

CARER INQUIRY

These three issues would have the most beneficial impact on the lives of carers. They are important because they supersede yet relate to each term of reference.

1. Find avenues for carers as a whole to achieve more effective representation in Federal and State Governments.
2. Ensure all Federal and State Carer legislation is regularly reviewed, is consistent Australia wide and is acted upon.
3. Carers in Australia are a large group so they should have genuine opportunities for their collective voice to be heard at all levels of Government. This can be achieved if peak State and Federal carer bodies/advocacy groups are:
 - democratically elected by a majority of (all types) of carers.
 - given adequate resources to fulfill their roles (carer support, research, advocacy, information etc.)
 - able to function autonomously so that they can always act in the best interests of all carers.

The role and contribution of carers in society and how this should be recognised.

When carers/families take on caring roles there are direct benefits to the community such as reduced costs to taxpayers and indirect benefits such as improved quality of lives for 'carees'. In our personal caring situation if we were not able to take on our caring role for our adult son then there would theoretically be payment for professional carers to replace us for our son's daytime and night-time personal care, medical and health emergencies, daily activities, recreational activities and transport costs (substantial costs for accessible van). We are largely uncompensated. If we didn't do what we do then our son would enjoy a lesser quality of life so we accept the resulting financial insecurity.

Adequate carer support such as information, respite and networking is critical and is a means by which the contribution of carers can be recognised. To what extent such support is available and tailored to all carers and whether it is available at an adequate level is questionable. Better carer supports will obviously lead to savings for Government in caring related expenditure (respite, high cost accommodation etc.). What is equally important is the depressing level of direct support available for 'carees' who include people with disabilities and people with mental health issues. This poor direct 'caree' support has a substantial negative impact on the lives of carers. (see below)

The barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment.

Employers often aren't aware if any of their employees are carers or the extent of their caring role and hence fail to consider the need for special consideration. Similarly local communities and Local Governments are often not aware of carers in their midst. This is because such families tend to be isolated with neighbours and even immediate relatives not often wishing to become involved. Education programs need to be implemented for Government and private sector employers (including education on carer related legislative requirements) so carers can be more readily identified and adjustments made to help the carer's employment situation.

Young carers deserve special consideration in terms of identification and then improving their networks and other supports to reduce their caring role and allow social participation at an important stage of their lives.

The practical measures required to better support carers, including key priorities for action.

- 1) Identify and acknowledge the effects of the relationship between carers and 'carees'. This relationship can be complex and appears to be ignored by Government and carer/advocacy bodies (partly because of those bodies' funding criteria). Lack of adequate supports for the 'caree' (e.g. equipment, information, specialised medical support, transport, therapy, post school supports, education, recreation etc.) means that the lives of carers take on unnecessary challenges. Conversely adequate supports in such areas will improve the health and well-being of carers. Carers who rely on Government funded disability services are especially challenged as these services are poor and compound the stress on carers. Implementing all recommendations of the Senate review of the CSTDA¹ would be the first step to a solution.

¹ http://www.apf.gov.au/senate/committee/clac_ctte/completed_inquiries/2004-07/cstda/report/index.htm

- 2) Acknowledge (in funding arrangements especially) that different responses are appropriate for different types of carers. For example the needs of a families having young children with disabilities who may face many years of caring are substantially different to the needs of elderly people caring for their partners.
- 3) Provide better monitoring and better responses to the rapidly changing needs and situations for families caring for children with disabilities so as to provide supports when needed. These supports include:
 - a) Early intervention facilitating social and other support networks.
 - b) Housing and related accessibility.
 - c) Transport and specialised transport requirements.
 - d) Medical and therapy requirements of the person being cared for.
 - e) Special education support.
 - f) Equipment requirements (wheelchairs, ramps, hoists, continence aids, communication aids, etc)
 - g) Counselling including relationship counselling.
 - h) Supports for siblings of the caree.
- 4) Provide preventative programs that concentrate on areas of health that can alleviate caring stress (physio, mental health etc). Provide some form of subsidised or priority hospital care for carers as the cost of private health care is prohibitive, especially for older carers who are ineligible for the Government Lifetime Health Cover concession.
- 5) For carers who are Centrelink Carer Payment recipients their payments should be increased to better reflect the work they do and the opportunities they lose for employment, superannuation, education etc. These payments should also as far as possible be related to the level of care provided, varying when more intense care is provided e.g. post-operative. Give consideration to providing direct services (laundry, medical supplies, meals, house cleaning etc.) in lieu of cash payment as an addition to the basic carer payment.
- 6) Ensure the training, experience and knowledge of professional carers used in respite situations (that give carers a break) are underpinned by adequate qualifications and adequate remuneration levels.
- 7) Ensure Federal and State Government agencies remove many of the practical and administrative hurdles placed in the way of carers. (e.g. unnecessary duplication of information by Centrelink, Disability Services)

Strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

- 1) Carers' choice of service should be facilitated by the introduction of individualised and self managed mechanisms that empower carers to make those choices and place them at the centre of decision making processes. **(See attachment A - submission to 2020 Summit)**. If such mechanisms are thoroughly researched and properly implemented then there are likely to be cost savings for Government as a result. Maximizing Government carer related expenditure at the carer 'coal face' should be a priority.
 - 2) More effective planning for the future could be achieved by improving assistance for succession planning through subsidised access to the specialised areas of financial planning, taxation, wills, trusts etc. The Government would benefit financially in the long term if contributions to Special Disability Trusts were allowed for carers who are under the age pension age.
-

ATTACHMENT A

Cale

STRENGTHENING COMMUNITIES, SUPPORTING FAMILIES AND SOCIAL INCLUSION**People with disability and family carers.**

Australia trails world leaders in terms of models of support for people with disability and their family carers. Effective support is critical for individuals and families, leading to their social inclusion and ultimately stronger communities.

Over the last twenty years the United Kingdom stands out regarding the development of models of support that are conducive to independence and inclusion. Recent presentations in Australia by Simon Duffy², Chief Executive for the UK organization 'in Control'³ have highlighted how far Australia is behind. These UK models of support meet the whole of life needs of the person with disability, places the person and family in control and ensure there is accountability for funds.

In Australia many people with disabilities and their family carers have been handicapped not by their disabilities but by the systems that support them. Support systems in Australia have functioned to exclude people with disabilities and their family carers from the centre of decision making processes. It has therefore been difficult for these people to achieve self determination and independence which in turn can help them improve their health, well-being and quality of life and ultimately their participation in their local communities (social inclusion).

A few independent organizations such as the Julia Farr Association in South Australia are promoting such models⁴ despite reticence from State and Federal Governments and established service providers who may not understand the importance of self determination to people with disabilities and their family carers.

Research into and implementation of the best models of individualized planning and self directed support needs to be progressed urgently. Chapter 6, Recommendation 25 of the Senate Community Affairs Committee Report⁵ into the 'Funding and operation of the Commonwealth State/Territory Disability Agreement' comments on perceived benefits and limitations of individualized funding models.

Models must focus on individual and family capabilities and aspirations and offer them control of their services and lives without shifting costs from Government to the individuals/families themselves. Our outdated support systems will have to become more cost effective as demands for disability support increase because of our ageing population. Individualized planning and self directed support can provide a solution that will satisfy the new demands on Government for disability and carer support and at the same time ensure social inclusion for recipients.

² <http://homepage.mac.com/simonduffy/Menu3.html>

³ <http://in-control.org.uk/>

⁴ http://www.juliafarr.org.au/individualised_funding.asp

⁵ http://www.aph.gov.au/senate/committee/clac_ctte/completed_inquiries/2004-07/cstda/report/index.htm