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**National Industry Association
for Disability Services**

# Submission to the Senate Community Affairs References Committee Inquiry into Aged Care

This submission focuses principally on the interface between the aged care and disability service systems. It does not comment on the Inquiry's Terms of Reference relating to aged care workforce shortages, the Aged Care Standards and Accreditation Agency or the transition of the elderly from acute hospital settings.

It makes the following main points:-

- The ageing of the population points to the need for increased public investment in disability and aged care services and for improved linkages between service systems. A person with a disability who is ageing should have simultaneous access to both aged care and disability service systems and funding streams, according to their needs. The adoption of a person-centred approach to service planning would assist.

- Commonwealth aged care funding and State disability funding should combine to enable younger people inappropriately accommodated in residential aged care to relocate into the community with a sufficient level of support. The funding available to aged care services or to disability services is alone insufficient to support younger people who have complex medical support needs.

- The aged care system needs to be better equipped to respond to the needs of people with long-term disabilities – in particular, those with intellectual, psychiatric and cognitive disabilities.

- The Australian Government should boost funding for its community care programs and reform their structure to enable improved administrative efficiency and greater ease of access.

- As well as increased support for formal services, a strategy to respond to demand growth for services should include increased support for unpaid carers, without whom demand would be much higher.
- The Australian Government should join with State and Territory governments and non-government organisations in developing a properly resourced national equipment strategy.

### *The proportion of Australians who are old and have a disability is rising.*

The ageing of the general population – and, as a subset of that, the ageing of people with long-term disabilities – is accelerating demand growth for both Aged Care and Disability services.

The incidence of acquired disability increases significantly with age, and people generally, as well as people with life-long disabilities, are living longer than they once were. In the 20 years to 2021 the number of Australians aged 65 and over will grow from 2.4 million to 4.2 million (or from 12% to 18% of Australia's total population). At present, one in 17 Australians (5.9%) has a profound or severe core activity limitation (that is, they needed help with one or more of self-care, mobility or communication): among people aged 85 years and over this proportion rises to 54%.[1]

This trend has implications for the investment of public resources in aged care and disability services and for the interaction between service systems. Not only is funding failing to keep pace with the growing demand for services, but the funding formulae and administrative arrangements that govern the aged care and disability service systems seem to assume that a person is either disabled or aged, but cannot be both. They rarely allow for the growing human reality that a person may require a disability service and an aged care service simultaneously.

### *Service linkages are lacking*

At present, bureaucratic and jurisdictional boundaries impede effective service delivery to people with disabilities. For people with long-term disabilities who are growing old, this is particularly so. Such people often search in vain for effective pathways between Commonwealth and State disability service systems, and between aged care and disability service systems.

For example, a person with an intellectual disability seeking to retire from a supported employment service (administered by the Commonwealth

[1] ABS, 2003 Survey of Disability, Ageing and Carers, preliminary findings, May 2004.

Department of Family and Community Services) is likely to require an appropriate day activity (administered by a State or Territory disability department) and also access to the aged care system (administered by the Commonwealth Department of Health and Ageing). Because people with intellectual disabilities often adapt to change very slowly, the transition from work to retirement should be gradual, with the supported employee initially receiving a mix of non-employment activities and employment. In theory, bureaucratic and jurisdictional boundaries should not impede this, but, in practice, the boundaries are often barriers.

Exacerbating the situation is the ‘premature ageing’ that often characterizes people with significant disabilities. On reaching middle age, people with disabilities often experience the onset of health conditions and the deterioration in capacity that is commonly associated with later life – a fact which the age boundary between the disability service system and the aged care system fails to recognise.

Were people with disabilities who live in community-based supported accommodation to be given increased access to community nursing, palliative care, dementia support and allied services, it would help enable them to age in place, an approach which the broader community increasingly expects.

The boundaries between service systems are in part created by accountability requirements within and between governments; but they also reflect a focus on *managing* rather than *responding to* demand. Because demand for services (both aged care and disability) perpetually exceeds supply, more policy effort goes into determining equitable rationing methods than into ways of improving access to services. The consequence is service systems that often lack flexibility.

In the third Commonwealth State and Territory Disability Agreement (CSTDA), Disability Ministers have, in principle, supported the creation of improved cross-jurisdictional service linkages. This is one of five policy principles embedded in the multilateral agreement, although much work will be required to give this principle practical effect. The Agreement does not tackle the lack of pathways between the aged care and disability service systems.

Research, resources and cooperative effort are required to build improved linkages between Commonwealth and State service systems and between the aged care and disability service systems.

Research is required to map the gaps and barriers between the systems and identify the examples of flexible, responsive service models that do exist - including in allied programs. Reducing barriers will also require allaying the suspicions in both levels of government about cost shifting.

