



The New South Wales Council for Intellectual Disability

16 December 2004

The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
Canberra ACT 2600



Dear Sir or Madam

I am writing to submit a brief response from the NSW Council for Intellectual Disability (NSW CID) to the Senate Committee Inquiry into Aged Care. NSW CID is the peak body representing the rights and interests of people with intellectual disability in NSW. I apologise for the late submission of our response.

The response primarily addresses one term of reference:

(c) "the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, as dementia, mental illness or specific conditions are met under current funding arrangements;"

We anticipate that the Committee has received many responses from aged care service providers and representative organisations. We believe that these agencies are better equipped to comment on the broader terms of reference than NSW CID. However we will provide some comments on the issues for the growing number of people with disability who are ageing in the community.

Should you require more information please do not hesitate to contact me.

Yours faithfully

Helena O'Connell
Executive Officer

Level 1, 418A Elizabeth Street Surry Hills NSW 2010
Phone: (02) 9211 1611 or 1800 424 065 Fax: (02) 9211 2606
Email Address: mail@nswcid.org.au

SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE INQUIRY INTO AGED CARE

About NSW CID

The NSW Council for Intellectual Disability (NSWCID) is the peak body representing the rights and interests of people with intellectual disability in NSW. Some of the roles that Council takes on as a peak body include providing policy advice, systemic advocacy, community education and information provision and dissemination.

Appropriateness of young people with disability living in nursing homes

Introduction

This response focuses primarily on the following term of reference and we also focus briefly on the needs of people with disability who are ageing:

(c “the appropriateness of young people with disabilities being accommodated in residential aged care facilities and the extent to which residents with special needs, as dementia, mental illness or specific conditions are met under current funding arrangements;”

There are approximately 1,800 people with disability living in aged care facilities in NSW¹, 15% of these are young people with intellectual disability. It is the belief of NSW CID that it is never appropriate for people under the age of 65 years to be placed in a residential aged care facility.

Impact on people with disability

People are placed in aged care facilities for a range of reasons but essentially because both the accommodation and necessary supports to live in the community are not available. Often the reason a person with intellectual disability is placed in an aged care facility is when their ageing carers are no longer able to look after them and both the carer and the person with intellectual disability are placed together in a facility for older people. NSW CID is concerned about the negative impact on the quality of life for people with disability, which include the following concerns:

- Loss of skills and independence
- No opportunity for peer based relationships
- Depression – often caused by constantly being around people who are dying
- No community access for employment, education, recreation and various community services; this is often due to a lack of transport

In the case study below the young woman is only 21 and could have many decades of living in an inappropriate and understandably depressing environment.

Case Study

Ms T is 21; has a moderate to severe intellectual disability as result of a birth injury. She is in a wheelchair with heavy personal care needs; she has no nursing needs. Ms T was placed into a nursing home on leaving the residential special school she had been attending as her parents felt unable to look after her. The nursing home has

over 100 residents; she is the only person under 50. In the three years since her admission to the nursing home there has been an appreciable deterioration in her condition; she has lost self-caring skills and now exhibits challenging behaviours. Ms T has little appropriate stimulation and is depressed. It is the opinion of all professionals involved that Ms T's deterioration is due to the inappropriate environment.

Why does this occur and who is responsible?

In NSW we have been active in some collaborative work with a range of disability advocacy and government agencies to work to identify the causes and propose some solutions to this issue for at least 4 years. NSW CID collaborated on the development of the Discussion Paper mentioned in the introduction.

Clearly there needs to be a concerted response from both State/Territory and the Australian governments. State/Territory governments are responsible for accommodation services for people with disability. However through the CSTDA State/Territory and the Australian government are responsible for addressing unmet demand in disability services. It is clear that there is insufficient accommodation support for people with disability in the community and too many people continue to live with their ageing carers. While State agencies agree that this situation is not desirable they often operate at crisis point and do not prioritise people with disability in aged care facilities because 'they have a roof over their heads'.

The consequence of this for older people without a disability is that there are fewer aged care places available for them and there is then a further backlog effect when they remain in hospitals while waiting for a place in a residential aged care facility.

Members of the Aged Care Assessment Teams (ACAT) assess people with disability in order for them to be placed in nursing homes. Most are not equipped to assess people with disability and their role should be to refer people to the State/Territory disability agency.

Disability legislation

Quite apart from the negative consequences for people with disability of living in aged care facilities this situation is a breach of the *NSW Disability Services Action 1993(DSA)*, which was enacted to 'enable people with a disability to achieve their maximum potential as members of the community'ⁱⁱⁱ. However the DSA has no jurisdiction in nursing homes and some of the key principles of the Act could never be met in a nursing home environment e.g. 'to achieve positive outcomes, such as increased independence, employment opportunities and integration in the community, for persons with disabilities..ⁱⁱⁱ

What needs to happen?

For anything to change for people with disability there needs to be a commitment at both an Australian Government and State/Territory levels to address all of the issues that create this situation. In NSW CID's discussions with government representatives there is complete agreement that the status quo is unacceptable. However translating this into firm commitments is a different issue. We understand that State/Territory Disability Agency Administrators have commenced some scoping work on the issue. However a report based on this work is not due until 2006, which means many more

issue. However a report based on this work is not due until 2006, which means many more years in an extremely inappropriate environment for people with disability. Following are some of the key areas that need to be addressed:

- No new admissions of young people with disability to aged care facilities
- Relocation to appropriate community-based accommodation
- Develop appropriate community based facilities for people with nursing care needs
- All services should involve individual planning with a developmental focus with opportunities for community participation and interaction with peers
- Support for people with disability to transition to retirement
- Develop the concept of 'ageing in place' for people with disability
- There have been proposals to utilise Community Aged Care Packages (CACP) and Extended Aged Care at Home (EACH) at least initially to get people with disability into a more appropriate environment while the States/Territories and Australian government come to an arrangement to provide appropriate community based supported accommodation

People with intellectual disability who are ageing

For a range of reasons there is an increase in numbers of people with early onset or longstanding disability (acquired before the age of 18 years, e.g. people with intellectual disability), who are living longer and this is expected to increase. There must be a better response at all levels of government to address the needs of people with disability who are ageing. This should include:

- Research to develop and document examples of best practice
- Improved communication, collaboration and information sharing between government and non-government agencies and across all levels of government
- Funding of pilot projects to develop retirement options for people with disability who are ageing – and continued funding.^{iv}
- Access to clear pathways to transition from programs at different levels of government for people with disability as they age

Conclusion

Leading disability advocacy organisations have described this issue as a 'the biggest human rights issue in community services in Australia'^v. At NSW CID we might not describe as the biggest human rights issue but it is certainly does not reflect well on a country that prides itself on its human rights record and yet still allows young people with disability to live in such environments. The community would never accept this situation if it were applied to people without disability.

We urge the relevant governments to take meaningful steps to resolving this problem and avoid the temptation to treat it as a cost shifting exercise that

only leads to further buck-passing and continued suffering for people with disability.

**For more information contact Helena O'Connell, Executive Officer NSW Council for Intellectual Disability on:
(02) 9211 1611 or Helena@nswcid.org.au**

ⁱ *Younger people out of Nursing Homes*, 2002: Discussion paper; NSW Interagency on young people in residential aged care.

ⁱⁱ NSW DSA 1993 Object 3(a)

ⁱⁱⁱ NSW DSA 1993 Object 3(e)

^{iv} Eureka Disability Services in NSW has established such a project

^v *Young People in Nursing Homes – It's Wrong* MS Society Victoria