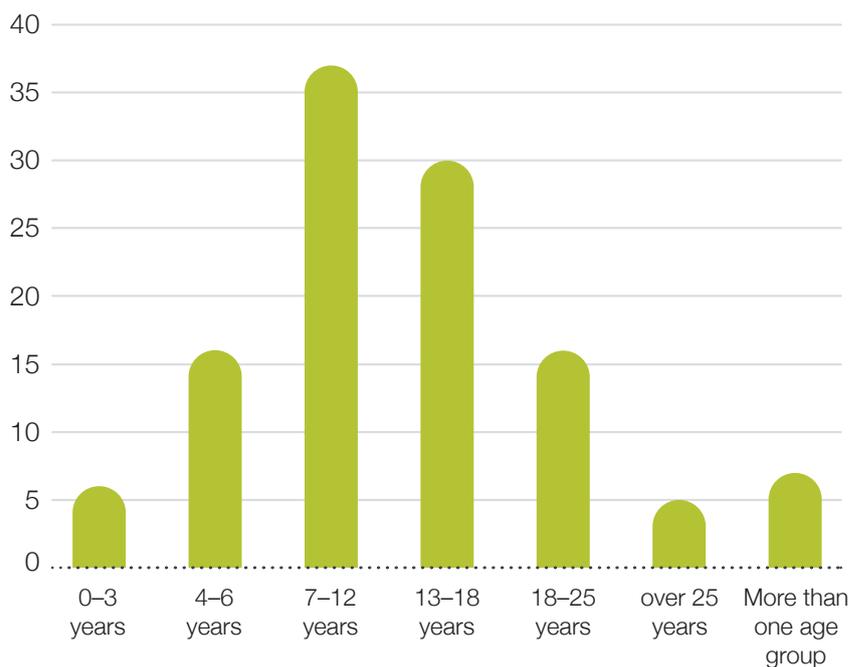


Regarding the age of the child or young person, Table 3 and Figure 3 show there was good representation across the age spectrum, although the majority of responses were for children between 7 and 18 years of age. Although there was no direct question about the number of children or young people, 7% of respondents selected more than one age group, indicating they had multiple children or young people within their household.

Table 3: Age of child or young person

Age of child or young person	Percentage of respondents
0–3 years	6%
4–6 years	16%
7–12 years	37%
13–18 years	30%
18–25 years	16%
over 25 years	5%
More than one age group	7%

Figure 3: Age of child or young person



One of the questions in the survey was to get a sense of which kinds of activities the child or young person participated in. As Table 4 demonstrates, there was a good representation of individuals across the range of different activities, although the largest group (43%) attended mainstream schools.

Table 4: Activities the child or young person participates in

Activity child or young person is engaged in	Percentage of respondents
Early childhood education and care	9%
Special primary school	16%
Mainstream primary school	25%
Special secondary school	14%
Mainstream secondary school	18%
Home school	3%
Day program	9%
Australian disability employment	2%
Open employment	4%
TAFE	1%
University	2%
Not in education or work	2%
Other*	11%

* free text provided more detail (e.g. some respondents specified a special program in a mainstream school)

The survey asked about the living circumstances of the child or young person, to elicit where they lived and with whom. As Table 5 demonstrates, the vast majority lived at home (95%).

Table 5: Living circumstances of the child or young person

Living circumstance	Percentage of respondents
Living at home with family	95%
Living in a group home	1%
Living in another form of supported accommodation	1%
Living in respite	1%
Living in private accommodation	2%
Other	2%

Regarding the proportion of children and young people who are National Disability Insurance Scheme (NDIS) participants, the overwhelming majority of those who responded (88%) were on a current NDIS plan.

Questions about state/territory and metropolitan, regional, rural or remote location were added later in the survey, but as this information was collected from fewer than half of respondents we have not reported it here. However, we can confirm that responses were received from all states and territories, and there were a good mix of metropolitan, regional and rural respondents, with a few also from remote locations.

Findings Impact of COVID-19

One of the things the survey attempted to understand was the impact that COVID-19 has had on children and young people with disability.

As Table 6 outlines, nearly 450 people cited access to essential supplies, with others concerned about a decline in mental health and cancellation of supports. We go into these issues in more detail below, illustrated with quotations from free text responses in relation to a number of different thematic areas.

Many of the impacts cited remained relatively consistent over the period that the survey was open, although we did see fewer people reporting problems with purchasing essential items over the survey period as supermarkets became restocked. Cancellation of support workers and other services increased over the data collection period. The survey also asked about whether children and young people with disability or their families had been affected by direct diagnoses of the coronavirus, but only one person recorded this kind of impact. The impacts did not vary significantly according to the age group of the children and young people or whether they were enrolled in mainstream schools compared to special schools.

Table 6: Impacts of COVID-19

Impact	Number of responses	Percentage of respondents
Unable to buy essential supplies, e.g. groceries, special dietary products, hygiene products	448	64%
Unable to buy essential medications	127	18%
Cancellation of support workers (either by self or service)*	222	32%
Cancellation of other NDIS funded services	187	32%
Closure of school or education	132	19%
Voluntarily self-isolating from school or education	116	43%*
Unable to work in usual employment	146	21%
Loss of income	138	20%
Required to self-isolate because of health information (e.g. experiencing symptoms, been in contact with confirmed diagnosis)	90	13%
Required to self-isolate because of child or young person with immune or other medical conditions	42	30%**
Decline in mental health and wellbeing of self or child	135	50%***

* Item added 20 March, percentage reflects N=272

** Item added 1 April, percentage reflects N=142

*** Item added 20 March, percentage reflects N=272

Educational impact

Free text responses indicated a great deal of uncertainty over whether schools would close. As outlined above, most of the responses were received in mid-March before state and territory governments took decisions to close schools. Many responses indicated people seeking clarity over what would happen and the need for advice over whether to keep students home from school, particularly if they had siblings who were also in school. As one individual commented, they needed:

“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?”

