

# Locked out: Vaccination discrimination for children and young people with disability

**Report on CYDA's Vaccination experience survey**  
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**For Children and Young People  
with Disability Australia**  
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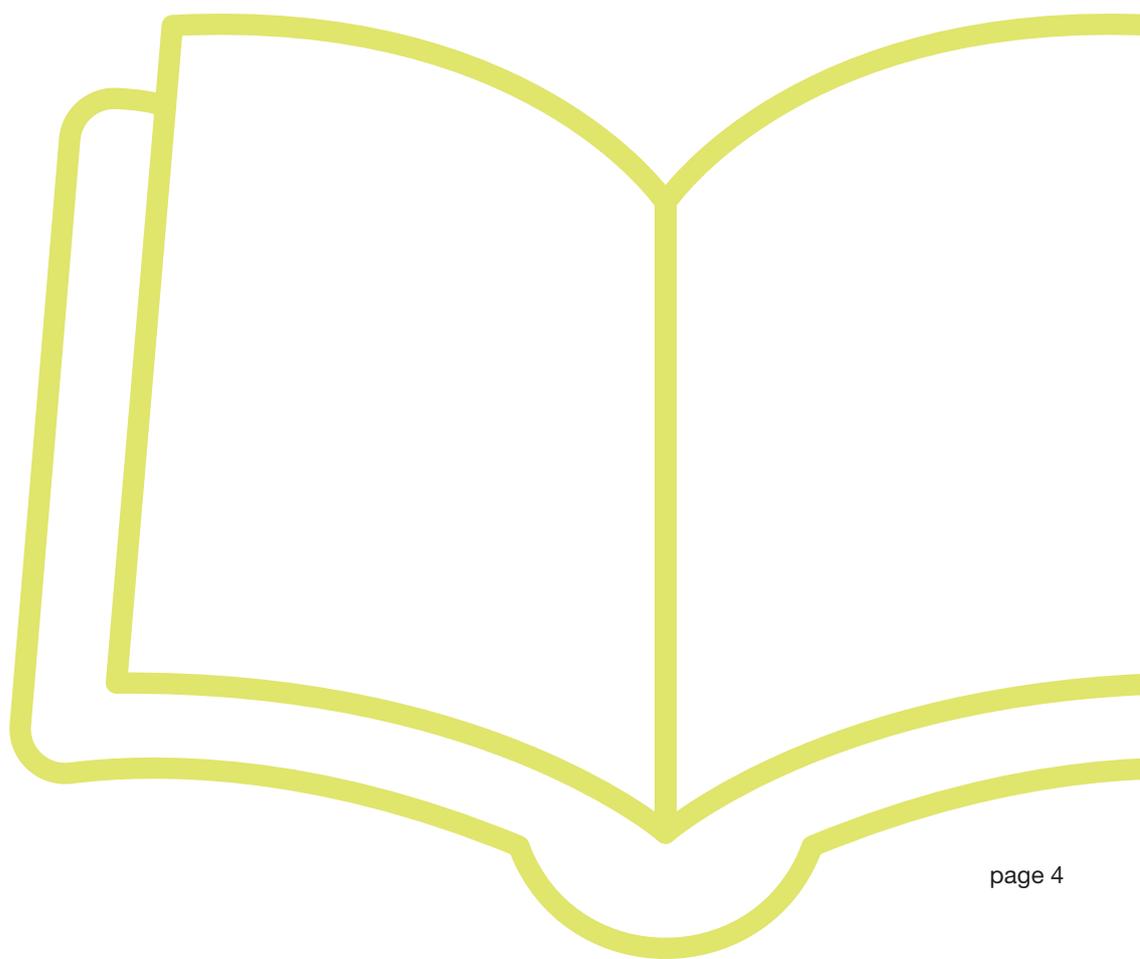
### **Acknowledgements**

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# Executive summary



# Executive summary



- Children and young people with disability are an 'at-risk' population in the COVID-19 pandemic and as such were prioritised for vaccination.
- Other countries have seen increasing numbers of children and young people being hospitalised as restrictions have been lifted, with those clinically vulnerable more likely to experience severe disease.
- Despite prioritisation, levels of vaccinations among children and young people with disability lag those of the general population. Given the significant levels of COVID-19 in some areas this puts children and young people at risk of severe disease as restrictions start to be rolled back.
- This report includes data from a survey undertaken by Children and Young People with Disability Australia (CYDA) and analysed by academics at the University of New South Wales and University of Melbourne.
- The survey was open for one week and received 150 responses.
- 62% of survey respondents were parents/ carers who reported experiencing difficulty in securing a vaccination for their child or children. Further, over 70% of respondents experienced difficulties in securing vaccinations.
- People encountered issues with the booking system, knowing if they were eligible, proving eligibility and not being able to book with General Practitioners. Parents and caregivers had to do significant amounts of work to get their child vaccinated.
- We find there is a gap in terms of specialist provision and particular challenges for people requiring sedation.
- However, where specialist services could be found there were a number of positive experiences and some families found GPs who went the extra mile to vaccinate in a safe and appropriate way.
- Vaccination systems were not designed with children and young people with disability in mind. This reinforces the message that this group have been forgotten during the pandemic, which potentially opens individuals up to greater risk of severe illness from COVID-19.
- There is a need for urgent action to identify which children and young people with disability have not been vaccinated and to provide support to ensure that they can access an appropriate vaccination experience. Without this there is a risk that we will see significant levels of severe disease from COVID-19 with this group.





