Submission to the Senate Community Affairs Reference Committee: Inquiry into Planning Options and Services for People Ageing with a Disability.

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Introduction

I have been researching the issues associated with people aging with a disability for the 15 years, in respect of both support to older parents to plan for the future care of their son or daughter, and services for aging people with 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 disability, and policy and service systems in responding to these (for example, Bigby, 2000, 2004, 2008, 2010; Bigby et al, 2008, Bigby & Knox, 2009);

In summary the key issues are:

- The increased life expectancy of people aging with a lifelong disability has created a new and growing population that requires significant support to maximize their quality of life and achieve a similar degree of health and social participation to that expected by other members of the population.
- People aging with a disability, are not just older people but also people with lifelong disabilities who require ongoing support from disability services as well as additional support with age related issues such as early onset dementia, complex health conditions which stem from the interaction of the original impairment, secondary impairments and aging, (for example people with polio or cerebral palsy) (Bigby, 2004)
- There is an almost total absence of policy in respect of this group at both Federal and State levels, and as a result ill prepared and unresponsive service systems in the health, aged care and disability sectors (Bigby, 2008, 2010).
- The lack of policy impacts on the lives of people with disabilities, who fear retirement from, for example supported employment services as there are no alternative forms of support to enable continued participation in meaningful activity and contact with friends. No part of the service disability service

system – be it day programs, employment services, group homes or respite services has a mandate to support either older parents or adults already using services to plan for their future as they age. As a consequence, decisions are made often about people's lives that are shaped by the needs of the service system (such as forced retirement or a move to an age care facility) which jeopardize relationships and purpose (Bigby & Knox, 2009).

- The combination of disability and age related needs has led to problematic service system interfaces that have not been sufficiently addressed by policy or specific programs. For example, age barriers exist to accessing the type of dementia diagnostic and intervention services available to the general community; those in the health system, both medical practitioners and allied health professionals have little specialist knowledge of the special needs of people aging with a disability. People living in group homes find it hard to access HACC services such as day centres, or services of OT's to adapt accommodation (Bigby, 2008).
- The absence of policy and programmatic support to age in place in group homes means that some people move prematurely and inappropriately to residential aged care facilities. There is also a lack of procedural processes and equity in the way decisions are made for people to move. In most instances a move is caused by a complex combination of a persons' existing situation, the degree of change that occurs and the capacity of the group home provider to adapt and gain access to additional or flexible resources (Bigby et al., in press)
- Residential aged care facilities are ill equipped to meet the needs of younger older people with a lifelong disability, and this group stand out as a minority group in that sector (Bigby et al., 2009).
- Respite programs for older carers do not have the expertise or mandate to support planning for the future and broker the realisation of such plans. They do support older parents and raise issues and begin separation processes that may lead to greater independence for the person with a disability and consideration of broader options. There is an absence of housing and or support services that work proactively and collaboratively with older parents to develop and implement options for care of middle aged and older adults with intellectual disability before a crisis occurs.

The Problem

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 life long 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 life long 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 life long 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. They are a diverse group that is difficult to define with clarity. The population of older people with disabilities in services funded under the 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 life long 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 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.

Despite the projected steady growth rate of older people with a life long disability, they will remain a very small sub-group of the total CDA eligible population and CDA 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*).

Table 4: 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

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

Although a diverse group, people ageing with a life long 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 that suggest they should be regarded as a distinct special group of older people, who cannot simply merge into the general aged population. For example, some groups of people with life long 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 disability type must be taken into account in predicting the increasing needs people ageing with a life long disability. 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 support activities of everyday living or to access purposeful day and leisure activities and will continue to require these as they age. Many will be aging within an accommodation service system rather than a private home. 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. Most 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).

As people with a life long 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 every day 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. They may require new types of support, such as access to specialist health or allied health care, or dementia assessment and care. 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 life long 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, 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 and of the level of participation in social, volunteer, leisure and recreational activities for which an older person with life long 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 mid level policies means there is considerable inconsistency and uncertainty in access to services for older people with life long disabilities. It also means people are unable to access appropriate support or may only be able to access inappropriate types of support.

