



ParaQuad
VICTORIA

Submission to the Senate Community Affairs References Committee Inquiry into Aged care

In this submission we are only commenting on the interface between aged care as it affects people with physical disabilities. How the aged care system accommodates those with both physical disabilities and the inappropriateness of accommodating younger people with physical disabilities along side the traditional aged resident.

We would also welcome the opportunity to give evidence to the committee at a public hearing.

Our submission makes the following points:

- It is inappropriate for people with a disability who do not have age related diseases to be accommodated in nursing homes because of the lack of more appropriate services at a state level.
- A path between aged care and disability services needs to be provided so that individuals can better negotiate between the two service systems. This could then enable aged care dollars to be provided to top up disability services.
- Pressure should be applied to the Victorian state government through the Commonwealth State and Territory Agreement (CSTDA) to provide adequate in-home services to people with disabilities to prevent them from entering the aged care system because no other options are open to them.
- Similarly this pressure should be applied to state governments to fund suitable accessible housing for younger people with disabilities.
- While we have a significant number of younger people with disabilities in nursing homes, appropriate training should be provided for the staff caring for these people and the particular nursing homes should be governed by their state disability standards in regard to those particular clients.

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Background Information

ParaQuad provides a range of services to people with physical disabilities, the majority are people with spinal cord injuries or people who have had Polio. Of the 1656 members and subscribers, 30.6% are between 50-65 years and 29.8% are over 65 years. Of the 305 clients who received services last quarter 40% are currently between 50 – 56 years of age and 8.25% are over 65 years.

We are the largest provider of the Victorian state based Home First program which provides home based attendant care support to enable people to live active lives in their own homes. We also provide case management, information services, counselling, volunteers, support groups and supported accommodation. This service is funded by the state government and provides shared housing for up to five people with a 24 hour attendant care support. Nursing services are provided morning and night according to the individual's needs for nurse specific duties. Although we have six of these houses and are planning to develop more over time we are unable to meet the current demand. The predicted future demand caused by our aging client base will only exacerbate this problem.

Until recently individual's with a disability seldom enjoyed the same life expectancy as their peers without disabilities. Secondary medical conditions coupled with a general lack of adequate primary care prevented most persons from experiencing their true life expectancy. Today advances in medicine and rehabilitation have made the expectation of living to late life fairly reasonable for most persons even those with significant disabilities. Research published in 1998 showed that many, if not most, people who live 20+ years with a disability encounter substantial new medical, functional and psychosocial factors.¹ While the exact causes are unknown the data has shown that people with a disability do not age in a typical manner. This relates to increased medical problems such as diabetes, osteoporosis and fractures and cardiovascular diseases. Also increased functional problems associated with activities of daily living such as dressing, shopping and recreational activities. These can then cause depression with the individual and associated stress on their families and primary carers.

Faced with these consequences many of our clients are fearful of the fact that they may be forced into nursing home accommodation at an earlier age than the normal population because there is a lack of community based supports to allow them to remain at home.

Terms of reference:

- (a) **Aged care workforce training** – specific modules should be available under the current aged care training packages that relate to the care of people with physical disabilities who are aging. This should include personal care needs, use and care of specialist equipment, the differing demands on staff, length of time required to service these clients, their differing expectation regarding community access and their need to retain existing links to their social support networks.

¹ Disabled People's International Vox Nostra *Aging with a Disability* 1998, <http://www.dpi.org/en/resources>

(b) (i) Assessing and monitoring health care and safety.

If the nursing home has people with physical disabilities the health and safety issues for this group and the staff caring for them are very different to the normal aged care client. Special note should be taken of the specific needs of these people when the monitoring of health care and safety is being considered. Their health needs and equipment needs are very different and must be separately documented and monitored. Nursing home clients with physical disabilities are not eligible for state based equipment funding, this therefore becomes the responsibility of the nursing home. Clients are often forced to use old and outdated equipment such as wheel chairs, hoists, commode chairs etc. This results in an increased number of pressure sores which require lengthy acute hospital stays sometimes for up to two years.

(c) Appropriateness of younger people with disabilities being accommodated in Aged care facilities.

