

Futures Alliance –
Seeking Better Futures for People with a Disability who are Ageing

28th March 2011

Productivity Commission
Inquiry into Caring for Older Australians
GPO BOX 1428 Canberra City ACT 2601
Email agedcare@pc.gov.au

Dear Sir/Madam,

Thank you for the opportunity to submit a response to the **Draft Report into Caring for Older Australians** on behalf of the Futures Alliance.

The Futures Alliance is a cooperative of community representatives with a single focus on removing boundaries and maximising community resources to deliver improved options for people with a disability who are ageing. The Futures Alliance made a submission to the Inquiry into Caring for Older Australians on 28th May 2010 in respect to the specific issues facing, and current policy gaps pertaining to people with a disability who are ageing.

Please find attached The Futures Alliance response to the draft report. For further information or comment we can be contacted via Kellie Van Gool.

Yours Sincerely,

Jo-Anne Hewitt
Chairperson

Futures Alliance – membership

Aine Healy	Council for Intellectual Disability
Chris Campbell	The Cerebral Palsy Alliance
Christine Regan	NCOSS
Ed McNamara	UnitingCare Ageing
Jo-Anne Hewitt	UnitingCare Disability
John Morgan	Consumer Advocate
Cheryl Morgan	Consumer Advocate
Leanne Dowse	University of NSW
Mark Clayton	Sunnyfield
Mike Blaszczyk	McCall Gardens
Brendan Moore	Baptist Community Service
Nicola Hayhoe	Ability Options
Patricia O'Brien	Centre for Disability Studies
Paul Sadler	Presbyterian Aged Care
Rachel Haggett	Parent Advocate
Roger Stancliffe	Sydney University
Ruth Wilson	Aged and Community Services Association (NSW)
Shannon McDermott	Social Policy and Research Centre
Trevor Parmenter	Emeritus Professor University of Sydney

Futures Alliance – *Seeking Better Futures for People with a Disability who are Ageing*

The Futures Alliance made a submission to the Inquiry into Caring for Older Australians on 28th May 2010 in respect to the specific issues facing, and current policy gaps pertaining to people with a disability who are ageing.

In particular our submission called for:

For People with a disability who are ageing:

- Genuine consultation about what they want and how their aged care needs will be met.
- Self directed individual funding options with the flexibility to meet complex and changing needs.
- Recognition as a 'Special Needs' group within the Aged Care funding and legislative framework.
- Eligibility and access based on assessments that are sensitive to ageing changes for people with a disability.
- Access to all Commonwealth Aged Care Programs, including packaged and flexible care options.
- Access to health, and allied geriatric expertise.
- Ongoing research to provide a solid evidence base for policy, planning and service provision.
- Flexibility and collaboration between all levels of government and their departments.
- Funded partnerships between disability and aged care providers to allow collaboration and cross sector development.
- Professional development of a workforce that addresses ageing and disability issues in practice.
- Consistency between disability and aged care standards to ensure human rights and accountability.

For Governments:

- Improvements to planning and service delivery which minimises the likelihood of people with a disability who are ageing falling into crisis.

- One Government agency charged with the responsibility to co-ordinate planning and service delivery.
- Reductions in unnecessary use of expensive health interventions, such as hospitalisation
- A more equitable system, where people's needs are met irrespective of how they arise.

For Service providers:

- Better exchange of knowledge across aged care and disability services.
- More effective use of resources through better targeted assessment.
- Capacity to support people to continue to live in the community as they age.

For Communities and Families:

- Reassurance that people with a disability who are ageing will have their needs met.
- More effective support for carers

The draft report into Caring for Older Australians acknowledges the unique needs of people with a disability who are ageing as well those of their ageing carers. The draft report goes some way to addressing the gaps in policy and service delivery for this group. The Futures Alliance is aware that the Productivity Commission report into Disability Care and Support (draft February 2011) makes recommendations which will better meet the needs of people with a disability who are ageing. Below we highlight some issues that require additional clarification and linkage in the final report.

In particular the Disability Care and Support draft report makes the following recommendations:

3.4. "The NDIS should put in place memoranda of understanding with the health, mental health, aged and palliative care sectors to ensure that individuals do not fall between the cracks of the respective schemes (ie. Aged care sector and disability sector) and have effective protocols for timely and smooth referrals.

3.5. Whatever the actual funding divisions between the NDIS and aged care that are put in place, people should have the option of migrating to the support system that

best meets their needs, carrying with them their funding entitlements” (Productivity Commission 2011, Disability Care and Support, Draft Inquiry Report, Canberra, p. 46).

These are critical enablers to meet the needs of people with disability as they age and require endorsement within the Caring for Older Australians final report.

