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**national council on
intellectual disability**

Committee Secretary
Senate Community Affairs References Committee
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Canberra ACT 2600

INQUIRY INTO PLANNING OPTIONS AND SERVICES FOR PEOPLE AGEING WITH A DISABILITY

1. Introduction

The Inquiry by the Senate Community Affairs Committee is timely as it will provide valuable information and recommendations to the Productivity Commission's Inquiry into Long Term Care and Support.

The Productivity Commission's Inquiry is looking at a new disability funding system which hopefully will encompass an individual's inclusion needs throughout their life, including as they age.

Immediate action is required though to end discrimination against people with disability where current government policy is in contravention of the UN Convention on the Rights of Persons with Disabilities. These policies, whether formal or de facto, must be changed immediately.

Organisations and professionals with expert knowledge will make submissions on the current situation of people with disability who are ageing and what specific actions must take place to ensure that they quality of their lives is equal to that of Australians in the general community. The Committee is asked to reflect on which of these relate to the disability system and how it needs to change; and which relate to a failure to provide aged care support to people with disability on an equal basis with all Australians.

2. UN Convention on the Rights of Persons with Disabilities

Article 19

Living independently and being included in the community

States parties to the present Convention recognise the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by person with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

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- a) persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;
- b) persons with disabilities have access to a range of in-home residential and other community supports services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation and segregation from the community.

The UN Convention is very explicit about the rights of people with disability in relation to supported living. The age related support needs of a person with disability does not in some way exempt governments from their obligation to comply with the Convention.

At one level the response is simple; what is the expectation and rights of the general population to support as they age? Once articulated these become the rights of all Australians including those with disability.

But, unfortunately the issue is much more complex as people with disability from the time of birth (or impairment) are discriminated against, seen as different. Thus unwritten rules are applied to them and when these are challenged policy is hastily drafted to justify the unwritten rule/ discrimination.

The 'classic' example is the double dipping rule. If a person with disability receives funding to support their inclusion in the community then they are seen as ineligible for support associated with ageing. There is no reason for this and there has been no broad general community discussion about why people with disability should be treated differently.

The UN Convention on the Rights of Persons with Disabilities addresses this issue directly. Whatever conflict or perception exists in the minds of officials the person with disability must not be treated differently to a person without disability. The funding that a person with disability receives to support them to live in the community has no direct effect on their entitlement, as an Australian citizen, to funding for their ageing needs. In assessing their needs for aged care support officials must disregard their disability support funding and assess their ageing needs as they would any other person.

3. Whole of Life ...

The problem is that officials do not see people as people. The general issues for people with disability who are ageing have been with them since they were born (or acquired their impairment), ie, being seen as consumers of funds (costs) and users of services (objects). There is no sense of entitlement or 'person-centeredness'. Costs are to be minimised and services/families are responsible not governments. Neither attitude is prevalent in aged care where nursing home places and community support packages are determined by an agreed formula.

There are no formulas in relation to disability funding. Individuals and their families are dependent on an ad hoc system from the beginning. There is no planning, coordination or giving people control over their own lives. From birth it is, 'you are lucky for what little you get'. Why would we expect that as people with disability become elderly and require aged care support that they would be viewed positively and that 'systems' would suddenly change to meet their individual needs?

There is no planning and hence no coordination and consideration of the funds needed to assist people throughout their lives as people with disability go through the important transitions of life. Planning not only for that transition but for the next.

How do we assist and support people to be as independent as possible into the future? This requires us to think about today what a person's needs will be tomorrow. When a person starts work we should be thinking about a home, a family; when a person reaches their forties and fifties we should be thinking about retirement, etc.

The general issues of planning, coordination and 'person-centeredness' are vital and they must be addressed by the Productivity Commission Inquiry so that the new disability funding system incorporates them.

The Senate Inquiry must call for the end of discrimination in the administration of aged care funding and the assessment of all Australians on an equal basis. Further, the Senate Community Affairs Reference Committee should continue to monitor the Australian Government's implementation of such a recommendation by a yearly meeting with opportunities or the non-government sector to report to the Committee.

4. A good life ...

National Council on Intellectual Disability is often asked for examples of what a good life for people with intellectual disability looks like. In relation to aged care the Young People in Nursing Homes initiative provides us with an interesting insight.

An important aspect of the Initiative is the diversion of younger people with disabilities from going into nursing homes. This part of programme is often overlooked but it is important for demonstrating what is possible not only for people who are at risk of going into nursing homes but for younger people living in nursing homes and for people who needs change due to ageing. It is suggested that the Committee talk to individuals who have been 'diverted' and their families.

To date the anecdotal evidence suggests that this group has different outcomes from those people who are in nursing homes and have received funding; by some comparisons the outcomes are seen to be much better.

Rob Allen
President

Mark Pattison
Executive Director

The National Council on Intellectual Disability (NCID) was established over 50 years ago by parents and friends, in an endeavour to improve the quality of life of people with intellectual disability and to fill the need for national unity and information.

The Council is the recognised national peak body with the single focus on intellectual disability, ie, our actions and priorities centre on issues that affect the lives of people with intellectual disability and their families. Our mission is to work to make the Australian community one in which people with intellectual disability are involved and accepted as equal participating members.

NCID has over 5,000 members representing all 8 States and Territories. In addition to having people with intellectual disability on its Board, NCID receives policy advice from Our Voice. Our Voice is a committee the membership of which is exclusively people with intellectual disability representing all States and Territories.