Submission to the Disability Care and Support Inquiry: Productivity Commission

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Introduction

In the main part of this submission I address specifically the question posed in the Issues Paper at page 19, '**How can the scheme address disability associated with natural ageing and why'**

I have been researching the issues associated with people aging with a lifelong disability for the past 20 years. I use the term lifelong disability to refer to people who have an intellectual disability or some other form of disability acquired during child or early adulthood. This work has considered both support to older parents to plan for the future care of their son or daughter with a disability, and services for aging people with lifelong disabilities once they lose the support of their parents. This work constitutes a significant body of Australian evidence about the issues that face people aging with a lifelong disability, and how policy and service systems currently respond and ways in which this might be improved. (for example, Bigby, 2000, 2004, 2008, 2010; Bigby et al, 2008, 2010; Bigby & Knox, 2009; Webber, Bowers, Bigby, 2010).

I support the notion of a National Disability Insurance Scheme. If implemented such a scheme would over time resolve many of the current issues faced by middle aged people with disabilities living at home with their older parents and provide much improved experiences in the earlier parts of the life course in respect of health, social participation and occupation for people with a disability which would significantly improve their chances of healthy and active aging.

My position is that the NDIS should include all people with disability whose disability is acquired before the age of 65 or the minimum expected age for access to aged care services **And** that there should be continued access to support from the NDIS system for people with lifelong disabilities after the age of 65. As I understand it this is the position proposed in the Report of the Disability Investment Group (2009). (It is important to note that at present the eligible age for access to aged care services is variable between programs and it would be important, if there was to be a cut off for NDIS based on when disability was acquired that consistent age eligibility was achieved across programs in the age care system).,

I set out a summary of the main points below and then a more detailed rationale for this position.

Summary of Main Points

- People with a lifelong disability who are older are not simply older people; their lifelong disability has a significant impact on the processes of aging and the types of needs they have when they are older.
- They require ongoing access to disability specific supports as well as access to expertise from the aged care system.
- Their aging processes are often complicated by the interplay of age related and disability factors, and to date neither disability nor aged care systems have had the expertise or mandated responsibility to meet some of these needs.
- Some types of support or services required by older people with lifelong disabilities are currently not available within either the aged care or disability service systems.
- The result of the current policy vacuum about the interface of disability and aging systems is that people with lifelong disability can be significantly disadvantaged and have decisions made about their lives that result in moves to inappropriate accommodation or retirement plans which fracture existing relationships and sense of purpose, and poor access to diagnostic, health and rehabilitative services.
- It is fundamentally important that the design of the NDIS takes into account the complex interplay between disability, health and age related needs as people with disabilities age.
- Many of these challenges relate to increasing the overall capacity of the disability, health and aged care systems to respond to the needs of people aging with a lifelong disability. Increasing system capacity should be a key part of the NDIS as well as providing more targeted individualised support or funding to purchase services. At present the system has few appropriate supports to purchase for this group.

Changing demographics

The prevalence of disability increases with age (AIHW, 2004a), but older people with disabilities comprise two distinct groups that are often confused: people with lifelong disabilities who are ageing and people for whom ageing is associated with the onset of disability. In the last 20 years, the life expectancy of people with a lifelong disability has increased to more closely resemble that of the general population. For example, the life expectancy of people with Down syndrome increased in the period 1960–95 from an average of 15 years to an average of 50 years (Haveman, 2004).