This sentiment was echoed by others, including one person who remarked:

“There has been no good information for people at high risk and families about distancing at home and keeping other kids at home from school. No advice about high risk conditions (or advice was slow and inconsistent).”

“I decided because of my child’s condition and safety it was best that she was removed from school. But I work fulltime in an essential service and had to take time off work to support her. If I don’t return to work our household income drops significantly.”

As a result of this uncertainty there seemed to be at least two different groups of perspectives on whether schools should be kept open or not.

The first group comprised respondents who wanted to see schools closed because either their child or young person was vulnerable due to medical conditions or they believe that it would be difficult for them to effectively socially distance or obey hygiene protocols. As one respondent commented:

“What are these children’s right in terms of getting an education but in a safe environment. Schools are not safe places, especially if the child has difficulty understanding the social distancing rules as well as complete basic tasks like washing their hands properly.”

The decision to keep a child or a young person home was not taken lightly, as we will demonstrate a number of times in this section. Many family members took this difficult decision because they feared for the safety and wellbeing of their child or young person. As one family member explained:

“I decided because of my child’s condition and safety it was best that she was removed from school. But I work fulltime in an essential service and had to take time off work to support her. If I don’t return to work our household income drops significantly.”

For some families, the pandemic struck quickly in the aftermath of the bushfires that devastated many areas of the country in late 2019 and early 2020. For those who experienced this, a degree of normality had returned only for things to become disrupted again:

“Have withdrawn my daughter from school as the extra hype of Social Distancing has been very difficult for her. Change of routines causing challenges under already challenging circumstances. (Teachers already have so many demands and we are just recovering from bushfires). We have own business which gives some flexibility to work from home, but having suitably adjusted school work is hard even though now Year 10. Lots of input required by me and school not yet set up to go online.”

Another group of respondents wanted schools to remain open for a range of different reasons. Some were concerned about the ability to balance home working and home learning. As one family member commented: *“Going to be difficult having no income when I have to stay home to care for my daughter when schools close”*. This was a common theme in survey responses. While this balance is a challenge for most family members, it is heightened for some of those caring for children and young people with disability because of low levels of independence in study or the existence of complex behaviours. For some, this means that they will have to give up work to care for their child or young person for the period that schools are closed. As one family member explained:

“My child needs 1:1 attention to control behaviour, engage and keep on task... can definitely not engage in remote learning without my contact supervision. I feel forced into a position of being unable to complete my last year of my masters (studying part time).”

Another respondent commented:

“I have concerns about at risk families. Families that have a child or children with significant behaviors. How are they going to cope if schools are closed?”

It is important to note that many families in this respondent pool had multiple children, all with different levels of need. As one family member explained:

“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?”

Another had similar concerns:

“I am finding it difficult with the home school, doing this with 3 children with ASD [Autism Spectrum Disorder]/extra needs. Current situation has taken away my usual coping strategies (separation, extended family & sport). Is distraction of each other & gets out of control with behaviour – constant fighting, name calling, violence...I feel I should be able to do the same as others in the community but am finding it too overwhelming to cope and to be able to explain to schools. My child does not accept support from services.”

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Although the data are not sufficiently robust to statistically demonstrate this, it does appear that households supporting multiple children and young people with disability were more likely to cite negative impacts to their or their children’s mental health.

Other respondents noted that their children had additional funding provided to schools to help support them and raised questions about whether they would be able to access this to support learning at home:

“The school has considerable additional funding to provide learning supports to them. If schools close, how can those funds be used to help the kids. Can they set up one on one zoom sessions to help support them with their learning.”

Schools are also a site where other services are delivered and with schools closed there were concerns expressed regarding access to these:

“What would the remote learning program look like for my child with a disability? Can we loan school equipment for the duration of term 2? How will my son access the lessons from the speech therapist and occupational therapist that he would normally receive at his school?”

Some respondents described that schools had already stopped support workers coming on to the premises to prevent additional potential for infection, but this had been to the detriment of the child or young person:

“School stopped allowing external support workers into the school to support children with disability – probably about 5 weeks before the term finished. Thus in a time of change and uncertainty routines were changed and therapeutic relationships disrupted.”

This kind of change to routine was described as highly problematic for many, provoking anxiety in children and young people. As one family member described:

“My daughter doesn’t have any underlying medical issues that we are aware of so I consider we are very lucky in this respect, but managing her anxiety during the routine changes and unknowns will be challenging and I am worried about the impact this situation will have on her.”

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In addition to home learning being difficult to balance, other respondents were concerned that progress gained by children and young people with disability would be lost during this period. One respondent summed up many of these issues, explaining:

“Recognition of the impact and intense nature of homeschooling child with disability – full time job in itself, then other siblings to care for and teach, and work full-time (in essential services) from home... not possible so only option is to take unpaid leave. The mental load of caring and schooling 24/7 for lengthened period of time/ptsd and anxiety inducing, grief relaying. Regression of skill-sets and progress gained, loss of structure – such negative impact for person living with disability.”

Schools are not just a source of education, but provide a range of other things such as social interaction. This is an issue for all children and young people, but for some with certain impairments a lack of school is even more problematic. One family member wondered:

“How not to have my child suffer from language deprivation (Auslan is their only language, they live with their hearing mother who can communicate with them in a limited manner). The risk to the mental health of the child is extreme if school close and no alternative e.g. online learning or socializing with anyone who they can communicate with.”

