

Submission No. 763

(Inq into better support for carers)

AOC 15/7/08

GEELONG PARENT NETWORK

BETTER CARE FOR OUR CARERS

**Submission to a Federal Parliamentary Inquiry
July 2008**

Contact: Mrs. Dot Leigh
91 Augustine Dve
Highton, Vic 3216

Phone: (03) 5244 4622
Email: barbara.brian@bigpond.com

ABOUT THE GEELONG PARENT NETWORK

Geelong Parent Network is made up of members who are lifelong family carers of people with intellectual disabilities in the Geelong Region. The Network was an initiative of VALID (Victorian Advocacy for Individuals with Disability) to provide a forum, support and voice for family carers. Most persons being cared for have an intellectual disability of some form and often other disabilities as well. They receive services from a wide variety of disability and community agencies throughout Geelong.

Summary highlights

‘Lifelong caring’ is where most of our members find themselves. Most have a son or daughter with intellectual disability or autism and in most cases the person with the disability is living full time in the family home. (p.3)

Lifetime caring receives little research attention and is neither well understood nor appreciated. (p.3)

The social lives of parent-carers are restricted primarily because they are built around the interests and needs of their sons and daughters with lifelong disabilities. (p.3)

Increasing age of parent-carers places significant strains on the parent-caring relationship. Caring roles find no relief in later middle age with retirement or children becoming independent as it does with most of the population. (p.4)

The overwhelming challenge and concern for parent-carers is what will happen to our sons or daughters when we are not able to care for them. The ‘biggest issue of all’ is future accommodation and support. ((p.4)

Parent-carers have a reasonable cynicism after decades of living with and adapting to government policy shifts and practices. (p.4-5)

Parent-carers become ‘experts’ although their ‘lay knowledge’ is not generally highly regarded by professionals, nor governments in their policies and practices. (p.7)

Development of supports for lifelong carers should be based on family care partnerships that will create more certain futures for both of them. One model that might be explored was developed in the United Kingdom based on that Government’s White Paper, *Valuing People*. “One size will not fit all” in addressing how caring can be better supported. (p.8)

There is much said and written over recent years about ‘community strengthening’, ‘community inclusion’ and ‘community participation. Members of the Geelong Parent Network welcome this inquiry which focuses on carers and how they might be better supported in their caring roles particularly through improved opportunities to participate in the life of their communities.

Our members come from a range of parent-caring relationships: most have a son or daughter with intellectual disability or autism; some are grandparents of a person with disability; some are parents of a person with an acquired brain injury. In most cases the person with the disability is living full time in the family home. Other arrangements include living in a residential facility, independent living with another person with a disability or alone, and living in a group home.

We know that caregiving research has focused almost exclusively on adult children caring for ageing parents and, to a lesser extent, elderly spouse carers (Llewellyn, Gething, Kendig and Cant, 2003). ‘Lifelong caring’ is less well

‘Lifelong caring’ is less well researched, understood and appreciated.

researched, understood and appreciated. Lifelong caring is where our members find themselves. An important study that is relevant to our members, particularly those at the older end of their ‘career’, was conducted by Llewellyn et al (2003) for the New South Wales State Government. The authors noted that nationally

Around 10% of primary carers aged 65 and over (approx 9700 in 2002) are older parents caring for their adult children. Around 40% of all primary carers in Australia have been in their caring role for at least 10 years. Of these, around 10% have been in the caring role for at least 25 years. Most of these long-term carers are parents of adults with intellectual disability. Their time involvement in caring is substantial; for carers caring for 25 years or over, half (50.2%) spend no less than 20 hours a week caring and the majority of these carers (76.2%) spend over 40 hours a week devoted to caring activities. (p.ii)

Many of our members are in the 10 percent of primary carers aged 65 years and over caring for their adult children and our other members will join them in their ‘lifelong career’. Their social lives are restricted to varying extents because they are built around the interests and needs of their sons and daughters. Despite lifetimes of

physical demands such as lifting, carrying and toileting as well as emotional demands, our caregivers find enormous satisfaction from their roles. Nevertheless, increasing age of parent-carers and their sons or daughters does place significant strains on the parent-caring relationship. But these older parent-carers remain responsible for their adult children with disabilities. The social and economic strains of perhaps twenty, thirty, forty years or more in their caring roles does not find relief in later middle age with retirement or children becoming independent as it does with most of the population.

