



Submission to the Disability Royal Commission: Emergency Planning and Response during COVID-19

Submission by Children and Young People with Disability Australia, 28 May 2020

Children and Young People with Disability Australia (CYDA) is the national representative organisation for children and young people with disability aged 0-25 years. CYDA has an extensive national membership of over 5,000 young people with disability, families and caregivers of children with disability, with the majority of our members being families.

CYDA's purpose is to advocate systemically at the national level for the rights and interests of all children and young people with disability living in Australia. To do this, we focus on the following:

- Listening and responding to the voices and experiences of children and young people with disability
- Advocating for children and young people with disability for equal opportunities, participation and inclusion in the Australian community
- Educating national public policy-makers and the broader community about the experiences of children and young people with disability
- Informing children and young people with disability, their families and caregivers about their citizenship rights and entitlements
- Celebrating the successes and achievements of children and young people with disability.

CYDA appreciates the opportunity to provide this brief submission to the Disability Royal Commission in response to the **Emergency Planning and Response Issues Paper**.

In mid-March 2020, when the extent of the coronavirus pandemic was becoming clear, CYDA identified that Australia lacked a coherent national information strategy and response for children and young people with disability. While swift responses were formulated in relation to some 'vulnerable' groups, for example people living in aged care facilities, there was a clear gap in relation to children and young people with disability and their families.

To collect data from this cohort, we conducted an online survey for five weeks from mid-March to late April. With over 700 responses received, the survey results show the COVID-19 pandemic has exacerbated the daily inequities faced by children and young people with disability and their families and caregivers, and has had additional unexpected impacts.

CYDA partnered with researchers from the Public Service Research Group at the University of New South Wales in Canberra to analyse the survey results, leading to the development of a joint report, [*More than isolated: the experience of children and young people with disability and their families during the COVID-19 pandemic*](#). We are pleased to enclose a copy of this report to form our submission to the Disability Royal Commission. A brief overview of key findings and recommendations from the report is also included below.

Key findings:

- Survey responses clearly demonstrated that people felt like there was a general lack of information about the coronavirus targeted to children and young people with disability and their families, with 82% stating they lacked information. Moreover, lack of information targeted to the particular needs of households was exacerbating distress and uncertainty.
- Uncertainty about education was a prominent theme, including school closures and challenges with learning from home, and concern that progress gained by children and young people with disability would be lost during this period.
- Half of survey respondents experienced a decline in their mental health either for themselves or for the child or young person with disability. This increased over the period of the survey.
- The majority of respondents were unable to buy essential supplies, e.g. groceries, special dietary products, hygiene products, which peaked at the commencement of the pandemic period.
- One in three respondents experienced cancellation of support workers (either by self or service) and NDIS services.
- There was significant concern in survey responses that people might lose work or be required to give up work due to the COVID-19 pandemic, and this would have an impact on household income.
- There were a range of health issues including inability to access COVID-19 testing, telehealth being inaccessible and fear of engaging with health services.

These findings demonstrate a clear need for action to address the challenges children and young people with disability, their families and carers face during this time of crisis and on the 'road out.' The pandemic is also a reminder of the ongoing inequalities and exclusion children and young people with disability experienced before the crisis that have been intensified during this time.

What these findings highlight is the systemic neglect that children and young people with disability face in all aspects of emergency planning and responses in Australia. Their vulnerability to pandemics and emergencies is heightened for a range of reasons. As 55 per cent of NDIS participants are aged under 25, any disruptions to the service system are likely to have a large impact on this cohort, and needs to be planned for and responded to with great care. While the NDIA did much work to address concerns during the pandemic resulting in far greater flexibility, because of inadequate emergency planning there were lags in support. Additionally the education settings children and young people attend are likely to close or be compromised when emergencies occur. This exacerbates the existing disadvantage and discrimination they face in their education.

In response to the systemic neglect in education that families and young people with disability were escalating with us, the Australian Coalition for Inclusive Education, which CYDA chairs and co-convenes developed [principles and recommendations for providing inclusive education in a time of crisis](#). On 24 April 2020 the ACIE wrote to every Education and Disability Minister in Australia about the challenges being faced by children and young people with disability and their families in their education at during the COVID-19 pandemic, providing these principles and recommendations, and invited them to a national roundtable to discuss these issues. This was held on 20 May 2020.

CYDA is also currently conducting a national survey exploring the educational experiences of children and young people during this time. We expect to have the results available in July 2020 and we will provide the results in future submissions to the Disability Royal Commission responding to both the Education and Emergency Planning and Response Issues Papers.

Recommendations:

1. *Address inequities for children and young people with disability in Australia* – The new National Disability Strategy currently being developed has a strong focus on reducing the inequity, discrimination, neglect and abuse faced by children and young people with disability across health, education, disability support and community participation. This requires the strategy has clear and measurable outcomes, transparency, accountability and appropriate resourcing.
2. *Urgently provide appropriate information* – The Australian and state and territory governments immediately boost relevant and accessible information is available and targeted towards children and young people with disability and their families and caregivers. Our report shows the impacts for children and young people with disability which means the ‘road out’ is going to be longer and harder for them.
3. *Reduce fragmentation* – Support jurisdictions to work together to deliver consistent, evidence-based advice and messaging to children and young people and their families and caregivers. This includes defining the responsibilities of different jurisdictions and service systems and maintaining accountability for the delivery of supports.
4. *Increase accountability and transparency* – The Australian government collects and reports data on the impacts of the COVID-19 situation on ‘at-risk’ groups and commissions research and analysis which tracks impacts over time.
5. *Ensure access to support* – Ensure children and young people with disability, their families and carers have access to the support and services they need – when and where they are needed. This includes extending the COVID-19 supplement to Disability Support Pension and Carers Allowance recipients, and further increasing the flexibility of the NDIS.
6. *Consider the intersections* – Design and implement an intersectional approach to planning the road out, to address overlapping issues affecting children and young people with disability including education, NDIS, health and employment.
7. *Respond to lived experience* – Build the voices and experiences of children and young people with disability and their families and caregivers into emergency planning and response at the national and state levels. This should be in the current pandemic crisis and for future emergency planning.
8. *Recognise and appropriately fund disability advocacy for children and young people with disability and their families* – Disability advocacy organisations like CYDA (funded by the Australian Government) and state and territory based advocacy organisations have been swamped during the COVID-19 situation. In some jurisdictions there are no funded disability advocacy organisations particularly providing individual advocacy for children and young people. This is despite the fact that 55 per cent of NDIS participants are aged under 25, and the well-known discrimination and disadvantage they face in their education, health and other aspects of their lives. Boosting funding for disability advocacy will assist

in ameliorating the disadvantage and inequity children and young people with disability face.

Thank you for the opportunity to provide our submission to the Disability Royal Commission. Should you wish to discuss any of the information contained in our submission further please do not hesitate to contact me on 03 9417 1025 or marysayers@cyda.org.au

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