

Liz

To: The Secretary of the House Standing Committee on Family, Community, Housing and Youth

### **Inquiry into Better Support for Carers**

#### **Terms of Reference Relevant to this Submission**

To obtain an improved understanding of the challenges facing carers and their support needs, the committee will inquire into and report on:

- the role and contribution of carers in society and how this should be recognised;
- the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;
- the practical measures required to better support carers, including key priorities for action; and
- 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.

#### **Background**

Disability is an inherent part of the human condition. In all sections of the community, disability is another pervasive dimension of human diversity like gender, race and culture. Almost every Australian family has been touched by caring for a family member with a disability, or knows of a family doing so. Many of these families fall through a huge gap in Australia's social services network. With the numbers of Australians with a disability increasing all the time, this issue affects every one of us.

A significant proportion of people with a disability live in poverty. As parent of a child with a severe disability I am afraid that if further changes are not made, my son, in the future, will still be dependent on a myriad of different funding arrangements offered by federal, state and local government as well as not for profit, private, and philanthropic organizations to cater for his needs. Consequently as his ageing parent I will have to continue to manage his care and the increasing concern of how he will get along when we are no longer around- Whether he will indeed end up in a Nursing home or some other home that does not understand his individual needs or respect his independence.

The time is right to reform the disability sector: to shift from the current crisis-driven welfare approach to a planned and fully-funded scheme that will underwrite

sustained, significant, long-term improvements in meeting the needs of people with disabilities and their families.

The cost of caring for people with disabilities represents a very large unfunded liability. In the next 15 to 20 years, the size of this unfunded liability will grow significantly due to increasing incidence of disability at birth<sup>1</sup> (older mothers, IVF and increased survival rates amongst very low birth-weight babies), increasing numbers of people with acquired brain injuries (due to alcohol and substance abuse, and domestic and street violence), people with disabilities living longer and others acquiring disabilities as they grow older.

Based on population projections, Australia's population will increase by around 3 million people over the next 15 years and almost 2 in every 5 of these people will have or acquire a disability.<sup>2</sup> At the same time the community's capacity to provide informal care will decline sharply; from 57 carers per 100 older persons needing help to 31.<sup>3</sup> We need to plan ahead before the current unmet and under-met needs become overwhelming. The situation is similar to the problem of an ageing population which led to the introduction of compulsory superannuation.

People with disabilities, and those that care for them should have economic control over the system that delivers the services they rely on to be an active and valued members of society. People with disabilities and carers should have the same rights, choices and control over their lives as all Australians. It entails allowing people with disabilities to be empowered so that they may undertake the same risks as others and resist a paternalism that fosters dependence. The system should be one where people know what they are entitled to and can control their money as much as they want. The system should be aimed at Self-Directed Support. The framework should **believe** people who need support can control their own lives and be full citizens - using Individual Budgets as part of their Self-Directed Support. It would provide a unique partnership between families, individuals, services, local authorities, Government and many other organisations. All these areas should work together to define best practice in Self-Directed Support and Individual Budgets.

## Issues

Too often funding is taken by the administration, of managing the risk and governance. A significant proportion is spent on ensuring the system isn't taken advantage of by the minority, with the aim of avoiding litigation or unfavourable media. This can lead to services being denied due to funding restrictions or limiting guidelines. Some specific examples I have experienced are outlined below:

- 1) Our family cannot access HACC funding for respite for times when my son requires feeding as he relies on a PEG feed- this is seen as a medical procedure.
- 2) My son attended a mainstream childcare for 3 days per week, so I could attend work. The childcare were able to access SNSS funding to support the childcare to include him. The funding guidelines have been changed to make it more difficult for childcares to access for children with complex needs ie

PEG therefore it would be unlikely that he would have been able to access childcare. If this was the case I wouldn't have been able to work and would now economically and psychologically disadvantaged, most likely severely depressed. This is one example of the consequences of risk averse bureaucrats making subtle changes to funding guidelines.

- 3) I recently called our local council who provides the HACC funded respite, service about having access to 4 hours respite during school holidays. I was informed that I could not use this service for respite as I was attending work. 7.9.1 states that the respite services "provide a service which responds to the individual needs of both carer and the person being cared for"- but then goes on to state "Respite is not available to provide care while the usual carer undertakes paid employment or unpaid volunteer work" (*HACC guidelines*)

In then goes on further to state in section 7.9.2 F Consumer Focused Approach "what is the best way to support this person in their caring role? What is the most consumer friendly and resource efficient option to choose" Respite providers are encouraged to be flexible, responsive and innovative in the provision of direct care" (*HACC guidelines*)

7.9.7 section A states under the heading Supporting the Caring Role it states "different carers will have different ideas of what a break means for them." (*HACC guidelines*)

It appears that by stipulating that respite under the HACC system can't be used to undertake paid work ,that there is no consumer choice and it is in contradiction to the idea of providing this support to maintain independence, as what better way of being independent is there for a family, than to have financial independence by being able to be an active member in the workforce. It is not responding to our needs as consumers, and does not support us in our caring role- as carers we just want what every other family has and takes for granted financial independence and the ability to access resources and make choices about the services we are provided so as to maintain our work/caring balance.

## **Recommendations**

- A Risk Enablement Panel is established to manage risk appropriately when developing policies – the policies are designed to support a quality of life, and should be less focused on the management of risk. This requires an element of Trust.
- Allow individuals and families have more control over their funding, ownership and are self directed to provide true flexibility and consumer choice.
- Create partnerships with service providers, business and government to develop an independent living account for people with disabilities. This private scheme would be administered by and for people with a disability, or their representatives, to purchase the services and equipment they require to truly become an independent and active member of society for life.

- Support the 2020 submission for the **National Disability Insurance Scheme (NDIS)** to cover the growing costs of disability, which is a risk faced by everyone in the community. This should be a fully-funded universal **National Disability Insurance Scheme (NDIS)**. It could be funded from a number of sources, including as a special supplement to the Medicare levy, third party car insurance and/or workplace insurance.

The models for a NDIS already exist, as there are already fully-funded no-fault insurance schemes to meet the needs of people injured in the workplace in NSW, Victoria, SA, NT and the Commonwealth and in car accidents in NSW, Victoria and Tasmania.

The costs would be modest (as little as an additional \$20 per annum on third party car insurance premiums in Victoria to cover all catastrophic injuries) and the benefits significant because a National Disability Insurance Scheme would be much more equitable than current arrangements (where a few can get multi-million dollar payouts and many others with similar disabilities nothing) and enable people with disabilities and their carers to be in control, make choices and plan their lives with confidence.<sup>4</sup>

*1 Victorian Birth Defects Reports and other sources*

*2 Estimates calculated based on ABS Disability Australia, 2003, ABS Disability, Ageing and Carers, Australia, 2003, ABS Population Projections, 2004 to 2101*

*3 National Centre for Social and Economic Modelling (NATSEM) 2004. Who's going to care? Informal care and an ageing population. Report prepared for Carers Australia*

*4 Bruce Bonyhady, Chairman, Yooralla and President, Philanthropy Australia  
Helen Sykes, Chair, The James Maccready-Bryan Foundation*