In looking to provide this Parliamentary Inquiry with the ‘lifetime’ caring experiences and views of members of the Geelong Parent Network, we wish to strongly emphasise that an overwhelming challenge and concern for parent-carers is what will happen to our sons or daughters when we are not able to care for them. Who will provide the care that we would want for them? Provision of such accommodation and support is for lifetime carers “the biggest issue of all” (Magrill, 2005), not just in countries such as the United Kingdom in which accommodation for persons with intellectual disability has been described as a “timebomb” (Mencap, 2002), but in Australia also. Addressing this issue is fundamental for lifetime carers to sustaining their health and wellbeing.

The views of the Geelong Parent Network to the terms of reference for the *Better care for our carers* Inquiry focus on this ‘biggest issue of all’ – accommodation and support - when we and other ‘lifetime carers’ are not able to directly provide this.

**... this ‘biggest
issue of all’ –
accommodation
and support**

Barriers to our caring

Llewellyn et al (2003) identified stressors that affected the health and caring relationship of older parent-carers. Their findings suggested an association between having a locally integrated support network and better mental health. This of course is encouraging in relation to this Parliamentary Inquiry’s focus on better care for carers being connected to ‘community participation’. It should not however mask ‘the

biggest issue of all' that is a barrier to peace of mind for lifetime carers. In coming to understand this barrier, it is necessary to understand the reasonable cynicism of parent-carers to decades of living with and adapting to changing government policies.

Interests of government seem to be primarily around "Who will pay for the care?" far more so than the actual health and welfare of the parent-carer and their child with a disability. A question of fundamental interest for parent-

"Who will look after my child in the way I do?"

carers is "Who will look after my child in the way I do?" Clearly costs and budgets are vital to this. But so is recognition of the plight of these lifetime carers, and to the extent that this is not recognised in government planning, and red tape so often masked as accountability, it is a significant barrier to their caring roles.

A typical political response is announcement of , say, \$X million dollars being dedicated to people with disabilities or carers, generally not adding over how many years, what is the administrative component, and whether it is part of some previously announced package. The response is highly unlikely to situate the funding in a context of the full need and how government is planning to address what is 'unmet'. Not surprisingly lifetime carers have come to be cynical of government ever moving to genuinely recognise their interests and needs. In just one lifetime, government 'goal posts' have changed a number of times with related advice as to what would be in their best interests and that of their children with disabilities. It is exacerbated when different governments have conducted protracted blame games that have particularly affected people with disabilities and their carers.

When governments and their departments define the 'help' for carers they will provide and in the process exclude some carers, they are erecting barriers that impact on these carers. An example of this is in recently published Victorian Department of Human Services (2006) publication *Help for Carers: Information for Older Carers & Families of People with a Disability*. It notes that "If you are a primary carer you may be concerned about your own needs as well as how your adult family member with a disability will be supported when you are no longer able to support them" (p.7). It also adds "If we leave it too late we will never be able to plan. Don't leave it until it's too

late.” and “You can’t plan when you reach a crisis.” (p.15) Its advice is in the context of promoting independence of the person with a disability, meeting their individual needs and providing choice. Yet when it comes to the ‘biggest issue of all’ for people who require 24 hour support, the 8 accommodation options (p.52-54) boil down to just one, namely Shared Supported Accommodation. This ‘option’ in practice has seen no funding for development in spite of the need. Inevitably there are crises which then affect respite availability. Furthermore, the Victorian Department of Human Services’ Disability Needs Register only addresses ‘immediate needs’, so avoiding the embarrassment of having information of more extensive needs known and being more challenged to meet them. This is unhelpful to the needs and interests of lifetime carers and is inconsistent with calls made on carers for better future planning.

At one time this was to place the son or daughter in an institution and ‘get on with your life’. Parental response evolved to founding of kindergartens, schools, workshops and residential facilities that would provide safety and security at all stages of life to which governments came to provide support. Some of our lifetime carers have participated in all of these developments. Younger lifetime carers are meeting new challenges but seemingly no less diverse and demanding. The ‘biggest issue of all’ continues to be confronting.

