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Ageing people with a lifelong disability: challenges for the aged care and disability sectors

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Australia is experiencing a rapid increase in both the absolute numbers and proportion of people who are ageing with a lifelong disability. Aged care and disability are the two key social policy sectors that impact most directly on formal services available to this group. Potentially they may be included or excluded from either sector. This paper compares and contrasts Australian policy directions in aged care and disability. Using people with intellectual disability as an exemplar of those who are ageing with a lifelong disability, the paper analyses their location within and the services offered to them by each sector. The paper argues that neither sector adequately addresses the issues raised by the needs of this group and suggests why this is so. Directions for policy and service developments necessary to ensure that the needs of this growing population are met are suggested. These are broadly categorised as; systematically bridging existing gaps with specialist services; supporting inclusion and ensuring older people with lifelong disability are visible within the aged care system; adapting and resourcing the disability sector to facilitate ageing in place; and developing partnerships and joint planning aimed at the removal of cross- and intra-sector obstacles to accessing appropriate services.

Ageing people with a lifelong disability are a relatively new phenomena to confront policy and service systems. The current cohort of older people with disability is the first group to have survived into later life in substantial numbers. An increased life expectancy combined with the demographic bulge of the baby boom generation means that the number of older people with a lifelong disability will increase by as much as 20% in the next 15 years (Ashman, Suttie & Bramley, 1993). This is illustrated by the dramatic changes in life expectancy that have occurred in the past 50 years for people with intellectual disability. Their average age of death in 1931 was 22 years. This had increased to 59 years by 1976 (Carter & Jancar, 1983) and to 66.1 years by 1993 (Janicki, Dalton, Henderson & Davidson, 1999).

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Responding to the needs of people who are ageing with a lifelong disability is uncharted territory in Australia, and a key policy issue for both the disability and aged care sectors. Neither sector has significant experience, knowledge or expertise around the issues it presents, nor strategies for tackling these. Two distinct but interrelated sets of issues are raised. First, that of older carers, usually parents, who are increasingly likely to be outlived by their middle-aged child with a disability. The issues here centre around the changing needs of carers, support to continue caring, planning for the transition from parental care and replacement of parental caring roles. Estimates suggest that across Australia 7700 adults with a disability are living with carers who are aged over 70 years [Australian Institute of Health and Welfare (AIHW), 1997]. Second, issues revolve around ensuring positive ageing for ageing people with a lifelong disability, and assembling the most appropriate array of services to address their needs. Major foci of debates are which service system should be responsible, is there a point at which age-related needs overshadow those related to disability or do ageing people with lifelong disability have specific needs that differentiate them from other ageing people.

This paper primarily addresses the issues that surround successful ageing for those with lifelong disability. People with intellectual disability are used as an exemplar as they are one of the most vulnerable groups of people with disability, because of their difficulties in exercising choice and their often restricted social networks. Many of the policy and service issues raised in regard to them are common to other disability groups.

Although the majority of people with disability are older, a strong rationale exists for adopting a specific focus on people who are ageing with a lifelong disability. No clear age or stage exists at which ageing people with a lifelong disability simply become ageing people and can therefore be effortlessly absorbed into the aged care system. The life experiences of being a person with a disability impacts on the informal and formal support available and needs as a person ages. For example, few people with intellectual disability will have had experience of paid employment during their adult years, typically their social networks are limited lacking a spouse or children, few would have accumulated assets for their retirement, and most will have had some level of dependency on formal or informal supports for support with tasks of everyday living. Many will already be living in supported accommodation, such as group homes, as they begin to age. Those who have lived at home with parents will have a high need for supported accommodation in their mid to late adult years due to the loss of their parents rather than age-associated decrements. These factors differentiate people with a lifelong disability from others who are ageing and mean that they may have some different needs but also that similar needs may have to be met in a different manner. For example, the use of formal services in place of informal networks.

