



A national voice for families of children with a disability

Submission No. 581
(Inq into better support for carers)

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Committee Secretary
Inquiry into Better Support for Carers
House of Representatives Standing Committee on Family, Community, Housing and Youth
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To Whom It May Concern:

Australian Association for Families of Children with a Disability submission to the Inquiry into Better Support for Carers

The Australian Association for Families of Children with a Disability (AAFCD) welcomes the Parliamentary Inquiry into Better Support for Carers and believes that it will provide the Australian Government with the opportunity to improve real outcomes for carers and the people that they are caring for.

AAFCD is a national organisation representing families of children with a disability. We are recognised and funded as a national peak body through the Department of Families, Housing, Communities and Indigenous Affairs (FaHCSIA). We are a non-profit, community organisation run by families, for all families who have a child with any type of disability.

AAFCD:

- **Educate** national public policy-makers and the broader community about the needs of families of children with a disability.
- **Advocate** on behalf of children with a disability and their families to ensure the best possible support and services are available from government and the community.
- **Inform** families of children with a disability about their rights and entitlements to services and support.
- **Celebrate** the successes and achievements of children with a disability and their families.

In our submission we address the terms of reference of the inquiry in the context of examining three central areas of reform:

- Real change and recognition of carers;
- Service system reform; and,
- Financial assistance for carers.

Real change and recognition for carers

AAFCD welcomes the Inquiry into Better Support for Carers, as it provides legitimate recognition by Government of the central role that carers play in the Australian community. While the very act of recognition is important, it is vital that this inquiry is

not about tokenistic measures or empty rhetoric that simply highlights how important carers are, without delivering real outcomes on the ground for carers and the people that they care for. Therefore it is essential that a commitment to funding the recommendations from the inquiry is articulated by Government.

The emphasis of the terms of reference of the inquiry on practical measures and strategies to assist carers in having equitable access to the same opportunities as other community members is important and AAFCD encourages the Committee to take on board the recommendations and suggestions that are presented by families of children with a disability, as well as other peak disability and carer groups. We also urge the Committee to take into account the recommendations that were developed as part of the Carer Payment (child) Review Taskforce.

If practical measures and strategies are going to be developed as a result of this inquiry it is essential that this is undertaken as a whole of government approach.

Carers, for example, do not only interact with the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). Carers, in some way or another, interact with the myriad of Federal government departments, as well as State, Territory and Local Government. Therefore, if this inquiry is truly committed to developing better support for carers, then a national approach is required to ensure a joined-up and cohesive response.

Many State, Territory and Local Government's have their own individual policy mechanisms that recognise the role of carers; however it is essential that there is also a national policy response that provides not only recognition of carers but also a legislative mandate for real change that will result in a positive impact on the lives of carers and their families. For example, a National Charter for Carers or an Office for Carers may be worthwhile policy responses. However if they are not accompanied by funding, on-going program resourcing and support, and mandated legislation then the impact will not reach beyond the rhetoric.

Carers, by their very nature and circumstances, are not a homogenous group. Every carer of a child with a disability is facing a different set of circumstances. Therefore practical strategies and measures need to be developed that respond to the needs of individual carers. Many States and Territories are currently shifting towards individualised supports and planning. It is essential that any recommendations resulting from the inquiry aimed at achieving better support for carers also reflect this policy shift.

Service system reform

The role and contribution of carers in Australia cannot be underestimated. For a long time the role of carers has been undervalued. In part, the contribution that carers make in the lives of the people that they are caring for has resulted in Government and society relying too heavily on the commitment of carers, particularly when planning and funding disability supports and services.

Caring is inextricably linked to service provision. If the people that carers are caring for were supported by a well-funded, accessible and affordable service system then many of the pressures and issues that carers are confronted with throughout their lives would be removed. If any changes are going to be implemented to better support carers, these need to be done as part of broader service system reform.

There is an urgent need for investment and policy reform in both disability services and supports for carers – this will be one way that the role and contribution of carers can be recognised. This recognition needs to be at a national level. It is essential that this inquiry and subsequent recommendations are fed into both the COAG and the Commonwealth State Territories Disability Agreement (CSTDA) renegotiation processes.

“I am sick of governments blaming each other for why nothing gets done for our families. You talk to the state politicians and they blame ‘the Feds’. You talk to someone in the Federal Government and they blame the states for everything bar the bad weather. They all seem more interested in passing the buck and blaming each other than actually getting on with the job and working together to DO SOMETHING FOR OUR FAMILIES!”

When federal and state/territory governments don't work well together, it costs our children and our families because scarce resources are wasted on unnecessary duplication of effort and bureaucracy. There needs to be a commitment to work in co-operation with state and territory governments to ensure that every available dollar of government funding to support children and adults with a disability and their families is well targeted and well spent.