Finally, additional pressures on family members due to school closures and inability to leave the home may have longer term impacts on other services such as mental health, family violence, police. Indeed, one family member indicated that this had already arisen for their household:

“Police have refused to attend when I needed help on the weekend when my son tried to stab me. They told me it’s not their role and “What do you want us to do” they were aggressive and rude I felt unsafe.”

In recognition of the education-related challenges that households face, CYDA have launched a survey to capture these experiences in more detail.

Financial insecurity was a consistent theme in survey responses, with some households having to make some tricky decisions over how they would prioritise spending.



Employment and income

As indicated in the previous section, there was significant concern in survey responses that people might lose work or be required to give up work due to the COVID-19 pandemic, and this would have an impact on household income. Given the uncertainty at the time regarding who is vulnerable to COVID-19, some respondents indicated that they were unsure whether their employer would be supportive of them taking leave or if they would need to take unpaid leave. As one explained:

"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."

Some respondents talked of the difficult decisions within their household, with one family member going to work and the other attempting to isolate. As one individual explained:

"I am so worried because I am in isolation but my partner has to go to work I lost my job and now we can't afford for him to be home."

And for another,

"Their father had to stay in another state so he would be able to keep working, for three months, I am left on my own with my two children."

Financial insecurity was a consistent theme in survey responses, with some households having to make some tricky decisions over how they would prioritise spending. As one respondent described:

"Income has been decimated. Having to decide between paying rent and buying essential medical supplies."

Some of the young people who completed the survey also indicated they would lose income during the pandemic. For those who work on a casual basis it is having a significant impact on their income:

"I am a disabled young person with no family support. I work as a freelancer because traditional employment is inaccessible. My work is being cancelled, but there's no support for dealing with this lost income because freelancers don't have anywhere to get sick pay, and we're falling through the cracks."

Others had more secure work, but reported being unable to attend due to pre-existing health conditions:

"Because I'm immunocompromised and work in retail I had to cancel all of my shifts."

Many respondents also reported not knowing what financial support was available or expressed dismay over the fact that they were not eligible for particular payments. As one carer explained the need:

“Funding relief or additional leave entitlements for carers to take leave from their jobs (even if they are working from home) as it is very difficult to work full time and care for a child with a disability at the same time. The additional \$1500 per fortnight is only for businesses that have had a decrease in revenue by 30%.”

Others felt that carers of children with disability had been overlooked by the government in designing payment supports, for example:

“Financial support for families in our situations, we seem to have been overlooked by the plans rolled out so far. In my situation I might be eligible for a once off \$750 payment, but no further support. How does this make any sense when a teenager on Austudy can get \$550 a fortnight ??? No dependents, virtually no outgoing costs, especially if still living at home, but as a family of a child with a disability we are being totally forgotten about.”

“We need access to the \$550 covid supplement through Centrelink. On a day to day basis the budget is stretched. With loss of work, and increasing living costs we are falling through the cracks.”

As we will outline in more detail below, this loss of income was described as even more problematic because some households were facing increased costs in their day to day activities. As one respondent described:

“We need access to the \$550 covid supplement through Centrelink. On a day to day basis the budget is stretched. With loss of work, and increasing living costs we are falling through the cracks.”

For those with children or young people on NDIS plans a potential solution suggested was for them to be paid to work as supports during the pandemic. This is not currently a provision that is allowed for within the scheme (unlike some other countries with personalised disability funding schemes), but respondents explained that it would be a way to guarantee income to the family at this time. It would also reduce the numbers of people coming into homes, thereby reducing the risk of infection to household members. One respondent asked:

“WHY can’t family members who work out of home, work as supports for NDIS recipient family members temporarily instead of having to still attend external work, increasing risk for us all & threatening the lives of those of us who are high risk. It doesn’t need to be allowed for everyone, but the NDIS outright telling us our lives being at risk are irrelevant to the circumstances is appalling. (They told me this on the phone) They need to address this for those who are high risk.”

This sentiment was echoed by another:

“Due to virus myself and husband cannot work. We are looking after our son he is in the high risk if he catches covid-19. We have had to cancel day program and carers coming into our home. It would be great if the NDIA could pay us to care for him while this pandemic is taking place.”

Health

In relation to health services there were a range of different issues raised and concerns about the impact of COVID-19. As outlined above, one commonly cited impact of the pandemic was increased levels of anxiety and decreased mental health. As one respondent explained:

“Having loss of routine and access to community is having a significant effect on our mental health. Anxiety and depression, withdrawal from communicating.”

Another noted:

“She loves her therapies, but the changes to routines due to self distancing etc is making her anxious.”

And these impacts were being expressed through all age groups:

“His University has gone completely online – he has severe anxiety and has only just returned to Uni after 2019 being a year of severe depression and anxiety and now this has happened. We held 2 x 3hours meetings to get him set up, with adjustments and now this has happened. Uni is currently on early holidays but going back full time to online which he cannot handle, nor have we had any correspondence to get him ready. We cannot get onto any psychologist to manage his escalating anxiety and therefore challenging behaviour and I am very concerned for his own mental health as well as the rest of the family who are all trying to work from home, study from home. Extremely challenging times.”

For those with limited social support or services the sense of isolation and pressure to not let their child down has led to significant impacts on family members. As one parent outlined:

“I feel helpless with an ASD child. 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.”

Some respondents reported staying away from health services over a concern that they may contract COVID-19 if attending health settings. One family member explained:

“Avoided taking part in research projects at [hospital] as wanting to stay away from [hospital] at present. Avoided getting flu shot for child with disability as the only place we go for bloods or injections is [hospital] as they manage my child’s anxiety better.”