Practical measures for support

A measure that is available in Victoria but not nationally is the Companion Card that we believe exemplifies a practical support to better social and economic participation in our society. It encourages and enables for many people with disabilities and their carers access to community life. It is reasonably widely supported by government and businesses that include recreation, sporting and cultural groups. Further support of and expansion of this would only widen possibilities for community participation.

The Howard Government’s foray into supported accommodation in June 2007 was a practical measure to provide reassurance for parent-carers about future care and accommodation arrangements for their son or daughter with a disability. This Disability Assistance Package committed \$562.6 million over five years to develop

high quality supported accommodation services for people with disability. It raised hopes of many parent-carers even though the numbers provided for were only 1750 accommodation places over 5 years. The Australian Institute of Health and Welfare (2007) estimated that in 2005 the unmet demand for accommodation and respite services at 23,800 people, a sharp increase since 2001. In light of such needs, lack of consultation with States was extremely disappointing especially given States had the experience in providing disability accommodation services. Shallowness of Commonwealth expertise in the area was obvious to participants in forums which unfortunately reinforced views of carers of the distance from the everyday lives of lifetime carers, their children and families and the insincerity of those playing political games. The need however is authentic and desperate and the initiative would assist.

Equal opportunity

Parent-carers and their families who make the commitment to care for their child who has a disability at birth or later time accept that they will not enjoy the same range of opportunities and choices as other people in the wider community. Impacts on their social and economic lives are generally profound. These impacts will be ameliorated to some extent with external supports, but equality of social and economic opportunities is most unlikely in lifetime caring with which our members are most familiar. Self reliance, whether by choice or necessity, together with modifying their social and economic situations are means by which everyday life is made more 'acceptable' in spite of the often heavy physical and emotional demands (cf. Llwellyn, 2003 on Caring and Coping, pp.15-23). Additional costs associated with caring over a lifetime as well as income foregone are often substantial burdens affecting carers, the person cared for and whole families.

Impacts on their social and economic lives are generally profound.

Improved capacity for caring choices

Parent-carers go through a whole range of challenges in their lifetime caring and in a very real sense become 'experts' although their 'lay knowledge' is not generally highly regarded by professionals. This knowledge is hard won and improvements to

accessibility of information would assist. Over a lifetime, parent-carers will have built up a knowledge of specific disabilities, a variety of therapies and how to best develop abilities of and opportunities for their sons and daughters in kindergartens, schools, through community sport and recreation, negotiating shopping, cultural activities and transport, a diversity of workplaces (or just as challenging - a diversity of non-employment activities), adapting to changing interests and needs (including sexual development, menopause and often premature ageing) as well as adapting to changing government policies and fashionable philosophies. Few people are called on to this extent to search for, digest and act on such a breadth of knowledge outside and do this in addition to their other family and income generating activities. It is a mammoth and daunting journey. Improved access to relevant information, including support in its analysis and application, together with better appreciation of the 'lay knowledge' and individual understandings of parent-carers.

Planning for future

There is much that can be done to support parent-carers in planning for their futures and that of their sons and daughters. But we believe with Llewellyn et al (2003) that the basis on which this development takes place be through family care partnerships that will create more certain futures for both of them. This should include emergency planning. There has in recent years been courses conducted by Commonwealth Respite Care Centres about which participant 'older parent-carers' reported positively.

A model for family care partnerships that might be explored was developed in the United Kingdom based on the Government's White Paper, *Valuing People*. The various policies, practices and publications give emphasis to family care partnerships. Caring roles take many forms, but for those in lifelong caring roles with sons and daughters who do not have the capacity to fit government's preferred work and more 'independent' living arrangements, supports for such partnerships will be critical. "One size will not fit all" though in addressing how caring can be better supported.

A model for family care partnerships that might be explored was developed in the United Kingdom.

References

- Australian Institute of Health and Welfare (2007) *Current and future demand for specialist disability services*. Canberra: Author.
- Department of Human Services, Victoria (2006) *Help for carers: Information for older carers and families of people with a disability*. Melbourne: Disability Services Division.
- Llewellyn, G., Gething, L., Kendig, H. & Cant, R. (2003) *Invisible carers: facing an uncertain future*. Sydney: Faculty of Health Sciences, University of Sydney.
- Magrill, D. (2005) *Supporting older families: making a difference*. London: The Mental Health Foundation.
- Mencap, (2002) *The housing timebomb: The housing crisis facing people with a learning disability and their older parents*. London: Author.
-