

NSW Catholic Social Welfare Committee (NSWCSCW)
Submission to the Senate Community Affairs Reference Committee: Young People in Nursing Homes

In June 2004 the Senate referred a number of concerns to the Senate Community Affairs Reference Committee, one of which was:

The appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, such as dementia, mental illness or specific conditions are met under current funding arrangements.¹

Young people in aged care facilities are young people with high or complex care needs living in nursing homes due to a lack of alternative accommodation and care options. The problem of a lack of accommodation and support options for young people with disabilities, and their families, is highlighted in the NSW Ombudsman's report *DADHC: The Need to Improve Services for Children, Young People and Their Families* (April 2004).

The Ombudsman's report identified serious problems in:

- staff training
- case management
- delineation of roles and responsibilities
- communication within DADHC and between DADHC and DoCS²

More importantly, the report identifies a lack of support for children and young people with disabilities, and their families, in seeking specialist assistance. In the past the Commonwealth has permitted younger people with a disability to be admitted to residential aged care where no alternative provision existed. In these cases the Commonwealth funded the accommodation, equipment, and personal care services that were required. However, young people in nursing homes receive no disability support because disability services are a State responsibility and cannot follow a young person into the aged care system.

Most young people in aged care facilities are part of the Commonwealth State Territory Disability Agreement (CSTDA) target group. However they are increasingly unable to access funds and resources because of the poor capacity of the CSTDA sector, ongoing jurisdictional conflicts between State and Federal governments, and a lack of co-operation between the health, disability and community care sectors. The Ombudsman's report draws attention to the impact of these problems on young people and their families. It acknowledges the increased risk of family breakdown for some families and the distress associated with not being able to adequately care for a loved one.

The NSWCSCW believes the current definition of Disability as a State/Territory responsibility and Aged Care as a Federal responsibility intensifies the crisis in service provision, and the burden on people with disabilities and their families.

There are already more than 6000 young Australians aged between 0 and 65 living in nursing homes throughout the country. If current trends continue this number is expected to rise to 10,000 in 2007³. Some of these individuals will require ongoing support until they do

¹ Inquiry Into Aged Care *Terms of Reference*

http://www.aph.gov.au/senate/committee/clac_ctee/aged_care04/tor.htm

² NSW Ombudsman (2004) *DADHC: The need to improve services for children, young people and their families*, p. 10.

³ <http://www.ypinh.org.au/>

meet the criteria for aged care services⁴. Young people in nursing homes include individuals with acquired disabilities from:

- Unpredictable health events such as asthma and meningitis attacks which result in Hypoxic Acquired Brain Injuries.
- Catastrophic accidents or events where compensation is not available.
- Progressive deterioration caused by some degenerative neurological diseases like Multiple Sclerosis, Muscular Dystrophy or Parkinson's Disease.

The needs of these various client groups are diverse and this complicates service provision. Young people with brain injuries have very specific cognitive, physical and psychosocial issues. These individuals present challenges that can not always be met by current community group home models. In some cases cognitive and behavioural issues have resulted in services being withdrawn for occupational health and safety reasons.

Care for a person with a degenerative condition is also difficult to fund because the type of services required are likely to change over time. There is no flexible funding to accommodate changing needs. This is particularly true where the degeneration leads to higher health and other personal care needs, or involves a failure of cognitive function.

The NSWCSWC supports the expansion of statistical surveys maintained by the Australian Institute of Health and Welfare (AIHW), the development of high level long-term case management, and a system of flexible support and accommodation packages for young people with disabilities.

In a brief survey of 22 Aged Care facilities run by Catholic welfare agencies, each one was found to be providing a service to homeless young people with a disability. Some of these clients had received traumatic injuries through accidents, others had been disabled since birth but did not have a carer. In every case these young people had no accommodation alternative.

A young person in a nursing home is faced with inadequate rehabilitation services and a high risk of social isolation. Outside the aged care system the lack of coordinated long-term support for children and young people with disabilities, and their families, is well documented, and so is its impact. While nursing homes are not an appropriate accommodation solution for a young person with a disability there is a risk that loss of Commonwealth funds would make the transition to alternative accommodation impossible for many people.

The NSWCSWC is concerned about the untenable situation in which young people with disabilities and their families find themselves when seeking accommodation, care and respite services. The NSWCSWC supports a funding model which allows a young person leaving the aged care system to access ongoing funds for specialist disability support.

*NSW Catholic Social Welfare Committee
Thursday, March 31, 2005*

⁴ DADHC note that the number of people of all ages with a moderate, severe or profound disability is increasing at a rate faster than the general population. "Predicted to number 742,000 by 2011, an increase of 18% over the number in 2000 (628,000). In contrast, the general population is forecast to increase by 8% over the same period". DADHC bases these comments on ABS data. (DADHC (2004) *Future Directions: Older People with a Disability and Their Carers*, p. 2)