Others reported they wanted to attend for appointments, but these had either been cancelled or found waiting lists:

“OT [occupational therapist] and Physio have cancelled therapy. Specialist surgeon appointment postponed.”

For some these delays had led to concerns that opportunities for preventative interventions might be missed:

“Longer wait lists now and lack of access to health services...which can result in negative long term outcomes (significant orthopedic issues that will be delayed in being addressed, missing small window of opportunity for preventative measures).”

A number of health services, like schools, have transitioned online. Yet just as online schooling was not seen as accessible for some children or young people with disability, telehealth was also cited as problematic for some. As one family member explained:

“My daughter doesn’t do well with Telehealth she needs to see people face to face”.

Another had a similar experience, describing how:

“Our health services are still available via telehealth but this is not appropriate for my son.”

Others reported not being able to see their usual doctor as causing a challenge for their child:

“One of [our] children needs an essential script as he has run out and the 6 mth script is out of date can’t see either of our normal drs so have to see a stranger. Cant get script filled without attendance even though my son has been on it for approx 2 years. We are very concerned because anything requiring more than a basic consultation such as needles or x-rays ultrasounds etc. my son requires a general anesthetic. I have 2 kids but my son has us extremely concerned he is 6 and already gets pretty poor medical assistance due to his disability as he is non verbal.”

Other respondents were concerned more generally that health services might de-prioritise people with disability due to prejudice against this group.

One commented that they wanted

“Unequivocal guarantees there will be no ableism when health resources (ventilators, ICU beds) are getting scarce. But pigs may fly eh?”

Another described being:

“mentally exhausted from time spent rearranging care requirements due to staying home from school &/or carers self-isolating; fear of bad assumptions being made by hospital doctors, resulting in care priority disadvantaging [people with disability]; anxiety & fear of unknown long term.”

One issue a number of people noted was an inability to get tested for COVID-19 despite showing symptoms such as sore throat or cough, for example:

“I am not eligible to have covid testing as I have not travelled overseas, but husband has been in proximity of confirmed cases and we are all ill. If we were tested and confirmed we may be eligible for online grocery delivery.”

At the time of the survey, tests were only being provided to people on narrow criteria relating to contact with someone who had tested positive or having been overseas. But those with household members who are immunocompromised wanted to access testing for peace of mind.

Availability of services

A major issue for survey respondents related to services continuing to operate. Cancellation of support workers by self or provider increased significantly from 21% in week 1 to 60% in week 4, similarly cancellation of other NDIS services increased from 18% to 45% over the same period.

For respondents who commented on the cancellation of services this most often referred to cancellation by the service itself, sometimes at very short notice. This caused care problems for family members and reduced wellbeing for children and young people with disability. As this quote demonstrates, cancellation of support workers also has an impact on individuals being able to engage with their own work commitments:

“Our son will finish school tomorrow, our x2 support workers cancelled this afternoon and I will not be able to attend work or meetings.”



At the time of the survey, tests were only being provided to people on narrow criteria relating to contact with someone who had tested positive or having been overseas. But those with household members who are immunocompromised wanted to access testing for peace of mind.

Some respondents described how this puts even more pressure on their households, for example:

“We live in a 2-bedroom apartment with a small balcony. Now that parks, etc, are closed, my son has no access to outdoor areas, apart from walking around the streets, which is not enough. As he requires constant supervision, he can only go out if I am available to take him – we have lost most of our carers due to the threat of the virus. As my husband and I are supposed to be working from home, my son is cooped up inside for most of the day – This is not sustainable for any of us and is already causing significant difficulties for all of us.”

Other respondents cancelled services themselves due to concerns about vulnerability to infection:

“My daughter currently has pneumonia so is compromised so can’t have workers with symptoms with her so then I’ve had to stay away from work to care for her.”

While in this case the concern was over potential for infection to a child with disability, in other cases respondents cancelled services due to concerns over a family member being infected or who was being forced to isolate:

“Family member is required to self isolate, and therefore my disabled child must too. Therefore unable to participate in regular therapy, and upset by change of routine.”

Just as some education and health-related services have moved online, other services have also made this decision. Yet, a number of respondents described difficulties with children and young people engaging through this mechanism:

“All face to face support work has been stopped. They will conduct it over the phone or email. These services currently include Physiotherapy and Speech Pathology, which are best provided in person.”

This decision was not always taken in collaboration with children, young people or carers:

“Without consultation, the service provider has reduced the level of “support” they permit their workers to do down to phone contact. With someone with a documented history of going non-verbal on the phone.”

Service continuity was a major worry for carers of children and young people with high needs, not only in regards to their health and wellbeing, but also the mental health impacts of carers being required to cope at home with no support for long periods of time. As one family member explained:

“I am struggling significantly to meet my children’s needs. I have serious pain conditions and am trying to home educate my 9 year old. My 3 year old can scream for up to 2 hours nonstop. I am completely isolated from any therapies, support workers and family support.”

Respondents also expressed concern that those services that had been forced to close down might not be able to financially survive and this may mean less availability of services in the future. As one respondent explained:

“Two day programs temporarily closed. We are frightened they will collapse. Day programs MUST remain as an option for people with disabilities. (Some participants like the camaraderie and sense of having a ‘workplace’, just like an ordinary person.)”

Concern was also expressed about the business viability of individual support workers whose shifts were being cancelled over concerns about the need to self-isolate:

“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.”

Access to necessary supplies

Inability to access everyday supplies was a key concern for these respondents. Over two thirds reported being unable to purchase essential supplies, and this was the strongest theme in qualitative comments about the impacts of the pandemic.

