



6 November 2023

Secretariat - Community Services Advisory Group
GPO Box 9820
Department of Social Services
Canberra ACT 2601

RE: CONSULTATION - STRONGER, MORE DIVERSE AND INDEPENDENT COMMUNITY SECTOR

HeartKids is pleased government is committed to supporting and strengthening the community sector and ensuring a sustainable future to continue to deliver supports and services that improve the wellbeing of individuals and families impacted by Childhood-onset Heart Disease (CoHD). We are the only national not-for-profit organisation solely focused on supporting and advocating for all people impacted by CoHD, one of the largest causes of infant death in Australia. We seek to give every child, teenager, and adult in Australia with congenital or childhood acquired heart disease a fighting chance to live a long, healthy, and fulfilling life.

As a national charity the majority of our annual \$5M revenue comes directly from community fundraising and donations, with the remaining 40% of revenue derived from grants. State and/or Commonwealth grants make up just over half of our grant income, with the remaining portion derived from trusts, club grants, Community Hub grants and small annual grants (\$10K - \$50K).

HeartKids is grateful for grant revenue, although we support ensuring grants reflect the actual cost of delivering quality services to the community. Often grants have restrictions or exclusions which provide challenges to optimally deliver the actual cost of quality services. This can be in the form of the grant not supporting investment in capital or hardware costs, limited (or no) allowance for overhead or infrastructure costs or where actual salary and wage costs exceed market expectations. The opportunity to absorb infrastructure, capital, equipment costs is limited for a small charity, as is the capacity to scale programs if funding for salaries and wages is limited. In some instances, programs have to be scaled back to fit within the grant funding, which increases the risk of program failure and reduced impact for the CoHD community as key aspects of the program may have to be omitted and/or the program is unable to be delivered at all.

In 2019 HeartKids received a Commonwealth Grant to deliver the National Strategic Action Plan for Childhood Heart Disease. Our experience indicates the establishment of new national programs, new models of services, and the development of professional resources all take time. This is due in part to the need to undertake meaningful consultation and engagement with the community (in this instance individuals, families, health care professionals and a broad support network). The development of strong relationships with key stakeholders, and the resultant confidence and understanding, requires patience and persistence to nurture relationships to get the best results. Now in its fourth year (second tranche of 3-year funding) the program is starting to see the benefits of the longer-term investment with greater traction within the CoHD community only just being realised.

Last year HeartKids was the recipient of a 4-year SA Government Grant to provide three vital services –

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Community Support Services for families affected by CHD in regional and remote communities, minimising geographical isolation and financial burden; a mental health and well-being program to reduce the impact of medical PTSD on families living with CHD; and an Early Childhood Intervention Program for children who had heart surgery before the age of one, reducing the risk of neuro-developmental delay. Now in the second year of funding, the programs have evolved to improve engagement and ensure appropriate data collection in key deliverables to demonstrate the programs successes. Whilst the significant benefits of the programs are being realised for families in SA, as a small charity the capacity to undertake economic analysis of these programs and demonstrate a strong return on investment to government in these early stages is also limited.

Whilst now a national entity, HeartKids has evolved from a grassroots organisation with well embedded relationships and is recognised as a trusted community partner with strong local links. Our national profile, with local representation, enables HeartKids to be able to identify and understand key issues for the community. Additionally, we have the capacity to deliver a standardised best practice model of support directly to areas of need. However, fragmented grant funding means we are only able to deliver some of our newer innovative models of support to locations that have received State based financial support. Whilst we attempt to offer these programs in other unfunded States through donations and community grants, the limited funds and uncertainty of continuous funding creates a range of challenges, including attracting and retaining suitably qualified personnel.

Whilst the HeartKids business model is strongly supported by a large volunteer base, who can provide significant assistance with events and fundraising, the demand for quality services from suitably qualified professionals continues to exceed our capacity to deliver our model of support in the absence of secure funding.

In closing, HeartKids (as the only national charity supporting individuals and families impacted by CoHD) strongly advocates for appropriately funded multi-year government grants to provide stability of programs, opportunity to develop and evolve evidence-based programs and resources, and better meet the growing demand for support to the CoHD community. If you require any additional information, please don't hesitate to contact me on [REDACTED] or [REDACTED]

Yours Sincerely,

[REDACTED]

[REDACTED]

CEO

HeartKids Limited

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Supporting heart kids through life

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