The demographic characteristics of ageing people with a lifelong disability also single them out as a specific group. Growth of the 80 + age group is less significant among this group than older people generally. For example, only 7.6% of people with intellectual disability over 65 years are aged 80 years or more, a much lower proportion than the estimated figure of 20% for the general community (Ashman et al., 1993; Department of Health, Housing and Community Services, 1991). The differential life expectancy and premature ageing of some people with intellectual disability suggest that this trend of fewer "old old" people with lifelong disability is likely to continue. For example, people with Down syndrome experience high rates of early onset Alzheimer's disease and those with cerebral palsy experience an early decline in physical abilities and mobility (Janicki & Dalton, 1999). Additionally, although the numbers of older people with lifelong disability will increase substantially, because of a higher age-specific mortality rate than the general

population, they will remain a small group both in the aged care and disability sectors. For example, in Victoria although the number of people with intellectual disability over 60 years has increased from 321 in 1982 to 1201 in 1997 (Cocks & Ng, 1983; Department of Human Services, 1997) this group comprises only 6% of those with intellectual disability. Nationally, estimates suggest they comprise 0.07% of all older people (Ashman et al., 1993).

The debate on directions for policy and service development for older people with lifelong disability must be cast wider than which service system has responsibility. It should focus on questions such as: in what ways can disability and aged care service systems combine their resources (knowledge, services, personnel skills) and attain optimum outcomes for older people with lifelong disability? and what new or different policy responses and service developments are needed to ensure that both systems overcome obstacles to meeting identified needs? Three data sources will inform answers to these questions: research and knowledge in regard to the changing needs of ageing people with disability; the underpinning values and policy goals for ageing people with lifelong disability; and the current policies, configuration and performance of the two most relevant service systems. Substantial knowledge now exists about the needs and characteristics of people with lifelong disability, which is documented in recent texts (Bigby, 2000; Janicki & Dalton, 1999; Seltzer, Krauss & Janicki, 1994). Using people with intellectual disability as an exemplar, this paper considers the policy goals for ageing people with lifelong disability and analyses the impact of current policy and service configurations of the aged care and disability sectors on this group.

Policy goals and outcomes

The broad needs of older people with intellectual disability are not substantially different from others who are ageing and include an acceptable living environment, freedom to choose activities and friends, social and psychological well-being and physical independence through good health (Janicki, 1990). Janicki (1994) defines successful ageing as "an individual retaining his or her capacities to function as independently as possible into old age and promoting the belief that persons who age successfully are able to remain out of institutions, maintain their autonomy and competence in all activities of daily living, and continue to engage in productive endeavors of their own choosing" (p. 146).

Few differences exist between older and younger people with intellectual disability in respect of the essential factors that determine quality of life. Very broadly, these are physical, material, social, and cognitive well-being. The broad policy goals of choice, empowerment, integration, community inclusion and family support articulated in Australian disability policies (Annison, 1996) are not substantially affected by age. However, different emphasis or mechanisms may be required to achieve these goals for older people, due to individual age-related changes and the different external factors that make up their social ecology. For example, ageist community attitudes and the aged care service system provide very different backdrops to policy and services for older people compared with those experienced by younger people with disability. The different emphasis that may be required for older people is illustrated in regard to day activities where primary goals for a younger person may be skill development, particularly around vocational competitiveness and independence, while for an older person a focus may be on interdependence, social relationships and community involvement (Janicki, Otis, Puccio, Rettig & Jacobson, 1985).

Policy Sector	
Aged Care	**Intellectual Disability**
Demography	
Aged population increasing	Aged population increasing
Philosophies of Policy and Service Development	
Maximisation of independence, maintenance of skills, valued roles, positive community perceptions, rights, standards.	Normalisation, integration, self-determination, developmental perspective, quality of life, choice.
Policy and Program Directions	
Community care, support to carers, flexible individualised care packages, case management, brokerage.	Importance of family support, community-based services, needs based individualised services, case management, and brokerage.
Service Delivery and Entitlements	
Based on need assessment, no entitlement, need exceeds demand, rationed, resource expansion last 10 years, needs based planning, contracting out of government services, primarily access on functional capacity not age.	Based on need assessment, demand exceeds supply, waiting lists, expansion of resources last 10 years, only entitlement is preparation of service plans, contracting out of government services, no formal upper age limits.