The Futures Alliance strongly supports many of the initiatives recommended in the draft report into Caring for Older Australians. In particular we welcome the call for a comprehensive overhaul of existing Aged Care policy framework, service system, financing and regulatory mechanisms to ensure that all older people get the services and supports they need to live their lives with dignity and hope. Many of the key findings of the report offer the capacity to provide better care and support to all people, including those with lifelong disabilities and their carers. Some of the key strengths of the findings include:

- Giving consumers the choice of where they receive care and who provides that care
- Recognising that carers are also consumers of aged care services and that carers of a person with a disability experience particular needs and barriers
- Promoting the notion of a continuum of support in Aged Care from basic support and personal care through to highly specialised health and nursing care
- Addressing the equity issues in the current aged care system and making provision to allow access and entitlement for all people regardless of their financial circumstances.
- Acknowledging the weaknesses of the current system and the demand projections for the future, and in particular the growing incidence of people with a lifelong disability living to old age.

The Futures Alliance has identified the need for greater articulation of the relationship of the recommendations of this report to its implications for, and impact on the needs of people with a disability who are ageing. In particular, the following areas are critical:

Assessment

Whilst the need for improvement to, and streamlining of, the current ACAT assessment process is clearly spelt out, the interface between assessment of a persons disability support needs and the impact of the ageing process on a persons functioning is extremely complex and rarely recognised by the current ACAT

assessment mechanism. The assessment process will require sufficient resourcing and expertise to consider the complexity of assessing the needs of a person with a disability who is ageing. As such, aged care assessment processes must compliment and interact with standardised functional disability assessment. Assessment is one of the key areas discussed in the Inquiry into a National Disability Care and Support Scheme and there is a need for a strong interface between assessment instruments in both the disability and ageing context.

Interface between ageing and disability sectors

The Futures Alliance supports the reports recommendation that people with a disability who are ageing should receive services from providers best able to meet their needs within the range of funding options proposed to enable this. In particular, The Futures Alliance supports the enabling of people with a disability to be supported by the specialist disability service provider of their choice within a cost sharing model where the disability sector funds the disability support and the aged care sector funds additional supports required as a result of ageing needs.

Such an approach requires a more intentional and purposeful nexus between the disability and aged care sectors allowing for increased access by disability services to specialised health services, opportunities for sharing of expertise and resources, specialist training for disability workers in relation to ageing, and funding mechanisms which allow for and encourage cross sector collaboration in research, policy development, training and service delivery.

People with a life long disability who are ageing require specialised care to meet their ageing needs, and a particular understanding of the support needs of people with a lifelong disability. Where people with disability choose or require tailored aged care services, these services need to be able to respond to the persons unique and complex needs, for example, dementia care for people with Downs Syndrome.

An approach that supports cross training from the aged care and disability sector is critical to meet the needs of people with a lifelong disability who are ageing, both in the community care context as well as within other specialist aged care.

Special Needs recognition

Whilst the report is encouraging in terms of recommending a flexible approach to joint funding of services to people with a disability who are ageing, the report specifically refers to this as being appropriate for those people 'reaching pension age.' There is strong evidence to show that people with early onset disability experience the ageing process at an earlier age than the general population. For

example this is demonstrated by the high rates of early onset dementia seen in individuals with Down Syndrome, as well as other age related conditions manifesting prematurely in certain disability cohorts.

The Futures Alliance calls for the recognition of people with a disability as a “Special Needs” group within the aged care legislative and funding frameworks. Recognition as a special needs group under aged care legislation would encourage service responsiveness and innovation. This would ensure that people with a disability who are ageing are enabled access to increased supports if and when needed, and that this access not be determined by an arbitrary age limit of 65. . A greater range of options available to people with a disability who are ageing to receive support and services will avoid the inappropriate placement of people under the age of 65 in residential aged care due to lack of alternative options, or lack of expertise in the community context.

Summary

The Futures Alliance recognises that the Draft Report into Caring for Older Australians needs to be considered in the light of the Productivity Commission report into a National Disability Care and Support Scheme. The proposed introduction of a National Disability Insurance Scheme (NDIS) would radically change the face of the disability service system and allow many people with a disability, including those who are ageing, to receive the support and services they require and that meet their complex and changing needs. It is crucial therefore to ensure that public policy such as that pertaining to the care of older Australians, recognises and addresses the unique needs of people with a disability and their carers. By addressing the current gaps in policy and service delivery, the National Disability Insurance Scheme, in concert with proposed reforms to the Aged Care policy framework, service system, financing and regulatory mechanisms, has the potential to provide people with a disability, including those who are ageing, with the supports they require to live a good life as valued citizens in their community.