

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

18th May 2011

Productivity Commission
Inquiry into Disability Care and Support
Response to draft report
By email: disability-support@pc.gov.au

Dear Sir / Madam,

Thank you for the opportunity to submit a response to the **Draft Report into Disability Care and Support** 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 Disability Care and Support on 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.

Yours Sincerely,

Jo-Anne Hewitt
Chairperson

Futures Alliance – Membership

Aine Healy	NSW 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 Limited
Patricia O'Brien	Centre for Disability Studies
Paul Sadler	Presbyterian Aged Care
Rachel Haggett	Parent Advocate
Roger Stancliffe	Sydney University
Ruth Wilson	Aged & Community Services Association (NSW/ACT)
Shannon McDermott	Social Policy and Research Centre
Trevor Parmenter	Emeritus Professor University of Sydney

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The Futures Alliance made a submission to the Inquiry into Disability Care and Support 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 Disability who are Ageing

- Genuine consultation about what individuals 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 Futures Alliance congratulates the Productivity Commission on a comprehensive draft report that grapples with complex issues facing people with disability across Australia.

The draft report acknowledges the under resourcing of the current disability services system and the extent of unmet community need. The report seeks to identify a new way forward to ensure a system that is responsive to, and meet the needs of people with disability within our communities.

The Futures Alliance supports many of the recommendations in the draft report into Disability Care and Support. In particular the Futures Alliance endorses the principles which ensure a system that:

- Provides funding that is equitable and portable
- Puts people with disability first and ensure that supports and services are built around each person
- Maximises personal autonomy, choice and control, including self directed options
- Provides clear pathways for eligibility, assessment and access to supports
- Provides individual funding as a platform for service delivery
- Addresses long time care and support
- Is focused on early intervention

There are a number of areas where the detail around implementing a new system of disability care and support requires fleshing out to ensure that the rights of people with disability are maintained and quality of life outcomes as defined by each person are enabled.

In relation to the NIIS, we welcome an approach that makes provisions for care and support regardless of catastrophic cause of injury. The focus of our response is the proposal for a National Disability Insurance Scheme.

National Policy

The Futures Alliance recognises the critical interface between the Caring for Older Australians Inquiry (final report due shortly) and the Disability Care and Support Inquiry. This is acknowledged in the draft report, and has been stated at public forums (such as National Disability and Carer Congress in Melbourne on 1st May).

In addition, the National COAG Health Sector reform process is also currently underway. This separates funding for those over age 65 to the Commonwealth and under age 65 to the States. Within NSW we are waiting for further details as to how the COAG reforms will impact on disability services. Currently, we understand that initially this will be in the form of behind the scenes transfer payments between the States and the Commonwealth but will have little impact on service provision.

The Productivity Commission draft report into 'Caring for Older Australians', referred to the current inquiry in relation to meeting the needs of people with disability. The Futures Alliance supports many of the initiatives recommended in the draft report into Caring for Older Australians. (The Futures Alliance response to the draft 'Caring for Older Australians' is included as an attachment.)

In response to the Caring for Older Australians Inquiry we have welcomed 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.

Our critical concern is to ensure that there is responsiveness to needs of people with disability, continuity of care, and cross collaboration between the disability, health and allied care services and aged care sectors. Through such an approach each person will be able to access or source appropriate supports to meet their needs, regardless of whether they live at home with family, on their own, in supported accommodation or in residential aged care (if over 65).

The Disability Care and Support draft report makes the following recommendations that we endorse as critical enablers to meet the needs of people with disability as they age:

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 (i.e. Aged care sector and disability sector) and have effective protocols for timely and smooth referrals” (Productivity Commission 2011, Disability Care and Support, Draft Inquiry Report, Overview and Recommendations, Canberra, p. 46).

This is a critical proposal to ensure that the overarching principles of a three tiered scheme will work and interact. At the top level there needs to be a focus on influencing community attitudes and supporting civic engagement and inclusion. The second level, as a gateway and referral source, will need to:

- Communicate how services interact to ensure timely and coordinated access to services
- Be resourced to have personnel with local knowledge and capacity manage complex disability assessment processes and respond to cultural diversity.
- Be monitored to ensure a ‘no wrong’ door approach is able to be effectively achieved.
- Provide accountabilities in line with monitoring functions to ensure access and joined up service are achieved. This is particularly relevant for those with co morbid conditions and other complex circumstances, requiring access to a range of potential services, i.e. disability and aged care, psychosocial support needs, people of Aboriginal and Torres Strait Islander descent and those from diverse cultural backgrounds.

Currently, however, there are significant gaps in the capacity of the disability, aged care and health systems to comprehensively meet the needs of people with disability who are ageing.

Disability and Aged Care Interface/s

The Futures Alliance is particularly concerned with issues relating to ageing with a lifelong disability and the policy interface between these. The issues under examination by the Productivity Commission have been referenced in the parallel Inquiry, *Caring for Older Australians*. The Futures Alliance is concerned that neither report identifies people with disability who are ageing as a special needs group within the context of aged care legislation. Our request for such recognition is framed in the context of ensuring responsiveness to the needs of people with disability (who are likely to experience aged related changes prior to the age of 65)

that are not currently addressed adequately within either disability or aged care frameworks.

Appendix C of the draft report identifies the significant differences within the aged care and disability sectors, recognising that in effect these are currently parallel systems. Ensuring an effective interface between the two systems is a critical issue.

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.

Upon reaching the pension age (and at any time thereafter), the person with the disability should be given the option of continuing to use NDIS-provided and managed supports or moving to the aged care system. If a person chose to:

- Move into the aged care system, then they would be governed by all of the support arrangements of that system, including its processes (such as assessment and case management approaches
- Stay with NDIS care arrangements would continue as before, including any arrangements with disability supports organisations, their group accommodation, their case manager or their use of self-directed funding

Either way, after pension age, the person with a disability should be subject to the co-contribution arrangements set out in the parallel inquiry into aged care.