(source, Bigby, 1996)

Figure 1.
Common ground in the aged care and disability sectors.

Similarities and differences between aged care and disability sectors

A consideration of the similarities and differences between the disability and aged care sectors indicates what each has to offer in respect of older people with intellectual disability, the ease that boundaries can be crossed, and the policy and service issues that must be addressed. Similarities between the two sectors that may impact on older people with intellectual disability are summarised in Fig. 1.

At the broad conceptual level, policy documents suggest that both systems have similar philosophies, policy and programme directions and service delivery mechanisms. Both have adopted the principles of normalisation and a shift towards care in the community. The historic approach of "warehousing" the aged and people with disability has been replaced by the provision of environments, care and services that maximise independence, developmental potential, physical, social and mental capacities. Individual rights, choice and quality of life issues have been emphasised and service standards established with avenues for redress. Both sectors have attempted to shift community attitudes towards adoption of more positive notions of ageing and people with disability.

Similar types of programme have been used to implement policy. Both sectors have adopted varying forms of case management and brokerage approaches with an emphasis on tailoring packages of care to meet individual needs (Baldock & Evers, 1991). The nexus between a person's place of residence and the level of support provided by formal services has been broken for the elderly and people with disability as programmes aim to provide levels of support to people in their own homes that were previously only available in a

residential setting. The importance of carers and family support and the interrelationship of informal and formal support have gained prominence in both fields by the provision of programmes that support carers to continue in their role.

Both sectors have significant unmet demand for services despite the increase in resources that has occurred. No outright entitlement exists to either aged care or intellectual disability services and both confront the difficult issues of targeting services which requires judgements about who has the greatest need.

Some researchers from the UK and US (Walker & Walker, 1998; Wolfensberger, 1985), and commentators in Australia (Reeve, 1999) do, however, suggest that aged care services are poorer quality than disability services and orientated towards care rather than development. However, neither policy documents nor research evidence supports these assertions in regard to Australia. To the contrary, Sax (1993, p. 94) suggests that the reform strategy implemented in the mid-1980s has shifted aged care to a system aimed at providing care in the community or supported accommodation that supports quality of life activities and maintains the capacity of each individual at an optimal level.

Given the similarities between the two policy sectors, both may be able to provide services for older people with intellectual disability and it may matter little which sector takes on this role, especially if supports are based on individualised packages of care. However, aspects of the similarity of the two systems pose boundary-crossing issues. Both systems have high levels of demand and unmet need. Potentially this provides an incentive for the disability system to access or transfer older individuals to the aged care system, while at the same time these factors could provide a strong incentive for the aged care system to resist such moves without a transfer of resources. A heavy emphasis on support to family and informal carers by both systems raises concerns in regard to older people with intellectual disability who are unlikely to have co-resident informal carers.

Notwithstanding the similarities between aged care and disability, major differences exist between the two which impact on older people with intellectual disability. These are summarised in Fig. 2.

State governments in Australia are primarily responsible for disability policy and funding, particularly those areas that most affect older people: accommodation and day programmes. In contrast, the federal government has the major role in aged care funding and policy direction, although programmes such as Home and Community Care are cost shared between the state and the Commonwealth. The sectors have different conceptions of "an aged person". The aged are generally defined as 65 years and over in aged care and the main focus of policies has been on those over 70 years. The disability field has a somewhat younger conception of an "aged person". Because of the premature ageing experienced by some groups and sparse numbers of very old, this label is generally applied to people who are 55 years and over.