The Department of Health and Ageing’s Innovative Pool pilot is an example of a funding model that – although modest in its scope and resources – does indicate a way forward. It enables Aged Care funding to be used to top up State Disability Services funding to reflect the fact that people with lifelong

disabilities may develop additional needs as a consequence of ageing. That principle should be more broadly applied.

The adoption of a person-centred approach to service planning in both aged care and disability services would also assist. Such an approach – which constructs customised packages of supports to fit the needs and wishes of the individual, rather than trying to make individuals fit into pre-set categories – is increasingly recognised as good practice in human services.

***Younger people residing in aged care homes need community accommodation options.***

Around 6,000 people aged less than 65 years live in aged care residential facilities. Many of these are the victims of the barriers that surround the aged care and disability service systems. The psychological welfare and social development of these younger people would be better served were they to be housed in the community, with appropriate levels of support.

Were this to happen, places would be freed up in residential care. Given that one in four old people currently has to wait three months or longer to enter a residential care, the places vacated by younger people who relocate to community settings would easily be filled.

The principal barrier to this occurring is the disagreement between the Commonwealth and State governments about who has funding responsibility (and associated suspicion about cost shifting). The way forward requires a funding model that combines ongoing and indexed Commonwealth Health and Aged Care Funding and State Disability Services funding.

The younger people who reside in nursing homes often have high-level physical support needs or complex medical needs (requiring ventilator support and gastronomy meals, for example). But the funding available to aged care services or to disability services is alone insufficient to support these younger people to live in the community. Funding formulae have failed to keep pace with the real costs of assisting people who have complex medical support needs.

While the bilateral agreements linked to the CSTDA do intend to progress the issue of younger people inappropriately housed in residential aged care, they give it no urgency: unless given a higher priority, it is unlikely to be resolved by the conclusion of the Agreement.

In some States efforts have been made to provide some younger people in residential care with a community-based day activity service appropriate to their age. This is a positive move to ameliorate the effect on these younger people of residing in an aged care home in the absence of alternative accommodation options.

***Community Care programs should be expanded and streamlined***

Through the Department of Health and Ageing, the Australian Government provides a range of Community Care programs to enable people who need support to live at home because of disability or frailty. With annual funding at around a billion dollars the Home and Community Care program (HACC) - funded jointly by Federal and State governments – is the largest of these programs. The target population for HACC is older people and younger people with disabilities requiring personal care or domestic assistance.

While the funding for HACC is substantial it is spread very thinly across the program. The average amount of domestic assistance received by the almost 200,000 HACC clients last year was just 38 minutes per week. The 46,919 HACC clients aged 65 and over who received personal care assistance received an average of just 50 minutes per week. The 11,630 clients aged less than 65 received on average 2.4 hours per week of personal care assistance.

The community care system is unduly complex, making it difficult to navigate around, and it is fragmented, leaving significant gaps in terms of the availability of services. There are 17 separate Commonwealth funded programs providing community based care services. In addition each State funds many more programs all requiring separate reporting and administrative arrangements. For example, the Victorian Government administers another 22 separate programs that cover specialist aged health care, disability services and community health services.

The Australian Government should boost funding for its community care programs and reform their structure to enable improved administrative efficiency and greater ease of access.

***Carers need increased support.***

Most care for older people and younger people with disabilities is informal - provided by relatives and friends. In 2002, for example, only 3% of the 'potential population'[2] received a government-funded disability accommodation support service.[3]

Australia has almost 2.5 million unpaid carers of children or adults who have a disability, mental illness, chronic health condition or who are frail aged. More than 450,000 of them are primary carers.[4]

Seventy per cent of primary carers are female, mostly women who are not in paid work. In 1998, fewer than 2% of people in the labour force were primary

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[2] The potential population is defined as people aged under 65 with a severe or profound core activity restriction adjusted for the Indigenous factor
[3] Steering Committee for the Review of Government Service Provision, *Report on Government Services 2004*, Table 13A.8
[4] 'Facts About Carers in Australia', Carers Australia.

carers of people with disabilities, whereas 5.7% of people outside the labour force were. As the labour force participation rate of women grows, the availability of informal carers will fall. As a consequence, demand for formal services will rise.[5]

Social expectations also influence demand for services, with fewer people willing to be the long-term sole carer for a relative who is ageing or has a disability. Moreover, many parent-carers are reaching an age at which they can no longer care for an adult son or daughter with a disability.

These trends will place added pressure on the formal service system, which already lacks the resources to meet the high level of existing demand.

As well as increased support for formal services, a strategy to respond to demand growth for services should include increased support for unpaid carers without whom demand would be much higher.