Specific problems

Both anecdotal and research evidence indicates that people with life long disabilities have difficulty accessing the appropriate type 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 life long disabilities. There are unclear relationships between HACC and Disability services for people aging with a life long disability living in private homes in the community. They may access mmultiple 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., in press, Bigby et al., in press).

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 life long 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 life long 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.

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 life long 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 life long 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 life long disability.

Split of functions in CDA

Some of these problems stem from the nature of the CDA, that splits functions between the States and the Commonwealth. For example, people who retire from Commonwealth funded supported employment programs are reliant on State Disability services to meet their needs for support to participate in purposeful day time activities, yet for this group there is no explicit transfer of funds between the two levels of government to enable this to occur. This is not a problem for people aging within State funded disability day support services.

Assumptions about access to health and allied health services

The CDA is based on the assumption that people with life long 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 CDA must pay explicit attention to measures that support the inclusion of aging people with life long disability in health and allied health services and provides 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 life long 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).

No assumption of shared responsibility by disability and aged care sectors.

The current CDA 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. 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 seems to be that it is not a shared responsibility of both levels of government to meet the needs of aging people with a life long disability, but rather that of State governments 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 life long disability 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 loose 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 life long 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.

Evidence from the various Innovative Pilot Pool projects (see conference presentations; 2006 CID; 2006 ACROD SA, 2005 Armidale Challenge; 2005 ACROD Tas) which are brought together in the 2006 report by the AIHW demonstrates the success of partnerships between aged care and disability service providers in maintaining people with life long disabilities in their own home, which is shared supported accommodation. This reports suggest that the costs to the Commonwealth of topping up Disability accommodation services for older people

with life long disabilities is significantly less than the cost of a place in a residential aged care facility. The need for collaboration, shared funding and responsibility 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.

It is important therefore the CDA formulates clearly policies around the shared responsibility between State and Commonwealth and the Disability and Aged care sectors for aging people with life long disability.

Allied problems

A related issue is the need to recognise that some of the changing needs currently associated with aging may be simply changes that occur during adulthood and middle age. There is a tendency to class all such changes as due to aging. This arises in part because there are no mechanisms with in disability funding to increase resources to take into a person's changing support needs. Nor are there population based funding mechanisms in disability that clearly articulate benchmarks for service provision for people with disabilities across their life course. The CDA should encourage the development of both these mechanisms

Supporting Older Families to Plan for the Future

Some older families who support a family member with a disability are hidden and a small number out-of-touch with the service system. Few older families have in place firm plans for the future and most, including those who have made informal plans, have limited notions of what might be possible for the adult with a disability in the future. Older families are anxious about the future, and when plans have been made they did not necessarily reflect the preferences of the adult with a disability. Families have not generally compiled life stories or a central repository of information about the history of the person with a disability and their current and future needs and aspirations. However for some families, where the adult does not have a cognitive impairment such measures may be of little value. Building a relationship with carers can encourage planning, access to respite opportunities and mutual support from other carers (Bigby & Fyffe, 2009; Knox & Bigby, 2007; Bigby, et al., 2002)

While not conceptualized as such by families, use of respite does lead to separation between parents and their sons/daughters which is preparatory for future care transitions. Respite also has the potential to build new relationships, interests and skills for the adult with disability. The respite programs targeted at older carers could develop this aspect of their work by a more targeted focus that involves the adults with a disability in thinking about their own future, developing their skills and helping to develop their connections to their locality. Many of this group are lonely and lack opportunities to make friends beyond the household. Their current and future quality of life could be improved by a more concerted effort to build their involvement in their local community, as a source of new activities, relationships and skill building. All of which, in the long run will be useful for living without their older parents, and better enable them to remain in their chosen form of accommodation.

Many engaged families do want to plan for the future but the broader service context militates against the feasibility of long term planning. While the older carers programs can raise ideas about future options with families they do not have the expertise to take the next step of piecing together non-traditional options, that may involve complex partnerships between private and public resources, and the combination of housing and support for individuals or small self-chosen groups. Longer term planning is hampered by the lack of any service that fulfils a more specialist role of moving planning from thinking to action. This must take the form of regional capacity to provide expertise and work with (older) families, who are ready to take the next step, to develop alternative housing and support options which make use of assets and other resources families want to make available to add to community and government provisions.