# Introduction

# Introduction



Children and young people with disability are an ‘at-risk’ population in the COVID-19 pandemic. This was recognised by the Australian Government who prioritised people with disability for vaccination and allowed earlier access to the vaccine for young people aged 12-15. Despite being designated priorities in the vaccine strategy, the vaccine rollout has not progressed in these groups as many would have expected – as we have seen acknowledged in the recent Disability Royal Commission (2021) report into vaccine rollout for people with disability. The National Plan outlines an intention to progressively re-open the country when vaccination thresholds are reached in the general population. But this situation potentially puts children and young people with disability at risk of severe disease from COVID-19 as vaccination rates in priority groups lag that of the general population. Time is of the essence in increasing vaccination rates in priority groups given that some individuals will be at risk as restrictions start to lift.

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Children and Young People with Disability Australia (CYDA) is the national representative organisation for 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 some members were experiencing challenges in accessing safe and appropriate vaccination processes. As such they developed a short survey to better understand these challenges.

In this report we set out the findings of the survey. While we find that young people on the whole had few challenges securing vaccinations for themselves, around half of survey respondents were parents/carers who reported experiencing difficulty in securing a vaccination for their child or children. Further, over 70% of respondents experienced difficulties in securing vaccinations for themselves or their child, or both. The challenges encountered took a number of different forms, but largely revolved around difficulties with booking systems, not being recognised as part of the priority rollout and not being able to book with General Practitioners (GPs). We outline these findings, illustrated through the words of those who completed the survey.

Our findings show that systems were not designed with children and young people with disability in mind, so parents and caregivers struggled to get vaccination appointments and to prove their or their child’s eligibility. Many report having to do much work via a number of different channels to secure an appointment for their child or young person. Once appointments were booked several respondents report vaccination hubs and GP practices as not being accessible or able to cater to the needs of their child or young person. In some cases this exacerbated prior traumatic experiences with health services and more than one respondent reported the use of restrictive practices. Overall, we find there is a gap in terms of specialist provision and particular challenges for people requiring sedation. However, where specialist services could be found there were a number of positive experiences and some families found GPs who went the extra mile to vaccinate in a safe and appropriate way. There is evidence of good practice, but this is not widespread and the communication around specialist services is not as strong as it might be.

# Introduction



As the country moves towards living with COVID and progressively lifting public health restrictions it is imperative that as many children and young people with disability as possible are vaccinated or else we are likely to see significant numbers of infections, severe illness and potentially even deaths. Identifying individuals and families that are eligible and providing appropriate specialist support so that they can be vaccinated is a priority in avoiding significant severe illness in this group.



# Background and approach



# Background and approach



**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.**

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Across the world research shows that people with disability are more likely to face poverty, are less likely to be in work, and more likely to be socially isolated (Kavanagh et al., 2013, Emerson et al., 2018), 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 they often experience discrimination (Temple, Kelaher, and Williams 2018). For example, many communication systems are designed to cater to people who are able to access information through a particular spectrum of hearing and or seeing, without adaption for those who have abilities functioning outside of those spectrums. Despite the potential to provide services that cater to different functional needs, many times people still deliver services that do not consider the full human experience, and instead build systems that perpetuate discrimination.

Evidence from previous pandemics shows that health inequities worsen during epidemics (Quinn and Kumar 2014).

International experience clearly demonstrates the clinical risk that people with disability are under in the face of COVID-19. In the United Kingdom, people with intellectual disability were eight times more likely to die of COVID-19 than the general population (Williamson et al., 2021) and disabled people

made up 60% of deaths (Office for National Statistics, 2021). In the US, intellectual disability was second only to age as a risk factor for death from COVID-19 (Landes et al., 2021). Those living in congregate care settings (e.g., group homes) are particularly at risk.

Severe COVID-19 disease in children and adolescents is uncommon, and rarely causes death (Ledford, 2021) although children with pre-existing conditions are at greater risk of severe disease from COVID-19 (Murdoch Children’s Research Institute, 2021). Although we may not see significant numbers of deaths in children, severe disease requiring treatment in hospital can be damaging and distressing. We lack good data about long COVID in children, so do not know if this will be an issue for some as it is in the adult population (Murdoch Children’s Research Institute, 2021). The Delta variant of COVID-19 does not appear to cause more severe disease than previous variants. However, it does spread faster so the number of children who will develop severe disease will be increased. Moreover, because older groups have typically been prioritised in vaccination campaigns it means we will see infections in children grow as a proportion of overall infections. We have seen this clearly illustrated in the US as schools recommenced recently and the country reported its highest weekly rate of new cases in children and young people since the pandemic began (American Academy of Pediatrics and the Children’s Hospital Association, 2021). Children’s hospitals are reported to be straining under pressure

# Background and approach



as we have seen a fivefold increase in hospitalizations of children and adolescents associated with COVID-19 (Delahoy et al., 2021). Without action it is likely we will see these trends repeated in Australia and the most severe illness will fall on children and young people with disability.

Australia has had significant constraints on its COVID-19 vaccine supply. Given these, Australia's national vaccine roll-out strategy prioritised certain groups, and people with disability were one of these groups. Those living in residential settings (group homes) were in Phase 1A – the highest priority. People with disability with underlying conditions and those with severe mental illness and intellectual disability were included in Phase 1B. Included in group 1B were younger adults with an underlying medical condition, including those with disability although it was unclear whether this was for individuals over 16 or 18 years of age. Vaccination for Phase 1A was to commence in February and be complete by April 2021 and Phase 1B to commence in March 2021. From the 8th June NDIS participants aged 16 and over and carers aged 16 and over of NDIS participants of any age were eligible for vaccination. From late August NDIS participants aged 12 years and over and their support workers became eligible. The rollout to this age group happened ahead of the decision by ATAGI in mid-September to allow 12-15-year-olds access to COVID-19 vaccination.