***The aged care system should be more responsive to the needs of people with disabilities***

Improving the access of people with disabilities to generic services (such as health, transport and education) would both advance the goal of community inclusion and reduce demand pressure on specialist disability services. There is evidence that people with intellectual disabilities, for example, have poorer health outcomes and access to health services, especially preventative health care, than the general population.[6] People with disabilities – in particular those with intellectual, psychiatric or cognitive disabilities - often also experience the aged care system as ill equipped to respond to their needs.

Disability Ministers have acknowledged the need to improve the access of people with disabilities to generic services and have listed that among their policy priorities for the third CSTDA. A successful implementation of this policy priority will require Disability Ministers to persuade their colleagues of the need for a genuinely whole-of-government approach.

Better access to generic services is not a substitute for increased investment in specialist disability services. Both are needed.

Work and resources are needed to better equip aged care services to support older people with disabilities.

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[5] Social Policy Research Centre, University of NSW, *Methods to Address Requirements for Changes in Funding Disability Services Brought About by External Change*, Report presented to the Department of Human Services for the National Disability Administrators, April 2002
[6] Durvasula and Beange, Health inequalities in people with intellectual disability: strategies for improvement, in Health Promotion Journal of Australia 2001, Vol 11 (1).

***A national equipment strategy is needed***

The adequate provision of aids and equipment should be a component in any strategy to respond to the unmet need and demand growth for aged care and disability services. By enabling greater personal independence, the provision of aids and equipment can improve the lives of people with disabilities and reduce the demand for more costly personal assistance.

Both the Commonwealth and State governments administer schemes that provide cost-free or low-cost aids to people with disabilities. In addition, a number of non-government organisations provide aids and equipment.

Commonwealth equipment schemes include those administered by the Department of Veterans Affairs (Rehabilitation Appliances and Home Modification programs); the Australian Hearing Services; CRS Australia; the Department of Health and Ageing (Continence Aids Assistance Scheme); and FaCS (Workplace Modifications Scheme).

In a recent study of aids and equipment, the Australian Institute of Health and Welfare (AIHW) found that the jig-saw of Commonwealth and State administered schemes left significant gaps, despite recent reviews to improve the quality and delivery of aids.[7] AIHW's 2002 study of unmet need for disability services identified a range of difficulties in obtaining the use of appropriate aids and equipment.

The exclusion of employed people from most equipment schemes can cause financial hardship, particularly for those who require high-cost or numerous equipment items. People who are blind experience difficulty in obtaining communication equipment. People with disabilities living in rural and remote locations are disadvantaged by the absence of equipment outlets. The annual allocation of continence equipment is insufficient (According to a survey by the Australian Quadriplegic Association, 57% of respondents ran out of supplies in nine months or less). A survey by the Carers Association of Australia found that carers do not receive enough financial assistance to obtain aids and equipment, in some cases resulting in financial hardship.

In summary, AIHW found there to be: "a limited range of equipment, problems with cost, availability and shortage of referral services in remote areas of Australia, and a decline in equipment supply from traditional dispensing units such as hospitals. Systems for the provision of equipment appear to be nationally fragmented."[8]

Investment in improving the provision of aids and equipment would reduce the need for other forms of assistance that are labour-intensive and more expensive. Independent Living Centres Australia (ILCA) argues that such an investment would help frail older people to remain living in their own homes

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[7] AIHW, Disability: the use of aids and the role of the environment, Canberra, August 2003.
[8] Ibid, page 16

longer and reduce their reliance on formal community care services. It believes that a well-developed assistive technology strategy for frail older Australians would reduce the demand on hospital, residential and community care services.

In 1996, as part of the evaluation of the Commonwealth State Disability Agreement, Ernst and Young recommended the development of a National Equipment Strategy that improved the range and timeliness of equipment provision and lowered the cost of maintenance and repairs.[9]

In recognition of the key role that the provision of equipment plays in enhancing independence and in reducing the demand for recurrent support services, equipment should be seen as an essential part of the range of aged care and disability services. Funding for equipment schemes is currently insufficient to increase the number and range of items available to clients and properly cover the cost of maintenance, repair and replacement of loan equipment. Both Commonwealth and State governments have funding obligations in respect of equipment. All governments should review the adequacy of existing resources for the provision of equipment services.

The Australian Government should join with State and Territory governments and non-government organisations in developing a properly resourced national equipment strategy.

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**About ACROD**

ACROD is the national peak body for disability services. Its purpose is to equip and enable its members to develop quality services and life opportunities for Australians with disabilities. ACROD's membership includes over 550 non-government, non-profit organisations, which collectively operate several thousand services for Australians with all types of disabilities. ACROD has a National Secretariat in Canberra and offices in every State and Territory.

Among its national policy advisory committees is one on Ageing and Disability, which includes representatives from all States and Territories and from aged care peak bodies.

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[9] *Commonwealth/State Disability Agreement Evaluation: The Equipment Study, Supporting Paper 5*, Ernst & Young, January 1996