If a person over the pension age required long term aged residential care then they should move into the aged care system to receive that support.

In implementing this recommendation, a younger age threshold than the pension age should apply to Indigenous people given their lower life expectancy, as is recognised under existing aged care arrangements” (Productivity Commission 2011, Disability Care and Support, Draft Inquiry Report, Overview and Recommendations, Canberra, p. 46-47).

The Futures Alliance has identified several key issues impacting on the capacity of the aged care sector to meet the needs of people with disability where this has been identified as the most appropriate option and in line with a person's choice:

Service Delivery

Continuity of support is vital for people with disability who move from disability support into aged care or end of life care, and in particular for people who have limited social connections. There is currently limited capacity within the Aged Care system to meet the unique psycho-social needs of people with a lifelong disability.

Aged care should not be seen as the preferred option for people with Intellectual Disability (with low support needs) or other disabilities such as Acquired Brain Injury etc who are ageing prematurely. This cohort are currently particularly vulnerable to premature admission into residential aged care and new options for ageing in place support is critical. A new system should provide appropriate opportunities for people under the age of 65 in particular to maintain community based options, and for there to be choices to enable this.

The Futures Alliance is seeking a variety of models of community-based living and support for people with a disability under the age of 65 who are ageing, so that residential aged care is not the only option available to them.

In this we seek to ensure that people with disability who are experiencing age related changes earlier than the broader community will have their disability care needs met within community based settings. This will require access to appropriate assessments to reflect significant changes in support needs, and to have these met within appropriate community based supports.

Assessment

The assessment process for the NDIS should be focused on functional support needs of a long term nature, in line with the ICF definition and therefore include people with disability arising as a result of psychosocial support needs. The current difficulties relating to assessment processes are acknowledged in the draft report.

It is critical that any assessment processes recognise the complexity of disability, including effects of ageing and other significant factors such as mental health, on disability. Within the current system, gaps in policy between disability agencies and the health sector, means that people with a mild intellectual disability and with primary mental health diagnosis are not eligible for disability services despite the often significantly disabling effects of this co morbidity.

The assessment process for the NDIS needs to be able to identify and respond to changing needs over the course of the person's life. In particular the Futures Alliance are concerned that any assessment tool used for the purpose of determining NDIS eligibility is sensitive to changes in a persons function related to premature ageing and that funding and services are adapted accordingly.

Funding Options

The Futures Alliance endorses the proposal that separate funding for disability and aged care is maintained for the time being. This option is more likely to safeguard against potential reductions in quality of care through forced transitions of people with disability to aged care prematurely based on costs rather than quality of life and ensure a continued focus on maximising community based supports.

The capacity of individuals or their families to manage the costs relating to long term disability has been identified by the commission as a critical issue. In comparison, costs for those acquiring disability over the age of 65 are comparably less and more able to be met through co-contributions due to the greater likelihood of long term productivity and the accumulation of savings. We would however, also seek to ensure that any person over the age of 65 was able to adequately have their care needs met regardless of cause of disability or source of income.

Regardless of the proposed funding option it is critical that the needs of people with disability as they age, their disability supports and aged related changes are able to be assessed, and addressed across agencies without issues of cross subsidisation being a barrier to service access and solutions to meeting the needs of people with disability.

Co-Contributions

The Inquiry into Caring for Older Australians recommended a system of co-contributions to meet the costs of care. Whilst we acknowledge that this is based largely on capacity of people without life long disability to make a means tested co-contributions, we are concerned about the impact of this policy for people with lifelong disability.

It is not clear from the report whether a person covered by the NDIS, over the age of 65, and who lives within supported accommodation with a disability provider, would be subject to the co-contribution within the aged care system. If this is the case we would seek to ascertain that people with disability who wish to continue to live in their existing and satisfactory living situations will not be subjected to a reduction of funding that may impact on their quality of life. Therefore, that any co-contribution arrangements for aged care will not disadvantage those with a life long disability that may have limited access to financial resources.

Advocacy

People with a disability often require advocacy and support, including substitute decision making for those who are unable to make choices regarding their supports and services, making decisions relating to aged/end of life care. The report does not make clear how the costs of such advocacy services will be met.

Summary

The Futures Alliance congratulates the Productivity Commission on this comprehensive draft report into Disability Care and Support and endorses the principles contained in the report, in particular the recommendation for the adoption of a National Disability Insurance Scheme.

In finalising the report we urge the Productivity Commission to pay particular attention to the recommendations of the Futures Alliance specifically in relation to the treatment of people with a disability who are ageing within the NDIS.

The Futures Alliance strongly supports the principle that people with disability should not be living in aged care under the age of 65. The aged care system is typically utilised by people in their last years of life. It should no longer be the default option for people with disability, to compensate for system that lacks suitable alternatives.

People with disability who are under the age of 65 require appropriate community based living options and those over the age of 65 require the dignity and respect attributed to all citizens to have community based support, with residential aged care the option of last resort. People with a disability, like those in the mainstream population, should only enter the aged care system in the last years of their lives.

The Futures Alliance is appreciative of the opportunity to respond to the Draft report into Disability Care and Support and we look forward to the details of how the National Disability Insurance Scheme will work in practice to achieve the identified recommendations.

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.

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Chairperson

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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:

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For Communities and Families:

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- 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, and 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 a National Disability Care and Support Scheme makes recommendations which will better meet the needs of people with a disability who are ageing, however we believe that there are outstanding issues not resolved by either 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. Any changes to the ACAT process should 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.

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. 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. 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.

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