Aged care facilities are designed to care for people who have age related diseases. They are not designed in any way to accommodate people whose prime reason for being in there is their level of disability and the inability of the state government to provide sufficient community based supports. Younger people with complex support needs have the right along with every other younger person to appropriate social supports and access to their local community. They also have the right to live their day to day lives with dignity, to have dreams and to strive for independence.

To accommodate these people in nursing homes because it is the most convenient option is a national disgrace. They are doomed to live out their lives surrounded by people with dementia, with little opportunity for a normal adult conversation except with staff and no means of accessing their communities. They are faced with people who are in the final stages of life unable to converse and are stuck in the situation of bearing witness to a steady stream of dying people.

This situation applies not only to those people with disabilities who are considered young i.e. under 65 years but to those who are over 65 that are unable to access sufficient community based supports to remain at home leading active and fulfilling lives. This applies to people whose level of disability has increased or who acquire a disability when they are over 65 years.

(d) Adequacy of Home and Community Care (HACC) programs and the Victorian state administered, Department of Human Services (DHS) funding for people with disabilities wanting to remain living in the community.

The Victorian community care system is a mine field of different programs with differing and complex selection criteria. Case managers are needed by most individuals in order to source a number of different community based programs that may be able to provide some assistance.

HACC funding is delivered by local councils and will provide minimal assistance to people with disabilities and is usually restricted to domestic and home cleaning

services and meals on wheels. Many of our clients who receive disability pensions struggle to meet the co-payments stipulated by most local governments.

The main source of funding for people with disabilities is the DHS Home First program which provided up to 34 hours of attendant care per week. Although there are also up to 30 discretionary hours per annum which may be accessed by recipients, this is often inadequate for people with high levels of disability particularly if they do not have family and friends who are willing to provide additional care. These clients therefore are compelled to enter a nursing home which is an inappropriate environment for someone who could with additional community supports remain an active member of their community.

This program is inadequately funded and has a waiting list of several thousands who are classified as being in urgent need of care. That their situation is in imminent danger of breaking down i.e. the primary carer (s) are unable to cope with the burden of care placed on them or they are homeless or about to become homeless. This has resulted in many clients waiting up to two years for Home First funding. Clients and their families with newly acquired disabilities who are struggling to come to terms with the changes to their bodies i.e. newly diagnosed quadriplegics are faced with a long and uncertain wait for any assistance. Although ParaQuad provides up to \$100,000 raised through fundraising to provide some relief to these stressed families, these funds are inadequate to cover the need resulting in otherwise younger and active community participants ending up in a nursing home.

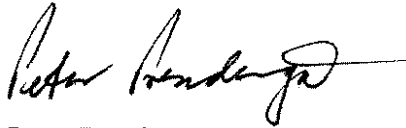
The other group of clients who are ending up in nursing homes through inadequate services are clients who have had their disability for a number of years and who are loosing function because of an aging process or over use of existing muscles. When people have a physical disability, existing muscles are used to compensate for those muscles which are weak or no longer functioning i.e. the upper body is used to propel a wheel chair in place of leg muscles. As a result they need more attendant care hours to function on a daily basis. As sufficient community services are not available these clients who would otherwise function as normal citizens often end up in nursing homes.

This is compounded by the fact that these people are not eligible to apply for funding through disability services after they turn 65. They are beyond that age considered to be part of the aged care system which does not provide sufficient supports for people with significant disabilities. These are people who in many cases would be able to live successfully in the community if they were not excluded from the disability system because of their age. The system recognises that people have a disability or are aged, but not both.

I would therefore recommend that the Commonwealth put pressure on the Victorian state government to increase the funding for community based support packages like Home First, and that the upper limit of hours of care available under these schemes be expanded into "Super Packages" to allow people with disabilities who have high care needs to continue to live in their own homes and participate to their local communities.

Also the availability of these packages should be extended beyond 65 years to allow people to enter into the disability support system at any age as long as their support needs relate to their disability.

Should both these recommendations be implemented this would reduce or eliminate people with disabilities from aged care nursing homes which should be preserved for people who have age related frailty or diseases.

A handwritten signature in black ink, appearing to read 'Peter Prendergast', with a long horizontal flourish extending to the right.

Peter Prendergast
Chief Executive Officer
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