At the time of the survey, much of the country was experiencing difficulties with accessing food, cleaning supplies and sanitary supplies during the early weeks of the pandemic. However, this situation put particular strain on the households of children and young people with disability, for several reasons.

Firstly, uninterrupted access to personal care products such as toilet paper, nappies and sanitary wipes is particularly necessary for the carers of children and young people with continence support needs. For example:

“Cannot buy toilet paper or wipes or hand sanitizer for my child who has a bowel condition”
and:

“Unable to buy usual larger quantity of incontinence pants in one transaction for incontinent child.”

These issues were felt all the more keenly because children and young people were now confined to the home:

“No community access and inclusion so at home all the time but impossible to buy toilet paper, paper towels, tissues, hand sanitiser and wipes – basics for all at home disability care let alone under pandemic conditions.”

Secondly, many survey respondents reported needing more of certain supplies (e.g. hand sanitizer) because they have a family member who is immunocompromised or because they are unable to follow hygiene protocols effectively (e.g. hand washing, avoid touching people or surfaces).

As one respondent explained:

“Immunosuppressed child with disability – unable to buy sanitiser and other supplies to protect through higher personal hygiene practices.”

Respondents were not just expressing concern over the availability of sanitiser and protective equipment for themselves, but also for support workers within their households. As one respondent explained,

“I need to have hand sanitizer available for support workers. I can’t buy any.”

Some respondents wondered why government agencies or NDIA were not coordinating to provide this, as had happened in relation to some other vulnerable populations:

“Why are there no masks or protective gear for Support Workers none of them have anything given to them from their employers or the government, why was there not enough supplies to cover such an event. It looks like the supply was so low it wouldn’t even have been available in WA if we had a fire let alone an outbreak of anything.”

Thirdly, a number of respondents were caring for children or young people with restricted diets or particular food needs. As one family member explained:

“We have no toilet paper, milk, bread and other food items. Our eldest has Autism and is very specific about what he eats and uses. Our youngest barely eats as it is and we are unable to get what he needs.”

Twenty-three respondents commented on not being able to get food for people with these specific needs. For some, the only foods these children and young people would eat were the first to run out:

“Both have ASD and will only eat certain foods. Pasta and mince feature high on the list of tolerated foods and I have been unable to purchase any.”

The inability to access these items was reported as distressing for many households, and for some has had health consequences. One carer to a ‘fussy eater’ explained:

“This has resulted in him actually going without food. Although nutritional value is of course a concern, the other concern is that he takes a daily ‘cocktail’ of medication that can have unpleasant side-effects such as stomach irritation and inflammation when he doesn’t have these with food. Since the stomach irritation and indigestion has started, he has started to not want to take his medication, which of course can have dramatic outcomes.”

As we saw supermarkets run low on key products, many restricted the number of items that shoppers were allowed to purchase. This too had an impact on some survey respondents. As one individual explained,

“Unable to buy enough milk to enable PEG [percutaneous endoscopic gastrostomy] tube stomach feeds.”

Accessibility of shops was also a concern cited in survey responses. If shops did not have certain products available, respondents found this problematic as they had to make a decision between going out again to another shop or going without:

“As my son has multiple medical conditions and severe disability and I have an auto immune condition I am having to go out multiple times a week to get the basics. We are unable to get hand gel or anti bacterial wipe or sprays and having trouble getting gloves. Even cleaning produces as you can only buy 2 at a time so I’m having to go back to get other produces at another store or at another time. This makes it impossible to self isolate and we can not get home delivery as it is not available in our area.”

Although for many people going to another shop is an inconvenience, this is more challenging for people with disability or those caring for children and young people with disability. Where ordinarily carers might shop while support workers are looking after children and young people, cancellation of support services makes this difficult. As one respondent explained:

“SW [Support worker] for today text last night to find out my thoughts about the shift today (slow transition to a new school). Participant woke this morning stating he had ‘a cold’. No temp, runny nose. Rang GP. GP said to self-isolate until symptoms were gone. Asked about SW, GP said it would be fine today and to be extra mindful of hygiene. Contacted SW. He gave a long response based on fear of not wanting it and his children.I could’ve really used the help to buy the groceries I need eg bread and milk. Under usual conditions I can’t take him to get groceries. Click and collect suspended. Next delivery is FRIDAY at a cost of \$15!!!! I’m on a single parent pension! Do these people not get how hard this is caring for a child with complex special needs? How do you get perishable groceries when it’s days before delivery and \$15????”

One way that some households balance caring commitments and getting access to essentials is through the use of delivery services. However, as more people started to isolate these became less available and households found they could not get access to home delivery or had to wait longer than usual. Although some stores set hours for vulnerable groups to shop, not all households met the requirements for this.

As one family member explained:

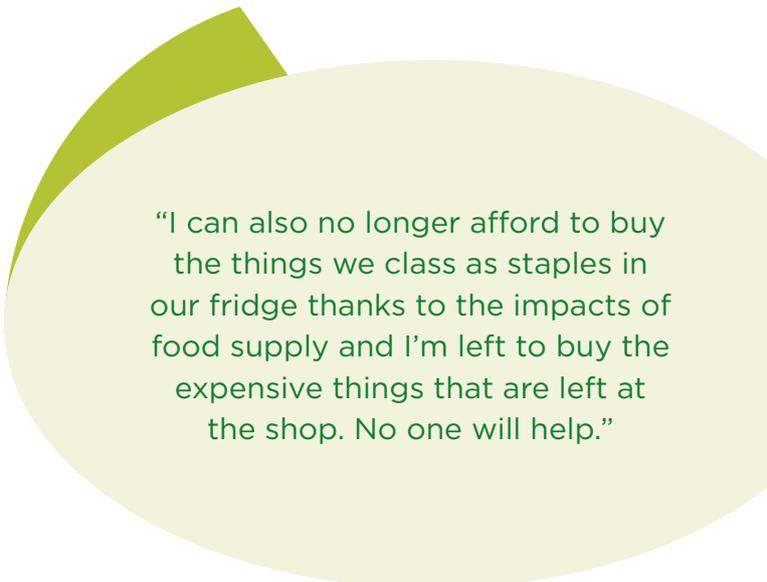
“Families with ASD [Autism Spectrum Disorder] children don’t meet criteria for special shopping times and so we have run out of essential items. In my spare time I’m running around all day looking for toilet paper and food that my child will eat. I’m exhausted.”

