

CYDA's response to the Disability Royal Commission's issues paper: The impact of and responses to the Omicron wave of the COVID-19 pandemic for people with disability

Children and Young People with Disability Australia

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Children and Young People with Disability Australia would like to acknowledge the traditional custodians of the lands on which this report has been written, reviewed and produced, whose cultures and customs have nurtured and continue to nurture this land since the Dreamtime. We pay our respects to their Elders past, present and future. This is, was and always will be Aboriginal land.

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Key messages and recommendations

That the Disability Royal Commission continues to highlight the impact of COVID-19 (including the impact of the Omicron wave) for people with disability.

- Children and young people with disability have been more at-risk during the global pandemic, not because of their impairment, but because of discriminatory, limited, or inappropriate policy strategies. It is clear that children and young people have, and continue to, experience complex barriers during COVID-19. It is therefore, important that their voices and needs are at the centre of policy planning and COVID recovery measures.
- An effective COVID recovery plan should be developed by government in consultation with children and young people to mitigate these ongoing impacts.
- As the pandemic is still not over and the threat of future COVID variants emerge, there should be continuous efforts by the DRC to highlight the social/emotional/health impacts for children and young people with disability.
- Throughout this pandemic, children and young people with disability have consistently been left behind, despite being at high risk if of contracting COVID-19, we expect equal treatment, to ensure the lives of people with disability are valued and protected. We strongly urge the government to take immediate steps to improve the federal, state and territory responses to the COVID-19 pandemic by implementing targeted actions for this group.
- The Disability Royal Commission makes strong recommendations to ensure emergency/disaster/pandemic planning, response and recovery adequately includes children and young people with disability as a distinct cohort, rather than a generalised disability approach that does not consider this cohort's distinct challenges and needs.

Introduction

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0 to 25 years. CYDA has an extensive national membership of more than 5,000 young people with disability, families and caregivers of children with disability, and advocacy and community organisations.

Our vision is that children and young people with disability are valued and living empowered lives with equality of opportunity; and our purpose is to ensure governments, communities, and families, are empowering children and young people with disability to fully exercise their rights and aspirations. We do this by:

- Driving inclusion
- Creating equitable life pathways and opportunities
- Leading change in community attitudes and aspirations
- Supporting young people to take control
- Calling out discrimination, abuse, and neglect.

CYDA welcomes the opportunity to provide a response to *The impact of and responses to the Omicron wave of the COVID-19 pandemic for people with disability issues paper*

This submission builds on our previous submissions and evidence provided to the Disability Royal Commission which highlights the systemic neglect of children and young people with disability throughout the pandemic.

This submission draws on the insights and direct quotes from young participants in our community. In early April 2022, we reached out to directly ask young people about their experiences during the Omicron wave. This was done through our social media platforms and a vox pop (short survey) sent directly to our youth network.

Further, our response draws on insights and quotes from young participants who attended our 2021 LivedX Consultations Series, a component of CYDA's Our Voices Our Visions: Youth Advocacy project. The LivedX Consultations were conducted to hear from young people with disability about what an ideal future looks like for them. This included collecting their ideas and solutions on topics and issues they deem important. The project is funded by a Youth Advocacy Support Grant from the Australian Department of Education, Skills and Employment.

Lastly, this submission was shaped by CYDA staff, the majority of whom have personal and/or family experience of disability. In April 2022, we held a targeted staff forum which focussed specifically on the COVID Omicron Wave and its impact on people with disability.

The stories shared during conversations held with CYDA staff and young people from our community about the impact of COVID, highlights a recurrent, underlying theme that children and young people with disability are not heard. Whether because of a lack of awareness or because of prejudicial attitudes, children and young people's needs in the face of COVID are being neglected. The government and community response to the threat of the contagious Omicron variant has neglected the disability sector and is putting the lives of people with disability at risk. Poor policy planning by government and a lack of understanding from the broader community is unnecessarily creating obstacles that prevents them to lead the lives they wish, and have the right, to live.

CYDA is committed to ensuring that children and young people with disability are afforded equitable opportunities to succeed and we advocate that this cannot be achieved until they feel fully included across all systems and community life. Throughout this pandemic, (including during the Omicron wave) children and young people with disability have consistently been left behind, despite being at high risk of contracting COVID-19.

We expect equality, to ensure the lives of people with disability are valued and protected. To prevent more lives from being lost, it is essential that Australia's governments listen to and work with the disability sector when formulating responses to the pandemic.

