HeartKids Australia

Submission for the Productivity Commission into Disability Care and Support

This submission is presented by HeartKids Australia, representing all those affected by Congenital Heart Disease (CHD) in Australia. Congenital Heart Disease is the most common birth abnormality, affecting approximately 1 in every hundred love births. This equates to 6 children every day and over 2000 each year. Alarmingly Congenital Heart Disease is still one of the leading causes of infant death, (35%) taking more lives than all other childhood diseases and twice that of childhood cancers.

Figures indicate that there are approximately 80,000 people in Australia with such conditions and with increased survival rates, we observe that for the first time in our history we have the same number of people over 18, as those under 18, living with CHD. Sources: Australian Institute of Health and Welfare, Australian Bureau of Statistics, American Heart Association, CONCOR Study.

Whilst about ½ of these conditions could be classes as minor, the rest often require significant medical intervention in the form of surgery and medication. For this group, the impact on the family and the need to ongoing care is often extreme, resulting in many families being left destitute as a result of having to relocate to a capital city for many months and through the medical support needs of the child. In many cases, ongoing surgery is required throughout their lives. Of the five major capital cities, only 2 provide facilities for the more complex CHD operations, resulting in many hundreds of families having to travel interstate.

HeartKids recognises the need to differentiate support needs for these two groups and suggests using the filter of support only being offered to those whose children require surgery.

Whilst care and support differs from State to State, many of our parents report significant difficulty in obtaining any support and financial hardship as a result of them having to cease work to be with their child. For those living in rural and remote areas of Australia, the issue of travel and the limited support on offer is also a major factor.

The most severely affected children have a major disability (sometimes not only affecting their heart) and they need permanent lifelong fulltime care - and usually one parent at least has to give up work to provide this care. This is the type of situation where we seek your support to develop/provide a national disability support scheme (no fault) which would be INVALUABLE and is overdue. Although these severe cases are a minority of all cases of CHD, these seriously affected children are really deserving of proper support. Therefore we are very supportive of a more equitable scheme.

Another issue for a percentage of those living with CHD is the factor of white matter brain injury. Research shows that between 10 and 50% of all people living with CHD will have some form of brain injury. This can be severe, but usually manifests itself in the form of slightly lower IQ and issues with concentration. (Brown MD Clinical Perinatol 2005;32) Many of the families affected, report issues with their child’s schooling and of the lack of testing and support. This has the long term effect of many teens and adults not being adequately prepared for the work force, resulting in high levels of unemployment, low self esteems and depression.

The other major issue for our parents and the clinicians who work to support them is the lack of a tick box for CHD on the Centrelink Carers Allowance Form TDR. It has been noted that a number of other conditions (which appear to be far less debilitating) are provided with this option. This results in a major hurdle being put in front of parents at their greatest time of need and when they are in desperate need of support. Whilst this relates to all States, it is more extreme in States such as South Australia, Tasmania and the Northern Territory who are required to travel interstate for their heart operations. Often the whole family has to relocate and parents report issues such as lack of funding or places in Day Care.

It should be appreciated that there is no ‘cure’ as such for CHD. Whilst we have an ever increasing cohort of teens and young adults surviving and living with CHD, many require ongoing specialised care to address their medical needs.

It should also be appreciated that many of those affected by CHD have challenges with their education, employment, psycho social issues, side effects of medications as well as the need for specialised support/advice relating to the use of drugs, pregnancy, smoking and alcohol.

Recommendations:

1. It is recommended that the Australian Government review disability and carer payments to ensure children and adults with congenital heart disease are not discriminated within the funding models.
2. That a tick box for CHD be provided on the Centrelink Carers Allowance Form TDR for those people whose children require surgery.
3. (As recommended by the NHHRC) That the Australian Government work with the State and Territory Governments to ensure the provision of more equitable coverage of the travel and accommodation costs for families required to travel to the designated CHD specialist centres.
4. That the Australian and/or State Governments ensure the designated care hubs have the required level of qualified staff and appropriate facilities to meet the population needs, including the required psychological care and social and neuro-developmental follow-up, supported by local health professionals.
5. Urgent need for prospective evaluation at key transition points in the child’s development with adapted assessment tools
6. Need to assess/evaluate for a range learning disabilities, speech, language, fine motor skills, and behavior (not just ‘IQ’)
7. Need to better inform schools about the incidence, consequences, management and potential developmental, behavioural, social and learning issues relating to children affected by CHD.

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