Committee Secretariat

Inquiry into Long COVID and Repeated COVID Infections

Standing Committee on Health, Aged Care and Sport

PO Box 6021

Parliament House

Canberra ACT 2600

Via email [Health.Reps@aph.gov.au](mailto:Health.Reps@aph.gov.au)

**18 November 2022**

Please accept Children and Young People with Disability Australia’s (CYDA) submission to the Standing Committee on Health, Aged Care and Sport’s *Inquiry into Long COVID and Repeated COVID Infections*.

Children and young people with disability have experienced a higher degree of risk during the global pandemic, not because of their impairment, but because of discriminatory, limited, or inappropriate policies that have been implemented to manage infection in the community. CYDA’s policy work (Appendix A) highlights the lack of a coherent national strategy in Australia along with the exacerbation of exclusion, uncertainty and distress experienced by children and young people with disability.

CYDA welcomes this Inquiry as a further opportunity to examine the inadequacy of targeted responses for children and young people with disability including the experience and response to Long COVID-19 and repeated COVID infections. Without targeted and adequate policy responses, action and intervention, children and young people will continue to feel the social and economic impacts of COVID for a lifetime.

The Australian Human Rights Commission has outlined the key rights captured within the United Nations Convention on the Rights of Persons with Disabilities ([CRPD](https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html)) which are most relevant in the context of a pandemic. Please also refer to the attached Appendix A for further information and Appendix B for more detailed responses to select terms of reference.

If you would like to know more about our submission or CYDA’s work, please feel free to contact me on (03) 9417 1025 or [lizhudson@cyda.org.au](mailto:lizhudson@cyda.org.au).

Kind regards,

Dr Liz Hudson

Policy and Research Manager

CYDA

# Appendix A Further information and resources

**CYDA’s COVID-19 work:**

1. [Response](https://www.cyda.org.au/resources/details/314/cyda-s-response-to-the-drc-s-omicron-issues-paper) to the Disability Royal Commission’s Omicron issues paper
2. Co-signatories on the Disability sector Omicron [statement of concern](https://pwd.org.au/wp-content/uploads/2022/01/Disability-Sector-Omicron-Statement.pdf)
3. [Concern](https://www.cyda.org.au/resources/details/261/drc-response-to-the-covid-19-hearing-report) about the DRC not making recommendations following the neglect of students with disability during the COVID pandemic
4. [Report](https://www.cyda.org.au/resources/details/332/how-did-covid-19-impact-post-school-transitions-for-young-people-with-disability-and-how-can-these-be-better-supported) “How did COVID-19 impact post-school transitions for young people with disability and how can these be better supported?”
5. [Report](https://www.cyda.org.au/resources/details/304/locked-out-vaccination-discrimination-for-children-and-young-people-with-disability) “Locked out: Vaccination discrimination for children and young people with disability”
6. [Submission](https://www.cyda.org.au/resources/details/187/disability-royal-commission-emergency-planning-and-response-during-covid-19) to the Disability Royal Commission: Emergency Planning and Response during COVID-19
7. [Report](https://www.cyda.org.au/resources/details/172/not-even-remotely-fair-experiences-of-students-with-disability-during-covid-19-full-report) “Not even remotely fair: Experiences of students with disability during COVID-19”
8. CYDA CEO, Mary Sayers Disability Royal Commission [witness statement](https://disability.royalcommission.gov.au/publications/exhibit-7-07-stat017400010001-statement-mary-sayers)
9. [Report](https://www.cyda.org.au/resources/details/161/more-than-isolated-the-experience-of-children-and-young-people-with-disability-and-their-families-during-the-covid-19-pandemic) “More than isolated: The experience of children and young people with disability and their families during the COVID-19 pandemic”
10. Co-signatories on [Open letter](https://dpoa.org.au/an-open-letter-to-the-national-cabinet-immediate-actions-required-for-australians-with-disability-in-response-to-coronavirus-covid19/) to National Cabinet Immediate Actions Required for Australians with Disability in Response to Coronavirus (COVID19)

**Other COVID-19 resources:**

1. Australian Human Rights Commission. (2020*).* [*Guidelines*](https://humanrights.gov.au/sites/default/files/document/publication/ahrc_covid19_guidelines_disability_2020.pdf) *on the rights of people with disability in health and disability care during COVID-19*
2. Australian Government. (2022). Department of Health and Aged Care, [*Getting help for long COVID*](https://www.health.gov.au/resources/publications/getting-help-for-long-covid)
3. International work on Long COVID in children and young people: Zimmermann, Petra MD, PhD; Pittet, Laure F. MD-PhD; Curtis, Nigel FRCPCH, PhD. (2021). [*How Common is Long COVID in Children and Adolescents?*.](https://journals.lww.com/pidj/Abstract/2021/12000/How_Common_is_Long_COVID_in_Children_and.20.aspx) The Pediatric Infectious Disease Journal: December 2021 - Volume 40 - Issue 12 - p e482-e487
4. Harris, D., Seriamlu, S. Dakin, P. & Sollis, K. (2021). *Kids at the Crossroads: Evidence and Policy to Mitigate the Effects of COVID-19*. ARACY. Available at [Kids-at-The-Crossroads-UNICEF-Australia-ARACY.pdf](https://www.unicef.org.au/Upload/UNICEF/Media/AboutUs/Publications/Kids-at-The-Crossroads-UNICEF-Australia-ARACY.pdf)
5. Green, C., Carey, G., & Dickinson, H. (2021). *Barriers and enablers in the development of a COVID-19 policy response for people with disability in Australia*. Melbourne: Centre of Research Excellence in Disability and Health.
6. Mission Australia. (2019). [*Young, willing and able*: *Youth Survey Disability Report 2019*](https://www.missionaustralia.com.au/publications/youth-survey/1610-young-willing-and-able-youth-survey-disability-report-2019/file).

# Appendix B CYDA’s response to Inquiry Terms of Reference

| Terms of reference | CYDA’s response |
| --- | --- |
| 1. The patient experience in Australia of long COVID and/or repeated COVID infections, particularly diagnosis and treatment; | \* “The nature of my child’s disability is such that he has extreme anxiety around medical systems and procedures, so we haven’t managed to have him successfully vaccinated for Covid. He’s now had Covid twice, three months apart, and although his symptoms were mild at the time, he now has ongoing complaints of feeling tired, nauseous, and having sore muscles. We’ve mentioned it to our paediatrician, but she didn’t have an answer or plan to deal with this. We have no idea what, if any, next steps to take”. |
| 4. The health, social, educational and economic impacts in Australia on individuals who develop long COVID and/or have repeated COVID infections, their families, and the broader community, including for groups that face a greater risk of serious illness due to factors such as age, existing health conditions, disability and background; | CYDA respectfully challenges the terms of reference by pointing out that vulnerable cohorts, such as children and young people with disability, are experiencing a non-symptomatic form of long covid in that they have little choice but to alter and restrict their lives in detrimental ways as a response to the inadequate approach of all levels of government.  \* “My child began prep this year and has had a lot of problems settling. He often tells us he’s tired and doesn’t want to go and we get calls from the school regularly to pick him up early because he’s feeling unwell. We cannot separate the impact of the Covid infections on this situation from the impairments of his disability. Either way, both parents in our family have had to significantly reduce the hours we spend in paid employment, and we’re really worried about the implications of this as well as our child’s ongoing health”. |

\*Response from parent of a child with disability