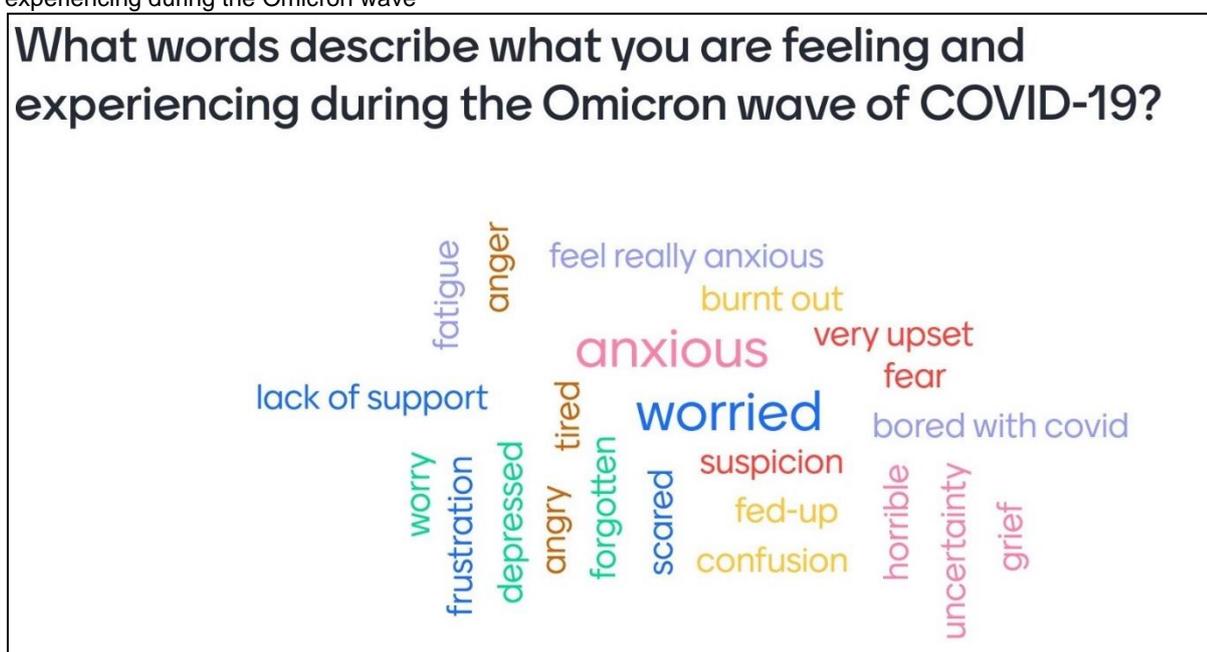
Hearing directly from young people

‘Vibe check’ on Omicron

CYDA reached out to young people in our community in early April 2022 to directly ask them about their experiences during the Omicron wave. This was done via our social media platforms and a vox poll sent directly to our youth network. Eleven young people responded with ages ranging from 12 to 25 years old.

When asked to describe what they were feeling and experiencing during the Omicron wave of COVID-19, responses were unanimously negative, with many reporting feelings of fear, anxiety and worry. See **Figure 1** for range responses, with the most frequently used descriptors represented by larger words.

Figure 1: A word cloud of young people’s responses to questions asking them to describe what they are feeling and experiencing during the Omicron wave



CYDA also asked young people if there was anything else people should know about children and young people with disability's experiences during the pandemic? Many conveyed feelings of despondency, with some young people expressing how that current situation impacts their wellbeing.

“That it takes a toll on [children and young people’s] mental health.”

“It is really hard to do everything on my computer. I got really sick of staying at home and bored and I had no friends and stopped all my things I practice to get better at.”

“...I think with the first wave it was quite accepted to not being doing well but everyone expects you to just get on with it now.”

Others commented on other’s changing attitudes around COVID and isolating.

“The world has seemingly conveniently forgotten that COVID deeply affects the lives of people with disability (although the shift to remote work has been beneficial for a lot of

people, as a potentially more accessible environment/option). Many of us are still concerned for our health and future and there is a pervasive feeling of being forgotten in society when everyone is rushing to 'get back to normal'."

"Everyone is acting like the virus is gone but it isn't."

Lastly, young people also commented to the availability, or lack thereof, of supports.

"The lack of support and resources make people with a disability unable to meet goals and the correct support to help them."

"Not enough support."