Despite people with disability being prioritised in terms of the vaccine strategy, we have seen significant delays in vaccinating priority groups. However, it has not always been easy to identify this. Until September 5th the government did not report any vaccination figures for disabled people or workers except in press releases, media reports and Senate

Committees. Since then, rates for NDIS participants living in residential settings and registered disability support workers are reported several times per week on their vaccine tracker dashboard. Moreover, routine reporting around children and young people is limited.

Figures at time of publication suggest that of people with disability in group 1A, around 74% have received a first dose and 64% are fully vaccinated. Of those in Phase 1B, 59% have had a first dose and 40% are fully vaccinated. This compares to 73% and 49% for the general population. This means we see a lag of the general population, even though much of the general population became eligible for vaccination after these prioritised groups. This level of uptake in prioritised groups is not because people do not want to be vaccinated, but a number of reports suggest people are struggling to gain access to appropriate and safe vaccination experiences. Even where people are able to book vaccines, supply constraints means that these appointments are often not for some months.

National Cabinet has developed a plan to transition Australia's National COVID-19 response from its current focus on suppression of community transmission to a post-vaccination setting that seeks to focus on prevention of serious illness, hospitalisation and fatalities. Different activities are allowed once the threshold of the population achieves particular levels of vaccination. Victoria and New South Wales have set out roadmaps that broadly align with removing restrictions when the thresholds are reached of 70% and 80% of their population having received two doses of vaccination. Concerns have been expressed about this situation as it might potentially mean that not all of the priority groups will

# Background and approach



be vaccinated when restrictions start to be lifted, rendering these clinically vulnerable populations at risk of contracting COVID-19 (Kavanagh et al., 2021). Given that under 16s have only become eligible for vaccination in recent months and the trends we have seen in infections in children in other countries it is imperative that we see vaccination levels in children and young people with disability increased to prevent risk of severe disease.

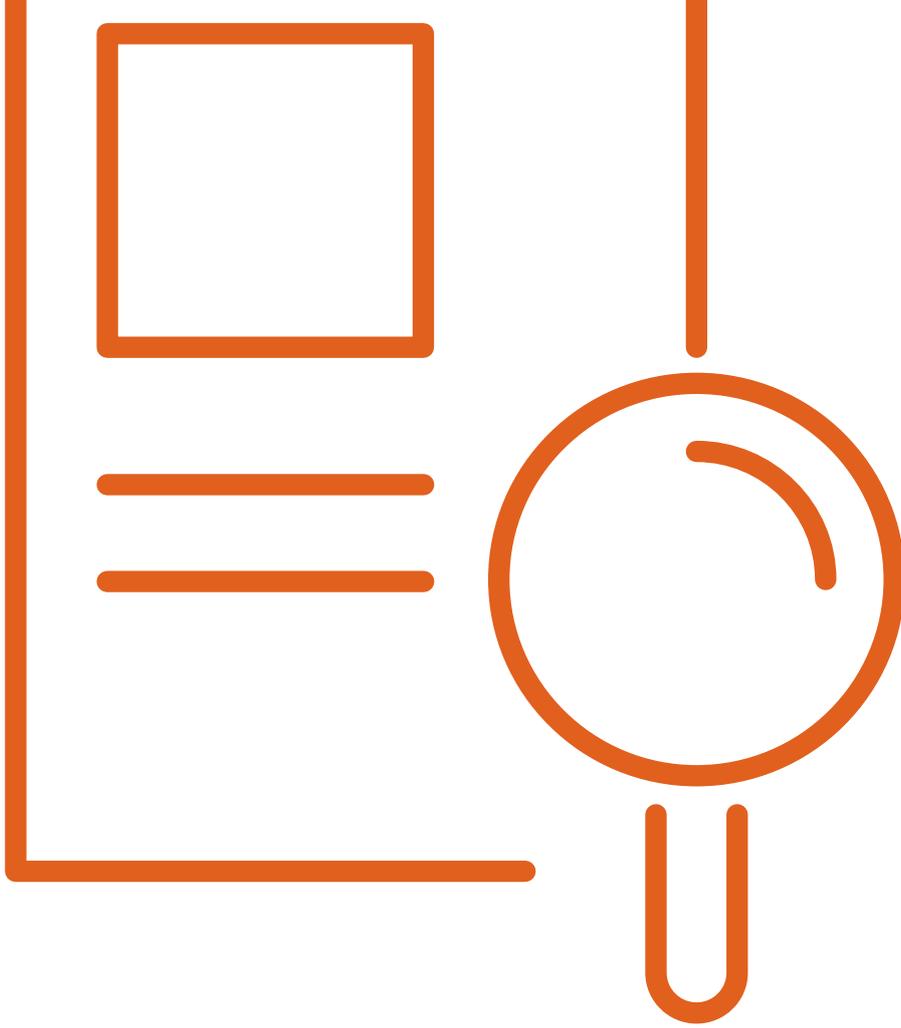
Against the background of the deadlines that the lifting of the restrictions potentially pose, CYDA wanted to better understand whether children and young people and their families were experiencing challenges in accessing vaccinations and if so what the nature of these are. In order to explore this, CYDA developed a short survey to better understand the experiences of its members.

The survey was launched on 10 September 2021 and remained open for just over a week until 19 September 2021. It was shared across social media and with CYDA members. As outlined above, the survey was designed to be short, exploring the experiences of young people and family members/caregivers with accessing COVID vaccinations. The survey comprised just five questions:

- **What was your experience in securing a COVID-19 vaccination?**
- **Did you face any challenges or barriers in securing a vaccination?**
- **What state or territory do you live in?**
- **What type of area do you live in?**
- **Is there any other feedback you would like to provide?**

CYDA sought the assistance of researchers from the Public Service Research Group, UNSW Canberra and Melbourne Graduate School of Education, University of Melbourne to analyse data and prepare this report. While the survey received 150 individual responses, figures in tables may not always add up to 150, because some respondents skipped some questions, and for some questions respondents were able to select multiple answers. Where we provide free text responses we indicate which state or territory this respondent resides within.