The population of people ageing with a lifelong disability will grow rapidly over the next decade, but will remain a relatively small proportion of the population of people with disabilities (4 per cent, AIHW, 2000) and an even smaller proportion of the population of older people. The population of older people with disabilities in services funded under the current Commonwealth Disability Agreement (CDA) services is a product of the potentially eligible population and the combined historic and current effect of service development and entry policies. Not all people who are eligible are in receipt of CDA services and supports, so any planning for aging people with lifelong disabilities must take account both of those in the service system and those who are currently waiting for services or may be expected to need services as they age. Middle aged people with disabilities living at home with parents or other family members are perhaps the largest group in this position. They are likely to require accommodation support services in their 50s and 60s as result of the loss of the support of their parents, and they will continue to require services as they age. {Clearly this may change into the future as the NDIS provides the means for young adults with a disability to live more independently of their parents}Another group are people with lifelong disabilities who have lived relatively independently and remained out of touch and ‘unknown’ to the disability service system for much of their life but whose functional capacity is reduced in middle-age as a conseqence of the progression of their disability combined with age related issues.
It is important therefore that entry to the NDIS system can occur at any stage of the life course and provision is made to assess middle-aged people with lifelong disabilities as well as younger people.

Despite the projected steady growth rate of older people with a lifelong disability, they will remain a very small sub-group of the total potential NDIS eligible population and NDIS service users. Excluding people in institutions, in 2003-04 there were 506 people older than 65 years in group homes or domestic scale supported settings and 1083 people in these age groups living in private residences with various forms of in-home support. People over 65 years in group homes were most likely to have an intellectual disability (78.8 per cent) whereas people over 65 years living in their own homes were most likely to have sensory disabilities (64.8 per cent) (AIHW 2005b Interactive data cube *www.aihw.gov.au/disability/datacubes/index.cfm*).

Primary disability group by over 65 years age group, CDA group homes and in-home support, Australia 2003–04

Primary disability	**Group homes**	**In-home support**
Intellectual	399	89
Physical	49	117
Acquired Brain Injury	13	24
Sensory	5	702
Other disabilities	34	70
Not stated	6	81
Total	**506**	**1083**

(AIHW, 2005b): Interactive data cube
http://www.aihw.gov.au/disability/datacubes/index.cfm

Our research suggests too that a significant number of ‘younger older’ people with lifelong disabilities are living in residential aged care facilities which are not well adapted to their needs. Most of this group are no longer counted as being in need of or receiving disability services. They have in many instances been placed there due to the absence of other alternatives when their parents die or other services do not have resources to adapt to their needs. This group of people are not the focus of the younger people in nursing home campaigns, but are significantly younger, enter at an earlier age and stay significantly longer in residential aged care facilities that other residents (Bigby et al., 2008). Many are misplaced and would potentially thrive in alternative living situations. Considering the cost savings that an NDIS could produce for other sectors such as the aged care system will be important.

It is important to note however that not all younger older people with lifelong disabilities are misplaced in residential aged care. For example, some younger older people such as people with Down syndrome and dementia may well require the specialist care and environmental adaptations provided by aged care dementia units. Our current unpublished work makes it clear however, that such units whilst meeting health related needs cope poorly with social needs of people with lifelong disabilities, reinforcing the continued need for ongoing disability related support and increasing the capacity of the aged care sector to adapt to the needs of people with lifelong disabilities.

Why distinguish aging people with lifelong disability, why is this group not simply older

Although a diverse group, people ageing with a lifelong disability share some common characteristics associated with their pattern of aging and the impact of their life experiences of being a person with a disability. This suggests they should continue to be regarded as people with a disability and a distinct special group of older people who cannot simply merge into the general aged population. For example, some groups of people with lifelong disability age relatively early, experience additional health needs or impairments associated either with ageing per se or with their original impairment. For some their age related health needs are a complex combination of disability and age related changes. For example, people who had polio may experience increased fatigue and reduced mobility from post-polio syndrome (Kemp & Mosqueda, 2004; McColl et al., 2003); people with Down syndrome have an increased likelihood of dementia, often in middle age (Janicki & Dalton, 1998). This means that both age and type of impairment must be taken into account in predicting the increasing needs people ageing with a lifelong disability. Current discussions in disability fail to take into account such condition-specific patterns of ageing and consequent optimum service responses.