The aged care system is geared towards the needs of the frail aged; health care, residential and community supports for this group attract the bulk of resources. Attempts to alter the balance of care from institutional to community care now mean that supported accommodation for the aged is populated by people who are much older and have much higher levels of dependency than previously (AIHW, 1997). For example, 72% of hostel and 68% of nursing home residents are aged over 80 years (AIHW, 1997). Less visible strands of policy, with far fewer resources, are those that foster healthy life styles and develop recreational, educational and productive daytime activities for all older people. However, the aged care system remains a specialist one that is only utilised by a minority of older people, and "the vast majority of people aged 65 and over neither need nor use services for the frail or disabled older persons" [Teshuva et al. (1994) cited in AIHW (1997,

Policy Area	
Aged Care	**Intellectual Disability**
Responsibility for Policy	
Joint State and Federal, lead role taken by Federal Government.	Lead role by State Government which is responsible for accommodation and support. Federal Government responsible for employment services.
Major Source of Funding	
Costs shared between State and Federal, major source Federal.	Cost shared between State and Federal, major source State.
Definitions of Aged People Used	
Usually 65 + .	Variable, usually 55 + but sometimes a much lower age.
Main Target Groups	
Frail Aged, people aged 70–80 + years, special need groups (people from non English speaking backgrounds, those on low incomes, those from remote and rural area and those with dementia)	> From early childhood upwards. In older age groups two major groups are aging parents and the younger aged, 55–65 years.
Scope of Policy and Programs	
Primarily focus on health issues	Primary focus on non-health issues such as developmental programs, social, educational, employment and accommodation needs.
Balance of care has shifted to community away from institutions, maintenance in own homes.	Supported accommodation, retirement programs.
Major Factors Determining Service Needs	
Age or health related loss of functional abilities and onset of late life disabilities, chronic health problems.	Loss of primary caregiver, pre-existing disability and need for support with activities of daily living, aged related loss of functional abilities, chronic health problems. Premature aging among a small group.
Demography	
Fastest growing group old old 80 + years.	Biggest increases in young old, 55–65 years.

(source. Bigby, 1996)

Figure 2.
Differences between the aged care and disability sectors.

p. 240)]. Most older people, particularly the younger old, meet their support and leisure needs from their own resources or those of their informal networks.

Despite policy directions, congregate care in large facilities such as nursing homes and hostels is still a major service response for the frail aged. However, in the disability sector the recent redevelopment of large community congregate care facilities into smaller units as a result of initiatives under the Commonwealth State Disability Agreement suggests that congregate care facilities are less acceptable and tolerated by consumers and their families than in aged care.

A significant number of aged people have superannuation funds and are less likely to be as dependent on public provision of services than people with lifelong disability. This means that more possibilities of innovative developments utilising a private–public mix exist within the aged care sector than in disability. The differences highlighted between aged care and disability policy suggest obstacles for individuals traversing the two systems and that the programmatic focus of aged care services may not address the wider range of needs of most younger old people with intellectual disability.

Availability, accessibility and appropriateness of existing services

An analysis of aged care and disability services, particularly those related to "ageing in place" and retirement, suggests that three common themes arise across the broad spectrum of areas where ageing people with intellectual disability require support (Bigby, 1999). These are: the existence of gaps where neither sector has appropriate services; problems with quality and access to existing services; and programmatic and funding mechanisms that create obstacles to accessing services and inter- and intra-sector collaboration to achieve desired outcomes.

Availability of services in aged care and disability

In areas such as day and leisure activities, supported accommodation, case management and retirement planning, neither sector has services appropriate to meet the needs of some ageing people with lifelong disability. The examples below illustrate these gaps and suggest it is particularly the younger old for whom they exist.

Most younger old people do not use formal "retirement programmes". Instead they access a wide range of social and leisure activities. These are usually self-selected and independently accessed, utilising pre-existing informal social networks. More formal structured day programmes such as day hospitals and adult day activity and support services are targeted at frail or dementing older people and require assessment and referral. However, no mechanisms exist within the mainstream aged care sector to assist those younger old people with lifelong disability who require support to locate, choose, attend, or access the smorgasbord of retirement activities. Disability day services, such as state-funded adult training and support services and supported employment services, are geared to younger age groups, and often have philosophies of intensive personal and skill development. Many are centre based and few are structured for part-time attendance or have a primary focus on social and leisure opportunities or skill maintenance, more commensurate with the needs of older people.