# Findings

# Findings



In this section we set out the findings that were gathered from the survey. We heard from individuals from all states and territories across the country apart from the Northern Territory, although with greatest proportions from Victoria and New South Wales (Table 1), which we might expect given that this where the largest numbers of infections are from.

**Table 1: What state or territory do you live in?**

State/Territory	Number	Percentage %
ACT	6	4
NSW	52	35
NT	0	0
QLD	28	19
SA	7	5
TAS	2	1
VIC	49	33
WA	6	4
	150	

As Table 2 shows, three quarter of responses were from people living in metropolitan areas, with a fifth from regional areas and very low responses from people in rural and remote areas.

**Table 2: What type of area do you live in?**

Location	Number	Percentage %
Metropolitan	109	74
Regional	31	21
Rural	4	3
Remote	4	3
	148	

# Findings



## Challenges in securing a COVID-19 vaccination

The first question we asked in the survey was whether respondents had encountered challenges in securing a COVID-19 vaccination over the past two months. As Table 3 shows of the young people that responded to the survey, most had not experienced challenges, with just 5% of total respondents being in this category. However, nearly half (48%) of respondents were parents or carers who had struggled to secure a vaccination for their child and a further 14% had challenges securing vaccinations for both themselves and their child. Lower numbers of family members reported difficulties in securing a vaccination for themselves. Overall, around 70% of survey respondents reported challenges in securing a vaccination.

**Table 3: Breakdown of respondents' vaccine experiences**

Description	Number	Percentage %
<b>Young person with disability</b> aged up to 25 who has had challenges in securing a COVID vaccination	8	5
<b>Parent/carer</b> for a child or young person with disability aged 12-25 who has had challenges in securing a COVID vaccination	78	48
<b>Parent/carer</b> for a child or young person with disability who had challenges securing a vaccination for <b>themselves</b>	8	5
<b>Both parent/carer and child/young person</b> had challenges securing a vaccination	23	14
<b>Neither parent/carer nor child/young person</b> experienced challenges with vaccination	45	28

# Findings



Of those who encountered challenges, as Table 4 shows these took a number of different forms. The most common of these revolve around difficulties in booking systems, not being recognised as part of the priority rollout and not being able to book with GPs.

**Table 4: If you faced challenges or barriers, what were they?\***

Challenge	Number	Percentage %
Unable to book a vaccination at a General Practice (GP) clinic	57	61
Problems accessing the online booking system	52	56
Online booking system was not set up so I could nominate or specify that I was priority	47	51
Difficulty booking a vaccination through a call centre/ by phone	47	51
Not being recognised as being part of the priority rollout, e.g. eligible in 1b but forced to join the queue with everyone else	43	46
Not having specific access needs met or understood	33	35
Lack of accessible information	21	23
Not having access to your vaccination of choice	17	18
Refusal due to an identified disability	7	8

\*Respondents could select multiple answers – percentage expressed as proportion of the 93 respondents who selected at least one answer

In free text responses, some individuals elaborated on the responses that they had given. These reiterate a number of the barriers that we asked about. We explore these now in more detail.

# Findings



## Booking systems not set up to accommodate children or young people with disability

From free text comments, one common theme is that booking systems were not set up to accommodate young people with disability. People had difficulty accessing the system, proving eligibility or knowing whether they were eligible.

From the outset of the process some struggled as the system was not set up to be accessed by people booking for young people or delegates booking on behalf of others. The online booking system initially only allowed one appointment to be booked at a time and this had to be booked by the individual themselves and not by a caregiver:

*Not being able to use the online booking system to book for my child – had to ring up because the online booking system wasn't set up to book for dependents (VIC).*

This issue was particularly problematic where the child or young person did not have their own phone number or email address as the system seems to have been set up requiring these details for an appointment to be made. Another parent explains that they phoned the call centre, who asked to speak to her son as the individual to be vaccinated, but this was not possible due to his impairment:

*The person at call centre only wanted to talk to my son who is 16 and non verbal. Refused to talk to me (NSW).*

In this case this would mean that this individual was unable to access a vaccination unless other arrangements could be made locally (for example with a GP).

For many respondents, proving their child was eligible was an issue and it seems that not all those booking or giving vaccinations were aware of the guidelines. As one respondent explained:

*When I turned up to the appointment with my 16yo daughter, the doctor refused to give the vaccination to her despite confirmation in writing that she was eligible and a letter from her usual GP. The response was – we don't vaccinate teenagers. I insisted & persisted & finally the practice manager agreed "to make an exception". It was very very stressful (NSW).*

As in the case described here, parents and caregivers often reported having to do a large amount of work to secure an appointment for their child or young person:

*I ended up spending 7 hours in total calling different GP practices and sitting on hold and eventually secured my child an appointment. NSW Health hubs took a month to catch up with priority eligibility for 12-15-year-olds with disabilities. I know people who have not been able to secure an appointment for their child with a disability. Many GP practices did not know that this group were eligible or would not accept anyone who wasn't an existing patient. This is inherently discriminatory (NSW).*

# Findings



Other respondents called the appointment line but were told they needed to speak to somebody different because their child was disabled. Unfortunately, in this case, despite being told they would be contacted to arrange an appointment, they did not receive follow-up contact:

*I rang the Covid Appointment line many times. After letting them know that my son had a disability, they took our information and said that someone would call us within 4 -5 business days (from memory). No call was returned. I rang again (after waiting) and was told to leave our information again and a disability officer would call back. I let them know that I had done this already and no calls were returned. I asked for their direct phone number or email. They refused. The call back didn't happen (VIC).*

Another respondent had concerns over eligibility in the sense that they were asked to prove that their child was an NDIS recipient:

*Requested NDIA letter at time of appointment, not all children with a disability will be NDIA participants. Specialist report (stating level of hearing loss) was accepted after some discussion (VIC).*

In this case they were able to secure a vaccination, but as they note not all people with disability are NDIS recipients. In fact only 10% of Australia's disabled population are eligible for the NDIS. Others with disability were not sure if they were covered under the priority groups and had to undertake a lot of work to discover if they were eligible:

*There was no information around as to if my disability (epilepsy) was covered. It was, but it took three people and a manager on the call centre to find out.... (ACT)*



# Findings



## Vaccination centres / services not accessible

In addition to having to contend with challenges in booking vaccinations, some respondents found that when they attended the vaccination appointment it was not accessible.

One respondent reported being able to book their vaccination appointment, but being turned away when presenting for the vaccination:

*We booked the vaccination fine online for [state vaccination centre] but were turned away at the door by a security guard saying “there’s been a balls up with the booking and you shouldn’t have been allowed to book an appointment” When we were given a slot the next day, the staff admitted they had no training in understanding neurodivergent individuals and sensory issues that would have made the whole process more accessible for my son (NSW).*

As this quote illustrates, accessibility for people with disability does not seem to have been a key consideration for all vaccination hubs. One respondent described that the vaccination hub they attended was a:

*Highly clinical environment with no opportunity to plan an approach that would work well for my child (QLD).*

Some of the issues that young people and their families face with vaccination processes relates to the fact that the health system is often not accessible for people with disability and many people have been traumatised through interactions with the health system previously. This means that any attendance at a health service can be a time of significant worry and distress:

*The process itself is broken and not set up for easy engagement for disabled people, children, or anyone with a history of trauma from the medical system (QLD).*

For some children and young people their impairments mean it is difficult to just turn up at a venue and work out a vaccination plan. There needs to be careful advance planning so the process is as effective as possible while not unduly stressing the young person or family. For the respondent below this was not the case for their child and it meant that he left the centre without being vaccinated.

*My son went to have his second covid vaccination. The vaccination centre was extremely busy. The wait much longer than the first time. The noise level much louder. The staff moving and talking quickly. The room filled with other people. Another young person was having a reaction and had to lay down as she felt like fainting. By the time it was my son’s turn he was already distressed. We tried for an hour to get his vaccination. The staff, though busy, worked well with us. But the environmental factors were unable to be addressed. He left unvaccinated. Not too sure what to do next (QLD).*

# Findings



Some respondents specifically wanted to avoid vaccination hubs as they did not believe it would work for them, and the large number of people at these hubs could pose an infection risk. But booking vaccination appointments with GPs was not an easy process for all:

*We were able to secure a vaccination at a Vaccination Hub, but not a local GP – even though my 2 sons have disability, local GP's not interested in prioritising them at all. My concern with attending a Hub came true – it became a Tier 2 exposure site, and we all had to be tested 5 days after exposure, which just added further stress to our family (VIC).*

Others found that vaccination centres were not accessible to particular equipment or needs and that other accessible options were not offered as they were not considered in the right zone:

*Wheelchair accessible vaccination centre and low sensory accessible vaccination not available to us. Was refused by a public hospital and a disability service provider as out of area. Ridiculous system not set up for NDIS eligible young people. Organised poorly, took months of calling, emailing, hot doc bookings and NSW health bookings as well as refusals to get my young person vaccinated (NSW).*

For those in regional areas the issues of scarcity of vaccinations have been compounded and, in some cases, involve people travelling large distances to be vaccinated. As one respondent explained:

*Got first shot appointment in timely enough fashion BUT was in the nearest capital city so a six hour round trip. Second was due when NSW blew up so very fortunate local hospital agreed to put him on their cancellation list and not risk going into Sydney. It took effort and contacts but was doable. Certainly would have been difficult for many (NSW).*

In this case the local hospital's flexibility meant the respondent was able to avoid both a long trip for vaccination and also the COVID-19 exposure risk of travelling to a large city.



# Findings



## Lack of specialist provision

One thing that featured strongly in free text responses was a sense that there was little specialist disability provision available.

Several respondents explained that their child has a needle phobia and therefore it would be difficult to vaccinate them. As one respondent explained:

*My son is Downs Syndrome and severe Intellectual Disability and going to a Vaccination Hub is traumatic. He has a phobia of needles and to take blood he has to go under general anaesthetic at [place] Hospital. His GP is the only person he allows with a bit of hesitancy to give him his flu injection (VIC).*

This comment and a number of others illustrate that the only way to vaccinate some people effectively is through general anaesthetic. But this sort of intervention has not been widely thought about or made available. As another parent explained:

*My son has intellectual disability, cerebral palsy & Autism is afraid of needles. He is 20 yrs old now and active in the community. In the past unfortunately to get any vaccination a collaborative effort with [name] hospital and paediatrician for my son to be put under just for his vaccinations and grey team involved at times. No provisions for this type of instances to cater for his needs to be able to get covid vaccinated. His GP response at this time is don't worry about him getting vaccinated for now. Who is thinking of disabled people with greater challenges for why should they be excluded. Very concerning (VIC).*

One respondent sums up many of the challenges in accessing vaccinations and the support they eventually received from a manager at a local primary care centre:

*Some providers were not offering vaccinations to the 12-16 cohort even though it was allowed by the federal government. The online information was also confusing some saying it was allowed and others not updated to reflect that. The eligibility checker did not reflect the rulings either so you could not get in to make a booking or get on the waitlist. There were literally no Pfizer vaccines in our area, they were all booked out and no-one knew when anymore were going to be available. I had to sit on HotDoc waiting to see cancellations and grabbing them the second they appeared. I got the appointments but had to try to make a change to one of them. I spoke to the practice and suddenly 3 other of my appointments disappeared. I would have been left till December for their first injection. They pretty much haven't left the house since July apart from a walk round the block. I managed to talk to the practice manager and let them know that my kids are disabled and she organised some appointments (NSW).*

As in this situation, the only option available for this individual was to try many sources and continually push to try and get a timely vaccination for their child/young person.

