

# The impact of ending mandatory self-isolation periods for people with COVID-19 on children and young people with disability

"By ending the mandatory self-isolation period for people who test positive to COVID-19, we are only decreasing the freedom of people who are at the highest risk of dying from COVID-19. The health of people with disabilities matters."

# October 2022



Children and Young People with Disability Australia

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# Introduction

On Friday 30 September, 2022, the Australian National Cabinet announced that the self-isolation period for people testing positive to COVID-19 would cease to be mandatory as of Friday 14 October, 2022.

As the national peak representative organisation for children and young people with disability, Children and Young People with Disability Australia (CYDA) have reached developed a community poll asking how young people with disability and their families will be impacted by this decision.

This report summarises the results of the community poll and CYDA's call to action in response.

# **Poll demographics**

# The poll had 142 respondents.

6% were young people with disability between 12 and 17 years old.

26% were young people with disability between 18 and 25 years old.

68% were parents or caregivers of children or young people with disability.





88% of young people with disability, and 81% of parents and caregivers,
do not support ending mandatory self-isolation periods for people with COVID-19 at this time.

# **Key findings**

When self-isolation is no longer mandatory for people with COVID-19:

**89%** of young people with disability who work or study will feel less safe attending their place of work or study.

76% of young people with disability who currently use public transport will feel less safe doing so.

47% will use public transport less.

**21%** will stop using public transport.

**72%** of parents and caregivers of a child with disability who attends school, will feel less safe about their child attending school.

12% are currently looking into home schooling.



# **Common themes**

At the end of the poll, respondents were asked to share their thoughts and feelings regarding the government's decision to end mandatory self-isolation for people who test positive to COVID-19. Some common themes emerged. These were:

- feelings of anger, exhaustion and grief at being forgotten, abandoned or "betrayed" by policy-makers
- lack of trust in the general population to take personal responsibility for COVID-19 mitigation in a safe and effective way without a mandate
- frustration that the weight of personal responsibility will fall disproportionately on those most at risk of long-term complications or death from COVID-19
- fear, anxiety or "terror" regarding the increased risk of being exposed to COVID-19 without a mandate in place
- frustration that a change in policy, promoted as an increase in personal freedom, will in practice reduce freedoms and safe access to community for an already marginalised group
- fear around being exposed to support workers with COVID-19 if they are no longer mandated to self-isolate
- fear that children and young people with disability will be at increased risk of exposure to COVID-19 at school
- fear that parents with pre-existing conditions will be at greater risk of exposure to COVID-19 via their schoolage children without a mandate to selfisolate in place



### **Community trust**

"No one considered those children like my son who doesn't make antibodies ... and ends up in hospital from a cold let alone the effects of COVID ... His life is worth more than the inconvenience of a mask or staying home if unwell."

Feelings of being forgotten, abandoned or "betrayed" were frequently expressed by both young people with disability and parents and caregivers of children and young people with disability.

The comments below are all from young people with disability.

"Disabled people appear to have been forgotten."

"I'm in year 11 and I can't afford to get sick ... I feel like I've been abandoned by health measures that are supposed to protect people like me."

"These are the times that I wish I wasn't chronically ill or disabled, because the choices that ablebodied people make about massive public health issues like this affect us and limit us from going about our normal days."

"[T]his decision is eugenic ... "

"The entire purpose of a society is to support and assist one another to thus be stronger together than we would be individually. This betrayal of Disabled people is a betrayal of all of Australian Society."

"People with disabilities are feeling betrayed and not respected by the wider community."

"The lack of care for [the] disabled community is exhausting."

"[I]t does feel like we're ripping the Band-Aid off and not implementing supports to those who need it."

"I'm terrified for my life, the lives of people I care about, and the lives of the wider community."

"Disabled people are part of the economy too"



# **Personal responsibility**



A common theme from both young people with disability, and parents and caregivers, was a lack of trust in the general public to take safe and effective precautionary measures to stop the spread of COVID-19, such as mask wearing and self-isolation, without mandates.

Some respondents felt removing mandates may signal to many people that the need for precautions is over.

Young people with disability talked about how this will impact them:

"[I] feel so much anger and grief ... I'm sad and scared all the time; people I thought I could trust to keep me safe won't even wear masks in the community anymore, because everyone wants to pretend that the way that COVID works has somehow magically changed over the past two years."