LivedX focus group – Experiences of LGBTQIA+ young people with disability

Throughout 2021, CYDA hosted a series of LivedX focus groups – designed, delivered by and for young people on the issues that are important to them. In December 2021, a focus group was run on the topic of LGBTQIA+ young people with disability's experiences in and of community. Eleven young people with ages ranging from 15 to 25 years old attended. The timing of the focus group coincided with when many COVID-19 related restrictions were being lifted across the country.

One discussion topic in the focus group explored how COVID-19 and lockdowns had made queer spaces more or less accessible for young people with disability. Many participants shared how over the previous 18 months, COVID-19 has presented them new opportunities to engage with their community and build a greater self-understanding of their own identity.

"So I think we should learn from the pandemic experience that actually obviously it sucks to be in a global pandemic but it doesn't suck that I got to attend things for the first and only time and that shouldn't end just because it's easier and we want to go back to the before times."

"For me like online spaces in general are far more accessible than in-person spaces could ever be, and so other queer people being forced to exist in online spaces was inherently more accessible for me, just like I can't even articulate how many ways online is better for me."

"Even like in the last two years [in restrictions and lockdowns], on my kind of like disability acceptance and pride journey, a lot of that happened because of my mutuals on Instagram and I guess that was really cool, is maybe we had to stay inside but I got to spend time on Instagram and I made cool friends and now we call and they teach me Auslan and things like that."

LivedX participants further shared how they were disappointed to see these opportunities change or end with lockdowns and restrictions lifting.

"... [I]t's been really great and we can interact with different queer people from all over so-called Australia, and then as soon as lockdown ends, people are like "Oh, I'm never going on Zoom again", and it's really disappointing because for once we've been able to kind of like join spaces that otherwise haven't been great for us."

"... [N]ow that things are shifting, it's doing the opposite, which is super disappointing because events aren't accessible for myself and my immune system just yet."

More specifically, some participants commented how the attitudes and the (un)awareness of their peers without disability and the wider community created barriers for young people with disability to attend events and activities in a safe and accessible manner.

“Especially when your disability could involve being immunocompromised, it's made it really hard, even like now coming out of lockdown, because I think a lot of people aren't too worried about COVID anymore. But when you're living as someone with a very compromised immune system, it's really scary to be able to go out into those spaces.”

“But I think one thing that's been hard is as soon as [COVID-19] restrictions have been eased ... there was this like resentment towards anything online by queer people, because they missed their physical spaces so much, which I understand. But that immediate kind of like abandonment of anything online has been incredibly isolating and more inaccessible, because there's no transition when they just want to go back to [popular queer venue] and stuff like that.”

Group members expressed how moving forward they would like to see more conscious efforts to make events and environments more accessible in a COVID-19 world.

“I think for me it was a bit of a mix because in person spaces before COVID-19 was a huge thing and masks weren't a thing, I could generally manage with lip reading. But now events are kind of like in person with masks or over Zoom without captioning and both of those are super inaccessible to me.”

“I think we should be learn to be able to offer both [safety for immunocompromised people as well as making it easy to know what people are saying behind masks] safely [using] social distancing, larger rooms, masks”.

“I don't know if there's a way to mandate accessibility measures, for in person and online spaces. I don't actually see the government ever doing that but it'd be epic if they could because yeah, we shouldn't have to choose between two inaccessible things and then end up doing none of them. We deserve access to queer spaces.”

Responses from targeted CYDA staff forum; Omicron impacts for people with disability

In April 2022, CYDA held a staff forum which focussed specifically on the COVID Omicron Wave and its impact on people with disability. There was staff representation from:

- Parents and caregivers of children with disability
- Young people with disability
- Adults with disability and;
- Notably, CYDA's Inclusion Support officer who also has a lived experience of disability, offered valuable insights into their practical experience of managing the challenges of COVID.

Insights from the staff forum are summarised below.

The impacts of the current wave of the pandemic on people with disability

Social impacts

In the first wave, when most people were in lockdown, there was a unifying experience of being 'in this together' – as many work and social events occurred online. In the current situation as the community opens up and COVID restrictions are lifted, there is a sense of increased isolation, particularly for those who cannot socialise in the community. Exposure to COVID is heightened where social distancing regulations are minimal or non-existent and the fear of contracting COVID is real, particularly for those who are immunocompromised.

“My daughter’s (who has a disability) social circle has narrowed down as she does not wish to socialise without wearing a mask.”