# Findings



Given the lack of specialist services and concerns about the clinical vulnerability of children and young people with disability, some services were having to resort to restrictive practices. As one respondent explained:

*Yes I know of many incidences where parents have had to do restrictive type practices to ensure that their child with a disability was able to remain still during their vaccination, lots of trauma and anxiety, not to mention the potential for future stress/trauma (NSW).*

Such practices are extremely traumatic and upsetting for the individuals and families who experience them as well as professionals. Even if a vaccination was possible under these circumstances, they will likely lead to greater challenges in the young person interacting with health services in the future. For this reason, some respondents were very keen to see alternatives to injections developed:

*Can the government look at an oral liquid or patches or somehow that is less traumatic and stressful? It is hard to support my son who is nearly 6 ft, non verbal, behavioural issues due to autism and anxiety. It took three people nearly an hour (QLD).*

What is clear is that restrictive practices are not appropriate for vaccinations, which can be planned for in advance.



# Findings



## Lack of coherence in vaccination response for children and young people with disability

A number of respondents expressed their upset about the lack of the coherence of the response and the lengths they had to go to in order to secure a vaccination for their child, despite people with disability being a priority group. As one explains:

*There is a real lack of coherence between what the Feds say/put out & what happens on the ground with the people administering the vaccinations (even the GPs who the Feds are directing). The Feds say disability is a priority (priority 1b) but in reality, this priority is not really recognised by the vaccine administrators. I really felt it was a dog eat dog situation, everyone just looking after themselves & no real priorities- just whoever could get in first to make an appointment. No one cared that should my daughter get COVID, she would have a HUGE chance of dying and so should be protected faster. ...I actually had such a hard time trying to get an appointment for her (despite the fact the eligibility checker said she was indeed eligible & a priority), I ended up securing one for myself & took her along & said I was giving up my vaccine for her. It was a "fight" but they finally conceded. I am still flabbergasted that I had to fight to get her vaccinated – eligible & a priority but it took subversive tactics to get an appointment & standing my ground to get it done. Worth it but so unnecessarily hard and stressful (NSW).*

As this respondent emphasises, what the government says should be happening in terms of a plan is not being enacted on the ground. While there is a strategy there does not seem to be a plan to put these aspirations into practice. This frustration is emphasised by another respondent:

*Eligibility and availability are two completely different things in this government's disastrous vaccine rollout. Families of PWD have wasted hours upon hours attempting to secure vaccination bookings for their family members. It is a disgrace (NSW).*

# Findings



Some people will not be able to get vaccinated given their pre-existing health conditions that also render them more clinically vulnerable in the face of contracting COVID-19. For these individuals, respondents were concerned that there does not seem to be a plan:

*That myself and my teenage son can't have any vaccines – at all – because of a rare, genetic disability. No one is advocating for people like us and we will be shut out of services, appointments, grocery shopping, etc, because everyone thinks in binary terms; they think if you're not having the vaccine, that you must be against it. No one is speaking up for those who, simply and genuinely, cannot receive any vaccinations. We're not anti-vax; we're just unable to receive any vaccinations and have specialists who are guiding us. No vaccine passport for people like us. I'm disabled and I'm a carer. The world is leaving us in the lurch and leaving us to rot (VIC).*

The roadmaps out of lockdown in many states and territories is contingent on a proportion of the population being vaccinated. Restrictions will be enforced by individuals having to demonstrate they are vaccinated to gain entry to things like schools, shops and entertainment facilities. While it will be possible to demonstrate exemption from vaccinations on a medical basis, many will be reluctant to reengage fully if there is COVID-19 still present in the population. While many people will be looking forward to the country opening up again, for this group there is no such excitement and only anxiety in the face of not having a realistic plan to accommodate their needs.



# Findings



## What worked in vaccinating children and young people with disability

Not all respondents had a difficult or challenging process in accessing vaccinations and there are some examples of good practice that we can learn from.

In Victoria a number of people mentioned Disability Liaison Officers as having been helpful in identifying an appointment and then ensuring the accessibility of the vaccination process. As one respondent explains:

*I called the hotline number for the Disability Liaison Officer to get assistance both in booking an appointment, but also to avoid long queues and crowds, and to make sure they had enough room to accommodate my sons wheelchair. Great service, got an appt 6 days away. Made the whole process much easier and have recommended it to others (VIC).*

Another respondent described in response to whether they were having challenges in booking a vaccination:

*Initially had this challenge until I was made aware of the Vic Disability Liaison support for COVID vaccination. They were awesome and my daughter was supported to have her first dose yesterday. Without them I'd still be waiting, without support and anxious. I understand this is only available in Victoria and should be available everywhere (VIC).*

Given that we know that the system does not work for many children and young people with disability, having an expert who can liaise in this way is beneficial in supporting a planned and accessible vaccination experience.

Other respondents found that their child's GP was more readily accessible than the online hub for booking a vaccination.