Some respondents also reported that where they could find products available, they were more expensive than the brands they would typically purchase:

“I can also no longer afford to buy the things we class as staples in our fridge thanks to the impacts of food supply and I’m left to buy the expensive things that are left at the shop. No one will help.”

Another respondent described a significant impact on the cost of their typical shopping:

“Online food and grocery services have been cancelled in our area. Cost of food has increased 300% due to cheap brands being unavailable.”



“I can also no longer afford to buy the things we class as staples in our fridge thanks to the impacts of food supply and I’m left to buy the expensive things that are left at the shop. No one will help.”

Findings Information and support relating to COVID-19 and pandemic impacts

It is clear from survey responses that people felt like they did not have enough information about how coronavirus would impact themselves and their families.

Moreover, lack of information targeted to the particular needs of households was exacerbating distress and uncertainty. The survey asked “Do you feel that there is enough information targeted at families or children and young people with disability about COVID-19?” and 82% responded no. Although the survey ran for more than five weeks from mid-March until late April, the number of respondents reporting a lack of targeted information remained consistently high.

Table 7 shows that the most commonly needed information and support related to health (301 responses, 43% of the total), with 76 people further clarifying they needed more targeted information on how COVID-19 affects children and young people

with particular conditions, immunosuppression, or co-morbidities. Over a third of respondents also said they required support for buying essential items. While responses about being unable to purchase essential supplies decreased slightly over time (as reported above), respondents requesting support for buying essential items remained high, at 70% in week 2, 61% in week 3 and 66% in week 4. Nearly 30% of respondents required education information and supports, and nearly a quarter required mental health information and supports. These results did not significantly vary according to the age group of the children and young people or whether they were enrolled in mainstream schools compared to special schools.

It is important to reiterate that over half of respondents had completed the survey before the information and support categories were added, meaning these figures almost certainly significantly underestimate the need for information and support felt by respondents.

Table 7: What type of information and support do you or your family require about COVID 19?*

What information/support	Number of responses	Percentage of respondents
Health information and supports	301	43%
Mental health information and supports	160	23%
Education information and supports	200	29%
NDIS information and supports	218	31%
Employment information and supports	82	12%
Getting support for buying essential items	239	34%

* these figures include free text comments from 16–19 March coded into categories that were subsequently added on 20 March

Several respondents cited messaging as being lacking or, when present, that it felt inconclusive or inconsistent. As one respondent explained:

“We need calm, consistent messages and leadership. This will then create calm communities. First people considered whenever a decision is made or info is communicated are our most vulnerable.”

Respondents explained that getting access from official sources had been a complicated process:

“Getting information from Health Line has been complex and difficult. We have felt incredibly isolated in managing this situation and the risk we expose our son to. We’ve had no clear communication from anyone about risk management so we have elected to self-isolate to minimise the potential harm to our son. The govt advice has been inconsistent. Clearer communication channels are required.”

Responses indicated 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 relatively overlooked, and this was problematic given the higher risk associated with the disability population:

“I don’t feel the government is taking an active enough approach to this issue. Those with disabilities are at very high risk of catching this virus due to disability specific issues eg poor comprehension/understanding of the wash hands message, physically reliant on others for hand hygiene, oral sensory seeking behaviours etc. Those with disabilities are also likely to be at higher risk of subsequent death due to likely co-morbidities. I feel that the hospitals are often ill equipped to deal with those with disabilities on an everyday basis (they aren’t funded/resourced enough to be able to provide the level of care needed) & in a pandemic with huge drain on hospital resources those with disabilities will be even less likely to receive adequate care. the governments lack of action.”

Another commented:

“No specific instructions have been given from medical places nor the government to keep our disabled children safe from harm. Not unusual to be forgotten.”

This was echoed still further:

“There is not enough focus or care in regards to this from the government and it makes you feel like disabled people are considered to have less worth than able bodied people which is disgusting.”

As mentioned earlier, respondents were keen to know more about the risks for people with disability, and receive more tailored information about children and young people with certain types of disability. Examples included:

“Information for immune suppressed individuals, what should they do”;

“Information about specific risks to this cohort”; or

“Why (in what way) my CP [cerebral palsy] son is more at risk. This would enable me to know what actions/precautions to take specifically for him.”

Respondents were unsure of how much more cautious they needed to be compared to the general population.

Where information had been made available, it was not always accessible. As one respondent explained:

“Auslan interpreters are severely lacking. I’d really like to see the disability community as a whole be included in any preparations. At the moment, it’s just business as usual and conflicting advice everywhere. I’m worried that we will be left to fall through the cracks again.”

For some this was indicative of the lack of consideration people with disability were being given:

“Meanwhile it is hard pressed to see an Auslan sign interpreter at top level media conferences of the PM and Chief Medical Officer. It is obvious our kids and other people with disability are not in their consideration.”