Young people struggle to balance their desire to mix socially in the community whilst at the same time protecting their health.

“We can’t all go to the events we want to. We have to look after our health concerns. There is a forced FOMO (fear of missing out).”

“In my experience, the physical environment especially in retail settings doesn’t support social distancing or physical access, so people with disabilities are still having to isolate.”

As schools gradually promote extra-curricular activities such as sporting events, easter raffles and after-school play, students with disability are still at high risk.

“My 10-year-old daughter won’t wear a mask, [she is] entirely reliant on other people [parents/caregivers] protecting her. This is socially and emotionally difficult for her and us as a family well.”

Education impacts

Lives of children and young people have been thrown into turmoil during the pandemic – exacerbated further by the onset of Omicron – as they already face multiple barriers and difficulties in accessing inclusive education, support for reasonable adjustments and the same curriculum as their non-disabled peers, placing pressure on them and their families.

In our previous submission, *Not even remotely fair: Experiences of students with disability during COVID-19*¹ we outlined the extreme systemic neglect of students with disability in the first waves of the pandemic.

CYDA staff who are parents of children with disability describe the significant impacts due to teacher shortages as school staff are being furloughed due to isolation requirements, support workers are limited, and reasonable adjustment arrangements are affected.

“Approaches to transition have been less desirable – reasonable adjustments are taking longer to implement or not happening all. Access to specialist staff – teachers have less access to specialists to design reasonable adjustments. If families have to stay at home to continue to self-isolate – it is very unlikely that families have access to learning materials that have been reasonably adjusted then there is less access to help them design or do the reasonable adjustments for learning materials that.”

CYDA staff also report an increase in home-schooling and distance education enrolments as families cannot rely on their schools to make adjustments via virtual learning.

“My daughter’s classes have changed to in-person rather than online.”

The situation is further exacerbated for remote learners in the Vocational Education and Training (VET) sector.

“Remote learners do not have access to computers...or they have disengaged. [Students with disability] cannot access internships and student placements. Disengagement [is] more likely.”

CYDA staff expressed concerns that consultation with disability representative organisations, has been inadequate.

CYDA’s CEO, (Mary Sayers’) statement to the Disability Royal Commission², in 2020 still has relevance today. Her statement highlighted that consultations with disability organisations by government education departments (both state/territory and federal departments) have been largely ineffective either because there is a lack of a consistent approach or pandemic committees established during the initial COVID wave, have since been dissolved.

“After making numerous inquiries about the national planning taking place for students with disability, CYDA was invited to sit on the Department of Education, Skills and Employment’s Education and Employment Sector Pandemic Preparedness Committee on 22 April 2020. This Committee had been running for seven weeks before we were invited to join, as we noted in our evidence provided at the Select Committee on COVID-19.” (Mary Sayers, CEO, CYDA)

This committee was abandoned in July 2020.

¹ Dickinson, H., Smith, C., Yates, S., Bertuol, M. (2020). *Not even remotely fair: Experiences of students with disability during COVID-19*. Report prepared for Children and Young People with Disability Australia (CYDA), Melbourne, accessed at <https://www.cyda.org.au/resources/details/172/not-even-remotely-fair-experiences-of-students-with-disability-during-covid-19-full-report>

² [Mary Sayers statement to the DRC](#)

Health care impacts

Anecdotal feedback from staff indicates that access to telehealth has been reduced as the community opens up. Some families are experiencing gate-keeping tactics adopted by health clinic staff, discouraging long-telehealth sessions. As a result, complex health issues are not dealt with effectively or families are expected to present at health clinics in-person in often over-crowded waiting rooms, placing children with disability at further risk.

Once staff member highlighted the adverse impacts of limited access to health services on the utilisation of NDIS plans. Parents of children with disability have not been able to use services during pandemic – this has meant a reduction in plans and potential future planning cuts.

Rapid Antigen Tests (RATs)

Whilst largely resolved at the time of writing – due to the increased availability of RATs – the RATs supply issue (both online and in-store settings) at the onset of the Omicron wave, is a stark reminder of the lack of preparedness by the government (across all jurisdictions) to effectively plan during a crisis situation, particularly for people with disability who are known to be of greater risk from COVID.

“Throughout pandemic, rushing in and queuing for ages to get masks, RATs, etc has been very hard, due to social distancing needs and also physical access issues. [It is an] enduring issue.”