*I was unable to book online for vaccine hub but was lucky my gp was able to provide a date within 2.5 weeks and is always up to date with best advice to suit my child's needs (NSW).*

This kind of positive booking experience was not widespread, and a number of respondents reported difficulties in booking a vaccination appointment with their GP.

In some cases GPs went beyond what was required and would vaccinate in other spaces, for example in a car:

*We booked with our local GP. We arrived late for our appointment as my daughter was very reluctant to leave our home. I was very stressed when we eventually got to the clinic- my daughter refused to get out of the car. Our beautiful doctor told me to stop stressing and she would come out to our car to vaccinate our princess. Our daughter reluctantly offered her arm to the doc – and then smiled and gave the doctor a hug. The same process was repeated in the car for the second vaccination though our daughter was happier that day! Very grateful that procedures can be bent a bit when needed (VIC).*

# Findings



Others were contacted by service providers or in some cases specialist schools who had set up clinics to facilitate vaccination and in some cases they were also able to offer vaccinations to families also:

*It was wonderful that for me, one of my son's disability service providers arranged a pop up clinic so that I could easily vaccinate myself and arrange for my children's father and aunt to also be vaccinated. However, I chose a medical setting for my children in case of adverse reaction given their complex conditions (VIC).*

As in the previous quote, the value of specialist provision is their knowledge of complex conditions and the ability to work in ways to alleviate anxiety:

*We were phoned and offered the pfizer vaccine from the Disability Employment service DSA. Appointments were easy and my sons needle anxiety catered for (NSW).*

However, these specialist clinics were not always well known or advertised, as one respondent explains:

*Once we obtained the direct phone number of a disability specific clinic, we had no more problems. But we only go that information through word of mouth – so we were just lucky that way. We also had difficulty with the vaccination itself due to high anxiety on the part of my son with autism and intellectual disability. We are still not sure if he will accept the second dose. It would be better if there was an option to get vaccinated at home or at school (SA).*



# Key lessons



# Key lessons



The data presented in this report were gathered from a relatively small sample, which we might expect given that it was open for a limited amount of time. While some people had did not have difficulties in booking vaccinations, more than 70% did experience some kinds of difficulties. This situation shows that we learned little from earlier in the pandemic when children and young people with disability and their families reported being forgotten as restrictions were developed and remote learning became common across the country (Dickinson et al., 2020, Dickinson and Yates, 2020). We find again that systems and processes have been devised without any thought given to children and young people with disability. This is not necessarily a new issue, children and young people with disability have long been ignored by policy makers and professionals. The COVID-19 pandemic has not necessarily caused these issues, but it has accentuated these.

Responses to the survey seem to indicate there where young people are able to advocate for themselves and to engage with booking processes, their experiences were more positive. But where children or young people had additional needs and were not able to advocate for themselves then booking and receiving a vaccination became more problematic.

It is clear the vaccination booking system was not designed with children and young people with disability in mind. Access through digital spaces was also confounding, and despite this 'digital divide' in accessibility to digital forms and information for people for disability being well documented (Glencross et al., 2021, AlSadrani et al., 2020, Macdonald and Clayton, 2013), systems for booking were not inclusive for many. Also, there are clearly challenges with getting messages about eligibility criteria to the front line. It is true that we have seen changes to these over time, but the message that the vaccination is not for children seems to have been pervasive.

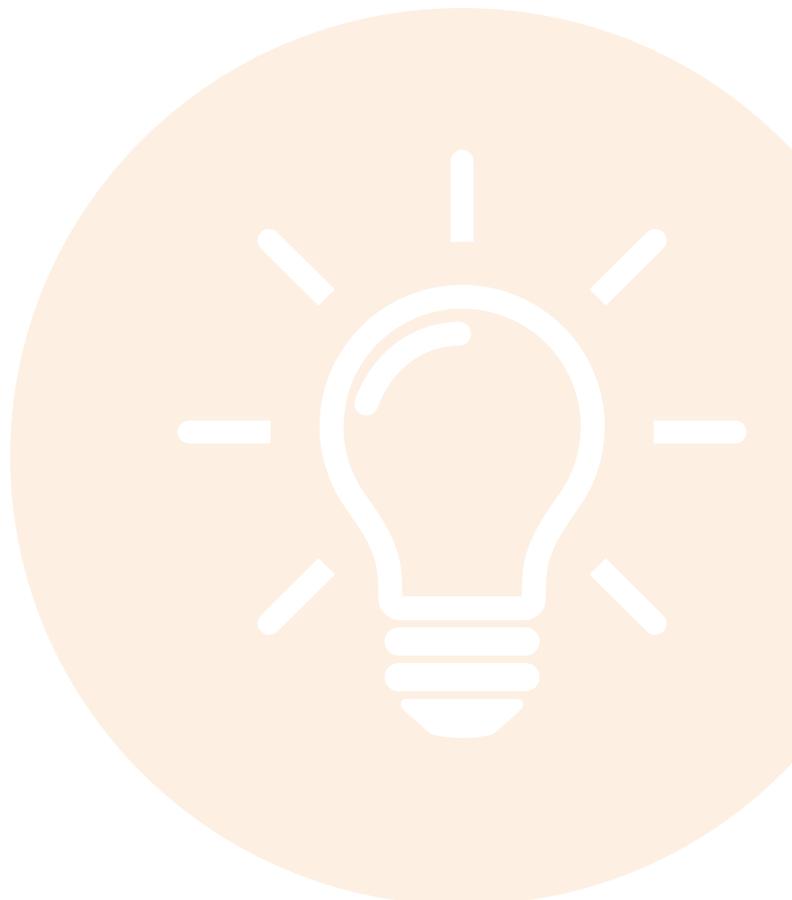
There are some examples of good practice in terms of single GPs and practices, but more needs to be done so that this experience is more widespread. For people with complex impairments, it is likely that their GP will be the best source of support, as professionals who are known to them and who should understand their health conditions. GP practices also tend to be smaller than vaccination hubs, which can be anxiety provoking given their size. However, not all GPs will be equipped to provide this sort of service, so specialist disability services or liaison officers are needed to ensure that people who are eligible for vaccination are able to take up this opportunity.