"I have to live my life in constant fear as it is, of catching COVID from unknowing people, and now I won't even have the security of knowing that people who know they're sick have to be in isolation."

"I think it will cause issues within families as people with disabilities and chronic illness are being exposed, and people just believe that the pandemic is over." Parents and caregivers of children and young people with disability expressed concerns about the increased risk of continuing to engage with necessary support workers and specialists.

"I feel nervous my son will be attending a day program where workers and participants may have COVID and aren't isolating."

"My daughter is supported at home with workers and is very vulnerable health-wise ... Having infected workers puts her at great risk."

"This will make it very difficult to protect our family and children with complex health issues ... Necessary therapists and support workers will also pose an increased risk and any community activities."

"We rely heavily on support workers, and with a further increase in infection in the community, we are likely to again experience shortages of workers and feel increasingly vulnerable in our own home."

### **Reduced freedoms**

Respondents talked about the mitigation strategies they will be using when mandatory self-isolation ends. A common theme was that respondents will be entering self-imposed isolation. Many felt that this is now the only way to stay physically safe.

"We are already restricted in our movements, we don't see our extended family, and this will further isolate us ... [We] are essentially prisoners in our home."

"I am terrified. We will definitely be spending a huge amount of our time at home and only going out when absolutely necessary (therapies and medical appointments)."

"Their grandmother passed away from COVID in April ... I am still worried for my young people, one has had COVID twice this year ... I'm so nervous to take them anywhere - we are still locked in and go very few places ..." Parents and caregivers talked about the disproportionate burden of leaving young people with disability and their families to manage their own risk, rather than sharing the responsibility across the community.

"Removing isolation further segregates an already marginalised group in our community."

"[It will] unfairly force vulnerable people into self-imposed permanent isolation."

"[I]t appears that instead of everyone sharing the burden of this virus ... the more able want to go about their lives enjoying everything while some are left to wonder how they will ever be able to enjoy their lives."

Some young people with disability reported ongoing complications from previous COVID-19 infection. As a result they felt strongly about avoiding further infection.

"I am now dealing with post-COVID heart problems and brain fog which has been more isolating than working from home." "I [had] only just begun restarting my life ... and I have to shut it all back down just to make sure I can stay safe. I've had COVID once, and I've been in and out of the hospital with complications since, and I fear any further exposure will be fatal."

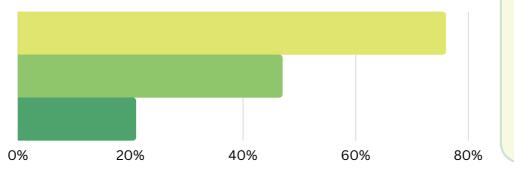
# Access to transport

Lack of access to transport is a barrier for young people with disability to participating in community, work and education.

We asked young people with disability who use public transport, taxis and/or rideshare, such as Uber, how an end to mandatory self-isolation for people with COVID-19 would impact their use of transport.

#### Public transport:

- 76% of respondents will feel less safe using public transport.
- 47% of respondents will use public transport less.
- 21% of respondents will stop using public transport.

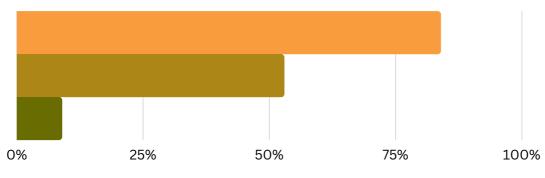


"This will increase my young adult son's isolation as we will not use public transport if there is no isolation period for people who have tested positive to COVID-19."

"It is already stressful with no mask mandates. It will now be scary. I have to use public transport to go to work. I travel during peak times. I'm now going to be really nervous."

#### **Rideshare vehicles and taxis:**

- 84% of respondents will feel less safe using taxis and rideshare vehicles.
- **53%** of respondents will use taxis and rideshare vehicles less.
- 9% of respondents will stop using taxis and rideshare vehicles.