Life experiences as a person with a disability will mean many will be aging from a particularly disadvantageous position. For example, many will have used the support of services throughout their lives to assist in day to day decision making, support activities of everyday living or to access purposeful day and leisure activities. They will continue to require such services as they age. Many will be aging within an accommodation support service system, where it is more complex to adapt to changed support needs, rather than in a private home with more flexible informal carers and drop in support (for example the ratio of people with intellectual disability living in the family home compared to supported accommodation changes from 70:30 to 30: 70 after the age of 55 years (Emerson et al. 2001). Most people with intellectual disability will not have married or had children and have very limited informal support networks as their parent's age and die (for example Bigby, 2008 found only 33% of older ex institutional residents saw a family member more than once a month and 50% only saw a family member once a year). Most older people with lifelong disability will not have been in paid employment, and have limited wealth or income to enable the exercise of choice and access to private health systems as they age (Bigby, 2004).

Again it is worth noting that a life course perspective to aging, that optimises opportunities for development, employment, participation and independence during child and adult hood will reduce the demands made on service systems by people aging with a lifelong disability.,

Changed Needs as People Age

As people with a lifelong disability age they will continue to require some of the types of support that have been available from the disability system for example, – aids and equipment, accommodation support, advocacy, family support, support with activities of everyday living and to participate in leisure and recreation. Age related changes may mean that the nature and intensity of such support may change. They may no longer need some types of support, for example, vocational support and may require new types of support, such as support with retirement plans, access to specialist health or allied health care, or dementia assessment and care.

They may require access to age associated care services at an earlier age (e.g. early onset dementia for people with Down syndrome); such services may require specialist knowledge (e.g. diagnosis of dementia in people with already impaired cognitive capacity). They may require age associated services that are not available or needed by other older people (e.g. access and linkage programs to negotiate and support access to meaningful retirement activities). They may require specialist health services associated with their long term impairment that are not currently available. They may require their existing disability service to provide additional or more intensive support (e.g. if they live in a group, modifications to take account of reduced mobility, more intensive health monitoring or night time support). Clearly some of their needs will be similar to those of the general aged population, some are however are likely to be quite different, as is the combination of their needs.

Currently, there is no firm policy as part of the CDA to guide the provision of support to aging people with lifelong disability, either in terms of what are reasonable expectations or which system or systems - aged care, community care, disability, or health, should take responsibility. There is for example, no commonly accepted definition of aging in place (does this mean, for example, remaining in the group home in which you live or simply remaining in services provided by the disability organisation), nor policy as to whether a person residing in disability funded shared supported accommodation can expect to age in place. There is no shared understanding of retirement, especially for those who have never worked, or of the level of participation in social, volunteer, leisure and recreational activities for which an older person with lifelong disability might reasonably expect to receive support. There are few mechanisms in place to ensure aging people with disabilities can gain access to quality primary and hospital health care responsive to their unique combination of disability and aged related needs. This lack of clear policies means there is considerable inconsistency and uncertainty in access to services for older people with lifelong disabilities. It also means people are unable to access appropriate support or may only be able to access inappropriate types of support.

Both anecdotal and research evidence indicates that people with lifelong disabilities have difficulty accessing appropriate types of support and care as they age. For example, people in shared supported accommodation cannot access HACC services available to people living in private homes, they may be unable to retire or reduce attendance at a day centre as no staff are available to support them during the day at home. Staff from shared supported accommodation may be required to accompany them during hospital stays. People with disabilities are seldom included in health promotion initiatives and have a very low level of preventative screening. Staff in the disability services may lack knowledge and skills of aging processes and feel ill prepared to provide care to people with age associated health needs. Staff in the aged care system, for example residential aged care, memory clinics, aged care assessment services lack knowledge and experience in assessing and treating people with lifelong disabilities. There are unclear relationships between HACC and Disability services for people aging with a lifelong disability living in private homes in the community. They may access multiple packages of care but be accorded low priority for HACC or Aged Care packaged if they are in receipt of disability funding. (Bigby, 2004; Fyffe, Bigby, McCubbery 2006; Bigby, Fyffe, Balandin, Gordon & McCubbery, 2001; Bigby, Fyffe & McCubbery 2005;Bigby, 2008, 2010; Bigby & Knox, 2009; Webber et al., 2010, Bigby et al., 2010).