If a whole-of-government approach is not taken, carers will continue to be under-resourced and under-valued, resulting not only in the need for more crisis supports but also increasing demands on an already over-stretched disability services system. This is why it is vital that carer policy reform be linked to broader services and supports.

Carers and the people that they are caring for need to be offered real choices when making decisions about their lives and the services that support them. Many families who are caring for their child with a disability on their own do so because they wish to, while others do so because, for many families, there are no alternatives. If there are no real choices for families then we will continue to see the exploitation and undervaluing of carers.

Carers need peace of mind that the service system that supports the person that they are caring for is accessible and of a high quality. Carers need to know that the service system will be there so that they can plan for the future.

“From the day we found out 15 years ago that our son had a disability, we have faced (and got through) many challenges. The first time I rang a service and asked for help was a day I'll always remember. It took a lot of courage for me to admit that we couldn't do it all on our own. We've been lucky over the years to have had the support of some great services but I am worried about the future. It is hard to imagine what life will be like in 10 years when our son will be 25. I am hoping by then that he might have somewhere to live and support to live independently”.

The advances of the past twenty-five years in the support available for our children and our families are at risk of unravelling due to political decision-makers not being prepared to acknowledge the demographic facts about disability and the Australian population, now and into the future. If Government honours a commitment to lifetime planning and access to supports for all people with a disability, then carers and people with a disability will have real choices.

If the Australian Government is truly dedicated to providing better support for carers then there needs to be a long-term commitment to increased public investment to

assist carers and children and young adults with a disability to lead full and independent lives, from the time of initial identification of disability, throughout childhood, the teenage years, early adulthood and later life.

There needs to be a new approach to lifetime planning for people with a disability. Lifetime planning principles need to include working co-operatively with states and territories to ensure that during the age of 18-25 years, every young adult with a disability is provided with supports and services to move to suitable out-of-home accommodation, with accompanying community and independent-living support.

A lifetime approach to support for carers and the people that they are caring for is essential. Currently there are a range of targeted supports for carers, such as supports for ageing carers. However there needs to be a commitment to support for carers throughout their caring lives. Anything less is not good enough for carers and their children.

Financial assistance for carers

"I need to go back to work. We need the money and I think I'm ready to do something other than just look after the kids and do the housework. Hopefully I am through the worst of the medical dramas with my daughter's disability, although I know, because of her needs, I'll only ever be able to work part-time. Having been out of the workforce for a while, I'm nervous about looking for a job and whether anybody will take me on. With all my focus having been on the kids and disability, I have lost a bit of confidence in myself when it comes to thinking about work. I haven't looked into the whole child care scene yet, but hopefully that will be OK. Unless I can find a job that gives me time off during school holidays, I am going to need help with care during the holidays, and maybe before or after school as well."

The costs of caring are astronomical. For many carers there are reduced opportunities for workforce participation, particularly given the limited availability of support services, such as supported accommodation, child care and respite. There is also an absence of industrial mechanisms that recognise the caring role.

Initiatives that encourage and support carers to return to the workforce are essential and need to be coupled with further investments to ensure that services and supports are available to assist them in this process. Not only does there need to be investment in the service system but there also needs to be supports for carers and employers to enable carers to return to work in an environment that is flexible and takes into account caring responsibilities.

Reduced workforce participation, as a result of increased caring responsibilities, has significantly impacted on the budgets of families, at a time when expenses are often at their highest. This is why AAFCD strongly encourages the Rudd Government to explore a National Disability Insurance Scheme for all people with a disability, as was put forward at the 2020 summit. A National Disability Insurance Scheme will provide a guaranteed mechanism of support.

As part of the broader Federal review of taxation that is going to be undertaken in the near future, the financial costs of caring need to be quantified and taken into consideration. Tax deductibility of caring expenses is one item that should be considered as part of this review.

The issue of superannuation is also something that should be looked into by Government, particularly for those people who are in receipt of the Carer Payment.

Caring is a lifelong responsibility and for many carers they have a limited opportunity to accumulate superannuation due to their caring responsibilities. It seems unfair that carers should face financial insecurity in their old age because they chose to take on a caring role. A national superannuation scheme for carers should be considered and AAFCD supports the work undertaken by Carers Australia and others on this issue.

AAFCD would like to continue to participate in the Inquiry into Better Support for Carers and we would like the opportunity to appear as a witness at the public hearings that are scheduled in Melbourne for August 12 and 13 2008. If AAFCD can further assist with this inquiry please do not hesitate to contact us for more information.

Yours sincerely,



Elizabeth McGarry
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Australian Association for Families of Children with a Disability