# Key lessons



It appears that the divide between responsibilities for State and Federal governments had an impact on access to vaccinations for this group. State-run vaccination hubs are large and are not designed to be accessible to complex needs on the whole. While Federal Government is theoretically responsible for funding and arranging delivery of primary care services, many GPs were not aware of eligibility criteria nor supported to ensure vaccination of this group. Some state governments have provided specialist supports (e.g., Disability Liaison Officers in Victoria) to attempt to patch over the cracks in provision. But it is far from an integrated and carefully designed system, and it is one that children and young people with disability all too often fall through the cracks of.

We are running out of time until restrictions start to be lifted and we 'live with' COVID. As 'return to work', 'return to care' and access to many settings for socialising becomes dependant on documentation of full vaccination, we need to consider the implications for this 'priority group' who have not been prioritised and build these next systems for full access. It is imperative that we vaccinate all children and young people with disability who are able to be vaccinated in order to give a high degree of protection to this clinically vulnerable population. It is clear that there is much yet to do and we need some urgent attention in terms of providing appropriate vaccination services to this population.





# References

# References



- ALSADRANI, B., ALZYOUDI, M., ALSHEIKH, N. & ELSHAZLY, E. E. 2020. The Digital Divide in Inclusive Classrooms. *International Journal of Learning, Teaching and Educational Research*, 19, 69-85.
- AMERICAN ACADEMY OF PEDIATRICS AND THE CHILDREN'S HOSPITAL ASSOCIATION 2021. Children and COVID-19: State data report. American Academy of Pediatrics and the Children's Hospital Association.
- DELAHOY, M., UJAMAA, D., WHITAKER, M. & ET AL 2021. Hospitalizations Associated with COVID-19 Among Children and Adolescents – COVID-NET, 14 States, March 1, 2020–August 14, 2021. *MMWR Morb Mortal Wkly Rep* 70, 1255-1260.
- DICKINSON, H., SMITH, C., YATES, S. & TANI, M. 2020. Not even remotely fair: Experiences of students with disability during COVID-19 – Full Report. Melbourne Children and Young People with Disability Australia.
- DICKINSON, H. & YATES, S. 2020. More than isolated: The experience of children and young people with disability and their families during the COVID-19 pandemic. Melbourne: Children and Young People with Disability Australia.
- EMERSON, E., LLEWELLYN, G., STANCLIFFE, R., BADLAND, H., KAVANAGH, A., DISNEY, G. & ZHOU, Q. 2018. A Fair Go? Measuring Australia's progress in reducing disadvantage for people with disabilities (2001-2016). Melbourne: Centre of Research Excellence in Disability and Health.
- GLENCROSS, S., MASON, J., KATSIKITIS, M. & GREENWOOD, K. M. 2021. Internet Use by People with Intellectual Disability: Exploring Digital Inequality – A Systematic Review. *Cyberpsychology, Behavior, and Social Networking*, 24, 503-520.
- KAVANAGH, A., DICKINSON, H. & BAXTER, N. 2021. Opening up when 80% of eligible adults are vaccinated won't be 'safe' for all Australians. *The Conversation*, 31st August.
- KAVANAGH, A., KMJACKI, L., BEER, A., LAMONTAGEN, A. D. & BENTLEY, R. 2013. Time trends in socio-economic inequalities for women and men with disabilities in Australia: evidence of persisting inequalities. *International Journal of Equity in Health*, 12, 73.
- LANDES, S. D., TURK, M. A. & ERVIN, D. A. 2021. COVID-19 case-fatality disparities among people with intellectual and developmental disabilities: Evidence from 12 US jurisdictions. *Disability and Health Journal*, 14, 101116.
- LEDFORD, H. 2021. Deaths from COVID 'incredible rare' among children *Nature News*.
- MACDONALD, S. J. & CLAYTON, J. 2013. Back to the future, disability and the digital divide. *Disability & Society*, 28, 702-718.
- MURDOCH CHILDREN'S RESEARCH INSTITUTE 2021. Research brief: COVID-19 and child and adolescent health Melbourne: Murdoch Children's Research Institute.
- OFFICE FOR NATIONAL STATISTICS 2021. Updated estimates of coronavirus (COVID-19) related death by disability status, England: 24 January to 20 November 2020. London: Office for National Statistics.
- ROYAL COMMISSION INTO VIOLENCE, ABUSE AND NEGLECT AND EXPLOITATION OF PEOPLE WITH DISABILITY (2021) Public hearing 12: The experiences of people with disability, in the context of the Australian Government's approach to the COVID 19 vaccine rollout. Sydney: Royal Commission into Violence, Abuse and Neglect and Exploitation of People with Disability.

# References



WILLIAMSON, E., MCDONALD, H., BHASKARAN, K., WALKER, A. J., BACON, S., DAVY, S. & ET AL 2021. Risks of COVID-19 hospital admission and death for people with learning disability: population based cohort study using the OpenSAFELY platform. *British Medical Journal*, 374.

WORLD HEALTH ORGANIZATION 2018. Disability and Health. Available from <https://www.who.int/news-room/fact-sheets/detail/disability-and-health> Accessed 15 March 2020.