A common thread to the difficulties of accessing appropriate support is that of double dipping – it is assumed that people who receive disability services should not also have access to community or aged care services. The other thread is a lack of resources and or expertise in health and community services available to the general community about people aging with a lifelong disability that means the needs of this group cannot be met by such services (Bigby & Balandin, 2005; Fyffe, Bigby, McCubbery 2006). As Bigby and Balandin (2005) found regarding access for people with lifelong disabilities to mainstream day activity and leisure services, it was not a lack of willingness on the part of services that created the obstacles but rather an absence of expertise, knowledge and resources to facilitate access. This speaks to the need for capacity building in mainstream community support services.

NDIS and Aging Issues

In summary, there is an absence of specialist health and allied health services to assess and respond to the health needs of particular groups of people aging with a lifelong disability. In particular those with cerebral palsy, polio, and Downs syndrome. Health, allied health and aged care services available to the general population are not knowledgeable or responsive to many of the needs of older people with lifelong disability. Disability services do not have the expertise, resources, or policy mandate to enable them to adapt effectively to the needs of people aging with a lifelong disability.

These issues can be addressed by the NDIS by ensuring mechanisms are built into the scheme that ensure funding levels can be adjusted as people age and their needs change and in setting clear expectations about aging; such as people’s rights to age in place even if their home is a group home and to continue to be engaged in meaningful activity even if they are no longer productive and require support to choose and participate in activities. The scheme must recognise the continued disability related needs of people as they age, as well as building the capacity of the aged care system to employ its expertise where appropriate to meet the needs of people with lifelong disabilities.

The NDIS must also avoid the assumptions that have underpinned the CDA to date that people with lifelong disabilities have access to quality health care. In their submission to the Senate Community Affairs References Committee on Quality and Equity in Aged Care (SCARCQEAC) the Department of Family and Community Services (FaCs) stated:

[people with disabilities] may need physiotherapy for their physical disability. They may need speech therapy for their communications needs. Beyond a very minor level, those therapy services and acute treatment type services are not considered to be part of the CDA…the purpose of the clause was very much around trying to draw a line between the purpose and scope of the CDA and the provision of health and allied health services that would generally be available to anyone in the community (Commonwealth of (Australia, 2005) 170).

FaCs concludes that if appropriate access is not available it is up to the State to address this issue rather than any shared responsibility as part of the CDA.

Whilst access to quality health services is an issue for people with disabilities across their life course, it becomes critical as they age, and a key program interface that has been ignored is that of health and disability. The new NDIS system must pay explicit attention to measures that support the inclusion of aging people with lifelong disability in health and allied health services and provide resources for specialist health services when required. Many examples are found overseas of initiatives in this area, such as specialist geriatric assessment clinics for people with developmental disabilities, liaison schemes to support the access and admission of people with lifelong disabilities to hospital care, employment of nurse practitioners to advise disability providers in regard to health issues, development of specialist dementia assessment tools for people with developmental disabilities and the establishment of specialist clinics or provision of consultation to generalist clinics (Janicki & Ansello, 2000); (Davidson, Prasher, & Janicki, 2003; Bigby, 2004, see also recent initiatives in the UK in response to the Mencap Death by Indifference Report).

Recognition a Person can be both a Person with a Disability and an Older Person.

The current CDA funding formulae and administrative arrangements that govern the aged care and disability service systems assume that a person is either disabled or aged, but cannot be both. This position is shared by State or Federal government departments and was illustrated by the submissions made to the SCARCQEAC by various departments. For example, the Queensland's' government submission stated clearly assumes a person is either aged or disabled but not both.