Various small-scale initiatives have occurred across Australia to adapt or develop disability day programmes to older people (Bigby, 1999; Bigby, Fyffe, Balandin, Gordon & McCubbery, 2001). Most of these, however, cater for existing service users rather than newcomers to the system in later life who are retiring from an employment programme, or have not previously used day services.

Within the aged care sector, few supported accommodation options exist for the younger old. The disability supported accommodation system that is largely based on a group home model does not easily adapt to changing needs as people age. The increased need for support, additional health issues and retirement from a full-time day programme for one member of a group home's household often lead to a crisis of care and an untimely or inappropriate move to a more restrictive level of accommodation (Bigby, 1998). No firm policies or services exist to promote ageing in place for people with disability. This

would require more flexible staffing models within disability services to take account of age-related changes.

Accessibility and quality of services

The principles of aged care and disability policies suggest that services should be accessible to older people with lifelong disability. Use of the services available to the general community is the preferred service model for people with intellectual disability (Annison, 1996). Nevertheless, access to aged care services and their capacity to deliver appropriate services to people with intellectual disability are recurring issues raised by both sectors. Several official reports suggest that older people with lifelong disability should be treated as a special needs group within the aged care system to ensure the delivery of appropriate services (Australian Law Reform Commission, 1995). For example, a federal government report in 1986 stated "when disabled people reach old age they should be provided with services in the same way as other aged people, but most residential facilities are not geared at present to cater for aged disabled people within the general group of residents … . there is no reason why existing general purpose facilities could not be adapted to meet their needs" (Department of Community Services, 1986, p. 50). Initiatives have occurred to make aged care programmes more accessible to groups such as people from non-English-speaking backgrounds, but none has occurred in relation to older people with lifelong disability.

These issues are exemplified by a study which found that family members of older people with intellectual disability expressed significant dissatisfaction with aged care services (Bigby, 1998). Concerns included the quality and appropriateness of aged care accommodation, staff not adequately attuned to needs, and environments that fostered dependence and provided insufficient stimulation. The comments of one man's sister encapsulated the concerns, she said "since he's been there (nursing home) the deterioration has been so great. There's no stimulation. They are just left to sit, left to rot. There are no activities for him. They weren't really listening to him" (Bigby, 1998, p. 238).

Several initiatives have occurred whereby the disability sector has tackled the perceived inappropriateness of mainstream nursing homes by complementing aged care services with specialist disability inputs or bypassing them completely and building dedicated nursing homes for people with intellectual disability (Bigby, 1999). However, no systematic response to tackle these issues has occurred.

The ability of day, residential and health-related aged care services to adequately meet the needs of older people with intellectual disability for whom such services appear appropriate, centres around the knowledge and expertise of staff. Older people with intellectual disability are a small minority group, which combined with their geographical dispersal and recent increased longevity, means that staff in aged care services have little exposure to them and are ill prepared to meet their particular needs. For example, the specialist protocols for diagnosing dementia in people with intellectual disability developed overseas have not been widely disseminated in Australia.

Similar issues of training and the development of knowledge and awareness of older people with lifelong disability arise within the disability sector where few staff have an understanding of the ageing process. This can result in age discrimination where service providers stereotype older people. For example, Walker and Walker (1998, p. 141) suggest that low expectations of staff alone are the primary barrier to social inclusion of older people with intellectual disability. Also, as a group, older people with intellectual disability experience fewer choices, less programming, decreased access to day services, lower quality programmes than their younger peers (Cooper, 1997; Walker & Walker, 1998).

Negative attitudes held by both staff and other participants in community-based programmes for older people create barriers to accessing services, even if appropriate supports are available. This means that attendance for each individual with a disability, unlike that for other participants, must be individually negotiated. No systemic mechanisms exist to tackle these attitudinal barriers to participation.