Family members reported finding it difficult to explain to children and young people with disability about the risks posed by the virus, the need for increased hygiene, and why they couldn’t participate in their usual daily activities. A number of respondents requested social stories to

“help explain to our kids. Especially if there are school closures.”

Further requests were:

“Social stories about hand washing/not touching face etc. Some way to help them understand the seriousness of the situation – they can’t imagine what they can’t see. Maybe some videos of people (actors) with the virus and how they feel and how it has impacted them (basic, not too detailed).”

Survey responses demonstrate a lot of households living with significant fear over what would happen in the event that a carer became sick. One respondent worried:

“What happens if I get sick????? Who will care for him????????”

Others echoed a similar fear:

“What are we going to do when/if in quarantine or sick ourselves so carer can’t care for child and others can’t come in to home to care for them.”

Such a concern is not without basis, given that a prominent news story around this time related to the death of a child with cerebral palsy in China when his father went into quarantine after developing COVID-19.

Many respondents commented on a specific lack of information and guidelines provided by the NDIA on how to deal with changes due to the pandemic circumstances. One respondent asked for:

“More about funding for NDIS and if we can swap funding to different categories, and what we can buy due to the circumstances of being in isolation.”

Another respondent requested:

“Reassurance from NDIS that COVID19 is a qualifying ‘Change in circumstances’ event that could trigger a funding review if closure of day programs etc requires implementing 1:1 in home or community support.”

In addition, a need for service continuity and increased respite support was clearly identified, with respondents commenting:

“[we need] continual access to workers to alleviate distress of changes.”, or wondering

“What will be put in place if support workers cease” or

“How can we continue therapy.”

Another commented:

“We would like communication from NDIS about what contingencies could or might be put into place for essential services to continue.”

This was thrown into sharp relief by family members contemplating long weeks at home during school closures:

“More funding for support workers when schools close as my two kids together need to be separated and 5 weeks of “forced holidays” will likely be the death of us.”

Indeed, one respondent identified a risk of children entering the child protection system if family members are not provided with adequate services:

“Some children will be at risk of entering the child protection system without adequate access to respite and service provision – this is a high risk area that attention to channelling funds into may avoid much more significant costs later and ensure they receive the same right to support as other children by remaining in the care of familiar relationships and environments at a highly distressing time.”



“I don’t feel the government is taking an active enough approach to this issue. Those with disabilities are at very high risk of catching this virus due to disability specific issues... Those with disabilities are also likely to be at higher risk of subsequent death due to likely co-morbidities. I feel that the hospitals are often ill equipped to deal with those with disabilities on an everyday basis... in a pandemic with huge drain on hospital resources those with disabilities will be even less likely to receive adequate care. the governments lack of action.”

Key messages

The findings of this survey represent a snapshot in time during a period where there was national and international apprehension and fear about the COVID-19 pandemic and how it would play out in local communities, some of whom had only recently emerged from a bushfire crisis.

The survey was put into the field and the majority of responses received before decisions were made to close schools and before the full details of different financial support systems were developed and rolled out. Survey findings are illustrative of this.

Respondents expressed a high degree of uncertainty – likely this would have been the same for most of the nation's population, but it seems to be enhanced for this group. What is clear from survey responses is that targeted information is missing around people with disability. Although some vulnerable populations (e.g. aged care) were provided with specific information and recommendations from the early days of the pandemic, this has been lacking for people with disability and their carers and families, which makes every day decision-making difficult. Moreover, many

respondents felt that people with disability and their families had been left out of the pandemic response, and were unclear or even sceptical about whether their needs would be equitably provided for in the coming weeks and months.

People across Australia have experienced work and income disruption, supply shortages and educational difficulties. However, all of these disruptions are exacerbated for the families of children and young people with disability. Reading responses, we gained 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 and young people. Many people can only manage these things when the world is operating as it normally does – however, this global pandemic (especially when immediately preceded by bushfires) has thrown these precariously balanced routines off to such a degree that families are struggling to cope.

Often these issues are interconnected – for example, immunosuppression and increased vulnerability to coronavirus leads to service cancellation, service cancellation disrupts employment and income, income disruption makes scarce supplies even harder to access, the inaccessibility of food supplies exacerbates challenging behaviour in some children and young people, and all of these things put extra stress 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, supporter workers and schools, and unsure of what would happen in the days and weeks ahead, many respondents to this survey expressed heartbreaking distress and worry.

People across Australia have experienced work and income disruption, supply shortages and educational difficulties. However, all of these disruptions are exacerbated for the families of children and young people with disability.

It is well established that people with disability face significant inequities in many different aspects of their lives (health, work, education and social interaction). Survey responses indicate that households have worked hard to provide the best possible outcomes for their children and families despite these areas being thrown into disarray in the face of a global pandemic.



There are lessons that we can learn from this pandemic that can inform future emergency responses. Survey findings point to the importance of tailored information for children and young people with disability. It is also important that intersectional issues (e.g. poverty, gender, disability) are considered together in their totality rather than as separate issues, given the compounding effects of different factors in practice. The fragmentation between national and state/territory responsibilities (especially around education) made for confusing messaging for families of children and young people with disability, and this continues to the current day. Finally, it is crucial that the voices of children and young people with disability and their families are heard and responded to in emergency planning.

But improving messaging and ensuring a more coherent response will not solve many of the issues outlined in this report. It is well established that people with disability face significant inequities in many different aspects of their lives (health, work, education and social interaction). Survey responses indicate that households have worked hard to provide the best possible outcomes for their children and families despite these areas being thrown into disarray in

the face of a global pandemic. Thankfully we have seen some progress around some of the issues raised in survey responses. The NDIA, for example, has made a number of changes to how funding might be used at this time and some organisations and workers may be able to access welfare supports ensuring their ongoing operation. While these are positive changes, the only way we will prevent an impact like this again is to address the various inequities faced on a daily basis by children and young people with disability and their caregivers. This is not a new observation, but is at the heart of the Convention of the Rights of Persons with Disabilities that Australia is a signatory to.

