

Submission
No 48

**INQUIRY INTO CHILDREN AND YOUNG PEOPLE WITH
DISABILITY IN NEW SOUTH WALES EDUCATIONAL
SETTINGS**

Organisation: HeartKids

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29 February 2024

The Secretariat
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SUBMISSION: Enquiry into children and young people with disability in New South Wales educational settings

[HeartKids](#) is pleased government is committed to supporting and strengthening the educational sector to support children with disabilities. HeartKids are the only national not-for-profit organisation solely focused on supporting and advocating for all people impacted by Childhood-onset Heart Disease (CoHD), a chronic health condition that impacts 1 in 100 babies born in Australia. We seek to give every child, teenager, and adult in Australia with childhood acquired heart disease a fighting chance to live a long, healthy, and fulfilling life.

Childhood onset Heart Disease, covers both congenital and childhood acquired heart conditions¹. Of the 1 in 100 children born in Australia with a Congenital Heart Defect (CHD), we know that approximately half of these children will require surgical intervention before the age of one. Similarly as surgical interventions are improving, mortality rates of children born with CHD have significantly decreased, and neurodevelopmental disabilities are common and potentially the most significant comorbidity. Recent studies such as the Queensland Health Department Pink Book², indicate that as more children with CoHD are surviving into adulthood, many are left with substantial developmental delays including physical, intellectual, psychological, and social difficulties, leading to an increased burden upon families, health care systems and educational facilities. There is a risk that an absence of caregiver activation and monitoring of neurodevelopment can delay referral to early supports and intervention services, which may negatively impact developmental outcomes and limit children from achieving their full potential.

As identified in the Australian National Standards of Care for Childhood-onset Heart Disease¹ for CoHD families living in regional and remote communities there is also a benefit to enabling coordinated high quality care close to home, reducing isolation, financial strain, and anxieties and trauma which may impact on mental health.

¹ Australian National Standards of Care for Childhood-onset Heart Disease.
<https://cohdnationalstandards.com.au/>

² Pink Book – Supporting the long-term developmental needs of children with congenital heart disease and their families (Queensland Health Department)
https://www.childrens.health.qld.gov.au/_data/assets/pdf_file/0021/180516/pink-book.pdf

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Access to specialist Early Childhood Intervention programs for children with chronic health conditions like CoHD across NSW, would assist in closing the health care gap for children who currently do not qualify for the NDIS. With just under 40% of the NSW population living in regional and remote communities³ there is a demand for targeted, integrated care for families affected by CoHD in these communities. HeartKids (with appropriate funding) are able to deliver specialist, integrated support services to families affected by CoHD across NSW through: Face to face assessments, Telehealth services, Partnerships and referral pathways with existing regional health services, and Peer Support Programs. Allowing these children to commence their educational journey at near parity with other children and relieve the educational burden of providing ongoing in classroom support.

In closing, HeartKids, as the only national charity solely focused on supporting individuals and families impacted by CoHD, strongly advocates for increased screening and appropriate referral to early intervention pathways, to enable a holistic model of care for these children. If you require any additional information, or would like to understand more about the work of HeartKids please don't hesitate to contact me on

Yours Sincerely,

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³ Australian Community Profile <https://profile.id.com.au/australia/population?WebID=180>

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