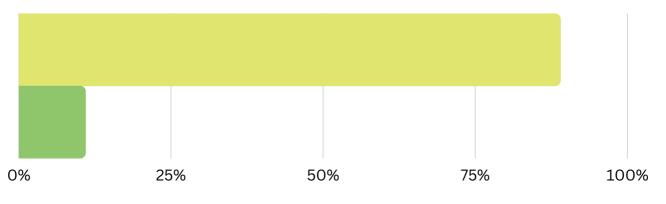
# Access to community, work and education



We asked young people with disability who work and/or study how they felt about attending their place of work or study after mandatory self-isolation for people with COVID-19 ends.

#### Work and education:

- 89% of respondents will feel less safe at work and/or their place of study.
- 11% will feel the same about attending work and/or study as they do now.



"My disability makes me more vulnerable to COVID ... With mandatory isolation now gone, I feel my risk has increased substantially, so I may be forced to give up some of my volunteer, work and usual social activities."

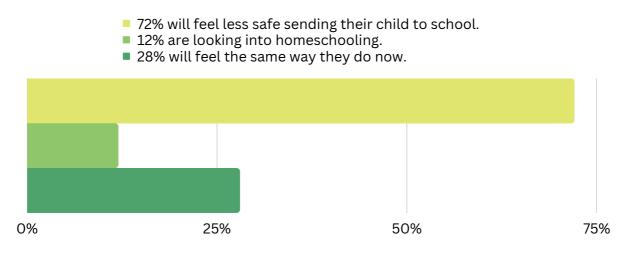
"For those of us who have autoimmune conditions, or who are immunocompromised, it adds yet another level of difficulty in accessing the community and being comfortable and safe in society."



# Access to education - parent and caregiver perspective



We asked parents and caregivers, with a child or young person who attends school, how they felt about the child or young person person they care for attending school when self-isolation for people testing positive for COVID-19 is no longer mandatory.



"This is really scary, and seems completely irresponsible to me. I'm so glad my child is not attending school face to face!"

"This will prevent school attendance, therapy attendance, respite, camps and day activities. [My daughter] will spend her life isolated in the house and NOT in the community."

"My son has not left the house, and rarely his bedroom, due to anxieties over COVID. He goes to Uni ... remotely ... He feels he has not done well remotely and was going to try face to face next year. I doubt he will manage this now."



# **Impact on families**

Parents and caregivers of disabled children can also be disabled or chronically ill themselves, and may have a higher risk of long-term complications or death from COVID-19.

Respondents in this situation expressed concern over the likelihood of their children bringing COVID-19 home from school, once teachers and students are no longer required to isolate.

Parents and caregivers were worried about their capacity to continue caring for a child in this scenario.

Some stated that they are planning to isolate with their child or young person with disability as a precaution.

"I and my son are both severely immune compromised. This decision means that we are less safe. We are now even less able to leave the house ... We are not able to participate in the community safely."

"The decision to end mandatory self-isolation has resulted in my child and I having to disengage from community and general life opportunities as we knew it. We have been forced into isolation."

"I care for a child, but I am immunocompromised, so am scared of what he will bring home from school." "As a Carer with health problems, I fear my child could bring home COVID, and if that happens, who will look after him if I end up hospitalised? We've got no family or friends to support us."

"My son ... can go to school catch COVID and bring it home to me a lot easier than when you had to isolate. I am a very high-risk person with a rare autoimmune disease. I only leave the house when totally necessary."



# Conclusion and Recommendations

This community poll has highlighted consistent concerns across our community regarding a lack of consultation, ongoing safety, and continued distrust of government policy. Young people stated they do not feel safe to return to work or study, access public transport, or participate in the community, once the mandate ceases.

CYDA highlight the concerns of, and for, children and young people who are mandated to attend school, where remote learning is no longer an option. Children and many young people are generally not in a position to make their own choices about attending public spaces or having contact with non-family members, including in spaces such as childcare or sporting clubs.

In light of the responses to our community poll, CYDA recommends the following actions be taken by Australia's National Cabinet and policy makers. 1. A commitment to listening to the concerns of the community about ongoing mitigation strategies for COVID-19, including the concerns of children and young people with disability

2. A renewed public health campaign to support the broader community to limit community transmission, particularly amongst Australians with increased risk of complications from COVID-19

3. To reconsider the decision to cease mandatory isolation from 14 October, particularly in settings which place children and young people with disability at increased risk.

CYDA continue to work alongside our community and government to systematically advocate at the national level for the rights and interests of all children and young people with disability living in Australia.