Community development workers have identified an absence of good system level data about older families and future needs for accommodation and support. There are a range of specialist and generic programs that work with older carers and/or adults with a disability and mechanisms are needed for such programs to shard resources. However, there continues to be no sense of a regional or sub-regional approaches or coordinated strategy to developing support for older carers and the transition to different options for adults with a disability who live with older carers.

Suggested Directions

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 life long 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 completed in February 2006 (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 any new disability strategy and CDA. Policy aims such as aging in place, retirement, access to specialist and appropriate high quality health and allied health care for older people with life long disability must be made explicit. Funding mechanisms to support the inclusion of people with a life long disability in primary and hospital care services, as well as the development of specialist assessment and medical services for particular groups must occur. Provisions must be made for aging people with life long disabilities in shared supported accommodation to access additional in home care to enable them to age place must be put in place, as well as consideration given the transfer of funds from Commonwealth to States when people with life long disabilities retire from supported employment programs.

In summary the following broad solutions are offered.

Federal Government Level

- **Develop Policy Directions & Articulate Commitments**
    - Aging in place where ever home is
    - Right to retirement But continuing support for purposeful activity
    - Equitable access to health and specialist aged care services if appropriate**.**
- **Implementation Strategies.**
    - Acknowledge premature aging -remove age barriers to Aged Care Assessment Services and Community Aged Care Packages.
    - Acknowledge people aging with a lifelong disability as a 'special group within Aged Care legislation - eg specialist wings in residential aged care that can build up expertise within this sector [note separate specialist residential aged care facilities are not recommended as this population is too small and too dispersed to make such facilities viable].
    - Establish specialist clinics in the health system to deal with complex health issues and diagnosis for people aging with lifelong disability.
    - Take measures to make health systems more accessible – for example liaison nurses, nurse practitioners to bridge gap –and in the longer term ensure disability issues are included in all allied health training
    - Revise funding mechanism to take account of changed needs as people age for those within the disability system – for example there could be a federal 'top up' to states based on the age profile of the population of people aging with a disability
    - A funded access and linkage scheme to support retirement for employees of business services and supported employment.
    - State mechanisms to adjust funding based on age profile of service

    - Specialist consultancy back up to health/ aged care/ disability services
    - Mandate decision making processes and individualised planning

State Government Disability Programs

- **Develop Organisational Policies and Capacity for Aging**
- **Articulate organisational approach and commitments**
    - What does aging in place/retirement mean in this organisation
    - What models will it put in place
    - Adopt a life course approach to aging – healthy life style, occupation, relationships across all ages and programs
    - Foster new accommodation and support brokerage programs with the expertise to support private public partnerships and develop options for people with disabilities wishing to move out of the family home.
- **Put on place planned organisational response**
    - Build knowledge and expertise through staff recruitment, training, specialist positions cross programs/ organisations
    - Develop organisational capacity –supervisors and managers
    - Build health advocacy skills within the disability workforce to leverage for health related resources, as a right
    - Develop mechanisms for individualised planning and decision making processes re transitions.
    - Education for people with disabilities about middle age and aging
    - Build circles of support and ensure external advocates involved in decisions
    - Seize rather than avoid responsibility at individual and organisational levels

I write in the knowledge that considerable reform is occurring in both the aged care and disability sectors that will inevitably impact on the organisation of support and services for people aging with a disability. These reforms however, that include a major new scheme of Disability Care and Support, and Aged Care and Health system reform, some of which are being investigated by the Productivity Commission must all address the issues raised by my broader research and this submission, and take specific measures to ensure the quality of life of this the small but growing group of vulnerable Australians who are aging with a lifelong disability.

Further Information and Attachments.

I have attached to this brief submission some of the material I have written in the last 15 years that reports the research I have undertaken around the specific policy and program issues of meeting the needs of people aging with life long disabilities.

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