"It is also evident that some people with a disability access aged care facilities due to an early onset ageing condition. In these instances the need for aged care nursing may outweigh

the need for disability support. For example, people with certain disabilities such as Downs Syndrome are more prone to early onset dementia conditions. As these ageing conditions progress, the individual may reach a point where their need for aged care and monitoring outweighs their need for disability support (Commonwealth of Australia, 2005, Section 108)

This leads to the position that all of a person's needs will be met by their accommodation provider. For example the FACS submission stated,

"Whether it is a CDA accommodation support service or an aged care place that is provided outside the CDA, I think it is fair to say that the assumption in both cases is that the service is meeting the needs of the person…if a person is receiving an accommodation support service or a nursing home service, those service providers are meeting that person's need" (Commonwealth of Australia,2005, Section 168)

The FaCs position also seemed to be that it could not be a shared responsibility of both the disability and aged care sectors to meet the needs of aging people with a lifelong disability, but rather that of the disability sector if they chose this as a priority. FaCs commented,

that there is no barrier in the CDA to anyone in a range of housing options from accessing a component of support out of CDA: It is up to the States and Territory how it manages the expenditure of those funds on people with disabilities…They know they are responsible for the planning and policy setting. It is possible that the States are making decisions about what they see as relative priorities…As long as they spend the money they have committed to spend on people who are in the target group of the CDA, which are essentially people with disabilities, it is up to them what they spend that money on". (Commonwealth of Australia, 2005, section 169)

The FaCs commented: *'We are clearly starting to face very real issues at that older age nexus. I admit that it is not something in the disability world that a great deal of attention has been paid to in the past. Increasingly we are doing that but I would still come back to my earlier point that it is really a case of the appropriate expertise and appropriate kinds of support, rather than trying to look at how a mix of services might go into the one service. I am happy to accept that there are needs for improvement in the services'.* (Commonwealth of Australia 2005, section 5.55)

The failure to see a responsibility for people aging with a lifelong disability as a being shared between the aged care and disability sectors, was confirmed by the report commissioned by the National Disability Administrators (Fyffe, Bigby & McCubbery, 2007). As argued earlier people do not lose their identity and special needs as a person with a disability as they age, rather they acquire additional needs that are more appropriately met by the aged care system in partnership with their existing disability services. The arguments about double dipping must be challenged. This can be done by a clearer articulation of the purpose of disability support services.

It is clear that different perspectives are held about fairness and role of Disability Services, primarily whether such services are compensating citizens with a disability for the additional needs that result from their disability, or whether they are designed to meet all the needs that a person with a disability might have. These different views can be illustrated by considering the response that each position would give to the question, is earlier dementia in people with Down syndrome, a disability or aging problem?

If a person with a disability is seen as a citizen first, then disability services compensate for disability – by for example, providing support with individual planning , the exercise of choice, advocacy and to carry out everyday activities and participate in the community. Early dementia then is an aging problem that requires narrow and specialist aged care expertise in addition to breadth of supports required by person with a disability as a result of lifelong disability. Aged care dementia specific services should top disability services, resulting in a partnership between the two not double dipping.

If on the other hand disability is considered as the person’s dominant characteristic rather than citizenship, then Disability services are seen to provide comprehensive support across and whole of life. From this perspective, early onset dementia for someone with a disability is a disability problem that requires continued support from disability services, adapted to the needs of a person with dementia. As the person already has substantial support from that system, and it is not equitable to involve aged care, when some other older people have no support at all. The imperative is to avoid double dipping which means the sectors remain mutually exclusive.

Clearly current policy directions in Disability policy regard people with disability as citizens first and foremost and disability services as compensatory to be delivered in conjunction with services available to the general community or as a means of making such services more accessible to people with disabilities. Disability services are not intended to be exclusionary, to cover all aspects of the person's life or to replace generic or specialist services available to other members of the community. But attention must be paid to making services available to the general community accessible and adapted to people with disabilities. This has been clearly demonstrated to require not only goodwill and partnerships but also dedicated funding (Putnam, 2004).