Programmatic and funding mechanisms that create obstacles to access

Various inter-governmental, intra- and inter-sector programmatic and funding issues create obstacles to successful ageing and use of the aged care system by people with lifelong disability. A common problem is access to home and community care services. Home, for most middle-aged and younger old people with lifelong disability, is community-based supported accommodation in which aged care policy suggests they should be enabled to age in place. However, this group whose "home" is state-funded disability accommodation are unable, except at full cost, to access a whole range of in-home support services available to other older people. In the current policy framework, financially it makes little sense for disability services to pay for HACC services to maintain people at "home" when they can shift the entire cost to the federally funded aged care system. However, the cost of so doing can be high, socially and emotionally, for the older person with intellectual disability and higher overall for the government as people are moved to a more restrictive level of care than necessary.

The split of funding responsibility for disability services between the two levels of government creates particular obstacles to retirement from employment programmes and the creation of community access programmes for ageing people with a lifelong disability. Retirement from federally funded supported employment programmes potentially results in an influx of participants into day activity services that are traditionally funded by state governments. The level of government responsible for funding retirement programmes, other dedicated services and staff training costs related to people ageing with a disability has not been negotiated. Within disability services, rigid programme boundaries between day and residential services create obstacles to retirement. Few supported accommodation services are staffed during the day and full-time day placement is often a condition of residence. Use of a residence as a base for "day" staff poses issues of privacy, liability and collaboration between staff from different services. Yet, central to notions of retirement are choice and flexibility of daytime activities, which for people with intellectual disability are dependent on the availability of daytime support at their place of residence. Service structures, client numbers and characteristics mediate the way such boundaries can be overcome.

Supported inclusion: future challenges and policy directions

A central theme of this analysis was summarised by a senior federal government officer who considered that, "Funding and service responsibilities in respect of this population are often vague and inconsistent" (Murphy, 1994). A major conclusion is inevitably the fundamental importance of developing coherent policy to provide a framework for service provision for the heterogeneous group of people who are ageing with a lifelong disability. Expertise from the aged care and disability sectors needs to be melded together to enable each to ensure its services are appropriate, accessible and sensitive to the needs of this group. Some existing gaps, currently filled by neither sector, should be filled by the design of new services.

One sector must take a leading role in tackling cross-sectorial boundary issues and ensuring that this group's needs are adequately represented in both service systems. This lead role, which is to date largely absent in most states in Australia, should not infer, however, that one sector "owns" this group. Cogent argument suggests that the disability sector should take the lead role, as a major part of needed policy and service development revolves around removing obstacles to access and facilitating the use of mainstream "Third Age" retirement activities and aged care services by older people with lifelong disability. Tasks of this nature, for people of all age groups with disability, fall within the existing parameters of disability policy (Annison, 1996). Also, many minority groups exist within the ageing population and responsiveness of the aged care system is reliant on the identification of a group's special needs and on effective external advocacy. The aged care system on its own cannot ensure responsiveness to all minority groups.

Several strands of policy and service development are needed to effectively meet the needs of older people with lifelong disability. These can be broadly categorised as: systematically bridging gaps with specialist services, where neither sector has appropriate services to meet needs; supporting inclusion and ensuring that older people with lifelong disability are visible within the aged care system; adapting and resourcing disability services to facilitate ageing in place; and developing partnerships and joint planning aimed at the removal of cross- and intra-sector obstacles. Policy and service developments rely on co-operation between the two sectors. Mechanisms to achieve this which have been successful in the USA are mandatory joint planning between sectors and the establishment of research and teaching consortiums on ageing and lifelong disability at key universities (Janicki, 1994). These initiatives have resulted in strategies such as regional joint planning forums between the sectors, regular conferences to share service development ideas, provision of educational and resource materials and joint initiatives between sectors to trial and demonstrate innovative programmes. Creation of a continuing focus through the development of similar mechanisms can be achieved in Australia at both a state and a regional level and will serve to maintain a momentum to address the complex issues that confront service systems in responding to older people with lifelong disability.

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