The effectiveness of government planning to ensure the health and safety of people with disability when restrictions to manage COVID-19 were eased in late 2021 and early 2022

The ‘let it rip’ approach is extremely stressful for people with disability and CYDA staff share the concerns of other disability representative organisations³ that the approach to opening up is an ableist response that does not value the lives of people with disability.

“As a person with a disability I was shocked when the government used the term 'let it rip'.”

“In some ways people with disability are worse off than before pandemic in terms of social and medical - before pandemic less risk of covid, during height of pandemic somewhat supported for safety / virtual access, nowadays barely any support / safety considerations ('let it rip') so people with disability have to safeguard selves and have reduced access with little / no social understanding / government support. Strong message that people are happy to forget about people with disability and won't make at the effort / be mildly inconvenienced just for us.”

Whether responses by government and service providers to the Omicron wave have been effective in lessening its impact on people with disability

On 4 January 2022, when Omicron cases were exploding in New South Wales and Victoria, CYDA CEO had to reach out to the secretariat of the Disability and Health Sector Consultation Committee (DHSCC) convened by the Commonwealth Department of Health to request an urgent meeting to discuss the lack of Rapid Antigen Tests and the risks in the community from Omicron. The DHSCC

³ <https://pwd.org.au/disability-sector-slams-national-cabinets-omicron-response/>

is meant to be a forum where action is coordinated across government. We asked that the following topics be discussed:

- Access to testing for people with disability, particularly RATS (those who are on the NDIS and those who are not)
- What the responsibilities of service providers and workers are
- How people on income support payments or facing poverty can access tests for free
- Any other information that is useful to inform our community, including in accessible formats.

This was in response to deep concern by our members. A meeting was subsequently organised on 25th January 2022. These three weeks of a time of turmoil for children and young people with disability and their families, and again highlights the lack of nimbleness in the government's response to disability advocacy sector's concerns, increasing uncertainty and harm.

In January 2022, CYDA was a co-signatory of the joint statement of concern by disability representative organisations expressing fears for the health, safety and wellbeing of people with disability during the Omicron wave. This was in response to what was seen by us as the failure in government's handling of the Omicron wave for people with disability. Despite repeated requests, the government continues to enact pandemic policies without consulting disability representative organisations prior to implementation.

Although, the sentiment from CYDA staff concurs with the above view, they also highlighted some good work in Victoria through assistance from [Disability Liaison Officers \(DLOs\)](#). The DLOs in Victoria help people with disability access COVID-19 vaccination.

CYDA recommends that such support be modelled nationwide.

The experiences of people with disability who have been affected by the recent severe flooding in Queensland and New South Wales or other emergencies

As a national organisation, CYDA represents the nation-wide concerns from our community during the recent floods in QLD and NSW, which were exacerbated by the onset of the Omicron wave.

- **Vaccination:** Floods and vaccine hubs - many in South East Queensland were flooded and no clear information given on where to go vaccinations. There was also a swell of those that were due for vaccination just as school started in 2022.
- **Supports in the home:** Particularly variability in supports for children with disability across states. And the time lag between information and website updates is inadequate.
- **Consumables:** Floods have impacted the availability of critical health care services and supplies. Access to goods and services (medical consumables that are claimable under the NDIS) are still limited due to logistics and delays in shipping and production to warehouses – accentuated by floods.

CYDA's COVID-19 policy work

Children and young people with disability have been largely forgotten in government responses during the height of the COVID-19 pandemic in Australia. In our recent policy work we highlighted how Australia lacked a coherent national information strategy and response for children and young people with disability, creating and exacerbating feelings of uncertainty and distress.

Our policy work also demonstrates the inadequacy of targeted responses for children and young people with disability spanning vaccinations, education, support services and a range of other impacts.

CYDA's COVID-19 work:

- [Co-signatories on the Disability sector Omicron statement of concern](#) (2022)
- [Locked out: Vaccination discrimination for children and young people with disability](#) (2021)
- [Submission to the Disability Royal Commission: Emergency Planning and Response during COVID-19](#) (2020)
- [Not even remotely fair: Experiences of students with disability during COVID-19](#) (2020)
- [CYDA CEO, Mary Sayers Disability Royal Commission witness statement](#) (2020)
- [More than isolated: The experience of children and young people with disability and their families during the COVID-19 pandemic](#) (2020)
- [Co-signatories on Open letter to National Cabinet Immediate Actions Required for Australians with Disability in Response to Coronavirus \(COVID19\)](#) (2020)