Evidence from the various Innovative Pilot Pool projects (see conference presentations; 2006 CIDA; 2006 ACROD SA, 2005 Armidale Challenge; 2005 ACROD Tas) which are brought together in the 2006 report by the AIHW demonstrates the success of funded partnerships between aged care and disability service providers in maintaining people with lifelong disabilities in their own home, which is shared supported accommodation. This report suggests that the costs of topping up Disability accommodation services for older people with lifelong disabilities is significantly less than the cost of a place in a residential aged care facility.

Collaboration and funded partnerships between the aged care and disability sectors has been strongly argued by service providers and peak bodies from both sectors. For example,

'Witnesses argued that people ageing with disabilities require specific and considered responses from all levels of government to meet their needs. ACROD focussed on the need 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 need'(Commonwealth of Australia, 2005, section 5.47)

This position is reflected in a Memorandum of Understanding, signed in July 2005 by NDS, ACSA, Carers Australia, COTA National Seniors and the Australian Federation of Disability Organisations, which affirmed a commitment to work collaboratively to raise awareness of issues associated with ageing with a disability, to promote information and training and to encourage policy development and partnerships within and between the Sectors.

Suggested Directions

It is important therefore the proposed NDIS formulates clear policies around responsibility for aging people with lifelong disability, ensures mechanisms for disability funding to be adjusted as people age and their needs change; and addresses access to generic community, health and aged care services, where appropriate, through capacity development initiatives and funded partnership initiatives.

The disability sector has taken the lead in adapting its services to the needs of people with disability but though many innovative developments have occurred they have been of an ad hoc nature, often with short term project based funding. Little systematic knowledge or service infrastructure, such as training and support has occurred to support service development for people aging with a lifelong disability.

The National Disability Administrators Group have funded major research projects on issues associated with aging, both on retirement (Bigby et al, 2001) and aging in place (Fyffe, Bigby, McCubbery, 2007). Yet no policy directions have flowed from this research. This is alarming given the considerable Australian and international research about the needs of this population conducted over the past 15 years.

Explicit policy directions and funding mechanisms must be built into the NDIS and any new national disability strategy and CDA. Provisions must be made for aging people with lifelong disabilities in shared supported accommodation or other forms of accommodation to access additional support and health care coordination to enable them to age place, as well as consideration given the transfer of funds from different parts of the service when people with lifelong disabilities retire from supported employment programs. Policy aims such as aging in place, retirement, access to specialist and appropriate high quality health and allied health care for older people with lifelong disability must be made explicit. Funding mechanisms to support the inclusion of people with a lifelong disability in primary and hospital care services, as well as the development of specialist assessment and medical services for particular groups must occur. The capacity must be increased of the aged care system to respond appropriately to people aging with a lifelong disability who require the type of care offered by specialist dementia or age care facilities.

It would be unfair and unjust for any NDIS to stop at age 65 and abandon people with life-long disabilities to an inaccessible unresponsive health and age care system, or vacate their homes and independence which are very dependent on funding and support based on their status as a person with a disability. Perhaps a transfer of funds from the Aged Care sector to the NDIS based on the age profile of people with a disability would be appropriate to consider in recognition of the significant savings and reduced demand on the aged care system that would result from people continuing to rely largely on disability services as they age and thus requiring only minor 'top up' from Aged Care.

On a final more general note, although there is no doubt that research on disability service systems has been neglected in Australia, it is also important to recognise significant research has been undertaken both in Australia and overseas on issues associated with policy and practice that supports people with disabilities to be socially included in society and lead the best possible quality of life. Academics are seldom listed in the NDIS documentation as stakeholders in the disability field yet the few academics working in this field scattered across Australia do have the potential to contribute to policy development both original Australian research and a strong knowledge of the literature on a wide range of issues .

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