There is a richness in diversity and human experience and this needs to be valued and planned for. During this period of the COVID-19 pandemic this seemed to be missing as all people were treated the same, not recognising that some groups might require more support and consideration so that they can be viewed as equally valued members of society.

Future research agenda

While the data presented here give a good overview of the experiences and needs of these families during the early weeks of the pandemic, this survey was not designed to really drill down into differing needs across the country. As such, in future research it would be helpful to have more detailed information about the situation in relation to geography but also a number of parameters such as school type, age group and others. Further, a gendered perspective would be useful to tease out in future research, as we know that disability care is gendered (see e.g. ABS 2019) and that the pandemic has had a differential impact on men and women, particularly in reference to care responsibilities (Alon et al. 2020). Lastly, responses to this survey were largely received from family members, meaning the voice of children and young people with disability is lacking. Further work to garner these perspectives would be a good addition.

CYDA is currently conducting a follow-up education survey that will explore some of these issue in more detail. In addition, we would support future research and policy development in relation to:

- Trauma experienced by children and young people with disability and the corresponding impact on their mental health in the longer term.
- How children and young people and their families are coping throughout the COVID-19 environment in the longer term, especially in light of the risk of long-term physical distancing that may be needed.
- The impact of COVID-19 on children and young people who are involved in the child protection system and whether this time exacerbated their risk (given the overrepresentation of children and young people with disability in child protection systems).
- The impact on educational outcomes in the longer term, including the post-school transition for students with disability who may be in the senior levels of their schooling.



Responses to this survey were largely received from family members, meaning the voice of children and young people with disability is lacking. Further work to garner these perspectives would be a good addition.

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Appendix 1

Survey questions, including changes over time

Note: only lists questions and changes relevant to the results described in this report (some items were excluded from analysis for reasons of late inclusion in survey or zero response rate).

About you:

- I am a family member of a child or young person with disability
- I am a person with disability (over 25 years)
- I am a young person with disability (under 25 years)
- Other (please specify)

You can complete this survey more than once as circumstances change for you or your family.

Have you completed this survey before? *[added day 5, 20 March]*

- Yes
- No

How old is the child or young person with disability?

- 0–3 years
- 4–6 years
- 7–12 years
- 13–18 years
- 18–25 years
- Over 25 years

Is the child or young person with disability currently participating in any of the following activities? Please mark all that apply.

- Early Childhood Education and Care (e.g. childcare, preschool, kindergarten)
- Primary School – special school
- Primary School – regular or ‘mainstream’ school
- Secondary School – special school
- Secondary School – regular or ‘mainstream’ school
- Home school
- Day program

- Australian Disability Employment (e.g. supported workplace)
- Open employment
- TAFE
- University
- Not in education or work
- Other (please specify)

What is the living circumstances of the child or young person with disability in the next two weeks?

- Living at home with family
- Living in a group home
- Living in another form of supported accommodation
- Living in respite
- Living in private accommodation
- Other (please specify)

Is the child or young person a National Disability Insurance Scheme (NDIS) participant?

- Yes
- No

Have you or the child or young person with disability been impacted by the COVID-19 (Coronavirus) emergency? If so, how have you been impacted? Please mark all that apply.

- Unable to buy essential supplies (e.g. groceries, special dietary products, hygiene products)
- Unable to buy essential medications (e.g. prescription medications)
- Cancellation of support workers by self or provider
- Cancellation of other NDIS funded services (e.g. by me or by the provider)
- Closure of school or education
- [added day 5, 20 March]* Voluntarily self-isolating from school or education
- Unable to work in usual employment
- Loss of income (e.g. through loss of employment, reduction in working hours)

- Required to self-isolate because of health information (e.g. you have symptoms or been diagnosed with COVID-19 or been exposed to others at risk)
- [added day 17, 1 April]* Required to self-isolate due to child/young person compromised immune system or diagnosed chronic medical conditions (such as lung conditions and kidney failure)
- [added day 5, 20 March]* Decline in mental health and well being (self or child) e.g. anxiety, fear and stress

Is there any other information you would like to provide about the impacts of COVID-19?

Do you feel that there is enough information targeted at families or children and young people with disability about COVID-19?

- Yes
- No

What type of information and support do you or your family require about COVID-19? *[this was the only question about information and support from days 1–4, 16–19 March, and was removed 20 March]*

What type of information and support do you or your family require about COVID 19? Please mark all that apply. *[added day 5, 20 March]*

- Health information and supports (e.g. can we go to the doctor or hospital, what happens if me and/or my child has a confirmed case of COVID-19, how to protect myself and/or my child from exposure to COVID-19)
- Mental health information and supports (e.g. for children and young people with anxiety or psycho-social disability)
- Education information and supports (e.g. the impact of COVID-19 on early childhood education, school, post-school education for me and/or my child)
- NDIS information and supports (e.g. how to change my plan quickly if needed, what happens support workers cancel or NDIS providers cannot provide support)

- Employment information and supports (e.g. how to get financial support, what happens if I lose my job or I am unable to work, what are my rights)
- Getting support for buying essential items (e.g. groceries, equipment and supplies, medications, personal protective equipment (PPE))

Are there any other types of information or support you or your family require about COVID-19? If so please specify. *[added day 5, 20 March – replaces previous open-ended question about information and support]*

Is there anything else you would like to add about responses needed in regards to COVID-19 and children and young people with disability?

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