

A Five-Country Comparative Review of Accommodation Support Policies for Older People With Intellectual Disability

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Abstract International covenants and domestic social policies in most developed countries regard people with intellectual disability as citizens with equal rights, suggesting they should have the similar aspirations of a healthy and active old age as the general community, and an expectation of the necessary supports to achieve this. This article compares the development and implementation of accommodation support policies for people aging with intellectual disabilities in five liberal welfare states. It describes the limited development of policies in this area and suggests possible reasons why this is the case. A review of the peer reviewed and grey or unpublished advocacy and policy literature on aging policies for people with intellectual disability was conducted which covered Australia, Canada, Ireland, the UK, and the U.S. Despite consistent identification of similar broad policy issues and overarching goals, little progress has been made in the development of more specific policies or implementation strategies to address issues associated with accommodation support as people age. Policy debates have conceptualized the problem as aging in place and the shared responsibility of the aged-care and disability sectors. This may have detracted from either sector leading the development of, or taking responsibility for, formulating, implementing, and resourcing a strong policy framework.

Keywords: aging, aging in place, comparative policy, intellectual disabilities

INTRODUCTION

Population aging is often couched in terms of crisis, but whether the increased longevity of the populations in developed countries is a boon or a threat to either the individual or society is not yet clear (Borowski, Encel, & Ozanne, 2007). In the last 30 years, the life expectancy of people with intellectual disability has increased more dramatically than that of the general population, and they are a small but increasing group that comprise between 0.13% and 0.5% of the population over 55 years (Hogg & Moss, 1993; LePore & Janicki, 1997; Wen, 1997). Since the mid 1980s researchers have warned of a need to understand the changing support needs of people with intellectual disability as they age (Hogg, Moss, & Cooke, 1988; Janicki & Wisniewski, 1985; Seltzer & Krauss, 1987; Sutton, Factor, Hawkins, Heller, & Seltzer, 1993). A 1993 review of perspectives on aging and developmental disabilities in nine countries suggested that there was “an increasing urgency of making policy and service developments” (Moss, 1993) for this group. One theme of this review was the difficulty of applying the principles of normalization and the inclusion of people with intellectual disability in mainstream age-related support services, while averting the devaluation, institutionaliza-

tion, and poor quality of care experienced by many older people in the general population (Blaney, 1993). At this time, the U.S. stood out as having clear policy directions that aimed to include older people with intellectual disability in “seniors day programs” and avoid inappropriate entry into residential aged-care¹ facilities. Hawkins and Eklund (1990) suggested a “surge of activity” had occurred, resulting in policy changes requiring access to aged-care services by older people with intellectual disabilities, and mandating cooperative planning between the two service systems (Janicki, 1994). The more indistinct direction in the UK was characterized as the retention of age-integrated intellectual disability programs, reflecting research about the less individualized and poor quality of care for this group in generic aged-care programs.

It is timely to review the progress of policy and program developments for aging people with intellectual disability, the need for which was first raised more than 20 years ago and foreshadowed as urgent in 1993. This article compares the development and implementation of one aspect of policy associated with aging of people with intellectual disability, accommodation support, in five liberal welfare states, Australia, Canada, Ireland, the UK, and the U.S. It describes the limited development of strong policy frameworks and implementation strategies and

Received January 8, 2009; accepted September 27, 2009
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¹The term “aged care” is used synonymously with terms such as senior services, senior citizen services, services for the elderly, older (name of nationality)—such as “older Americans services,” older persons services, services for 55-Plusers, and the like.

suggests possible reasons why this is the case. Further, as Blaney (1993) suggests, highlighting the absence of strategic policies may identify and counter the unfolding of more invisible and less adaptive ones. This article is based on the premise that specific policies are required to inform service development at the latter stage of the life course. This is because the application of first principles, such as inclusion, is particularly difficult in light of the differential and premature nature of the age-related needs of people with intellectual disabilities compared with the general population, and the devalued status and poor quality of services for frail aged in general (Robertson, Moss, & Turner, 1996; Wolfensberger, 1985).

APPROACH AND LIMITATIONS

The article is bounded by the difficulties in comparing policy and programs embedded in different administrative and service systems. Issues arise such as the use of similar names to refer to different types of service, differences in definitions of intellectual disability, use of different age groupings, and the extent to which policy and programs are differentiated by disability group. For example, in the five countries under review some disability policies encompass all impairment groups, in Ireland and the UK, particularly, specific policies are found for people with intellectual disability; in the U.S., people with intellectual disabilities are included in the broader category of developmental disabilities for whom particular policies exist, while in Australia and Canada, few policies are found that explicitly relate only to people with intellectual disability (Ad Hoc IASSID Working Group, 2005; Anttonen, Baldock, & Sipilä, 2003; Bigby, 2007). With the exception of Ireland, the absence of comprehensive national databases about the population of people with intellectual disabilities means data are often restricted to service users, which further compounds the task of cross country comparison.

While recognizing differences in definitions and nomenclature between countries, this article uses the terminology of intellectual disability, group homes, and residential aged care acknowledging their broadly similar meanings in the five countries considered. The statistical data used can only be indicative because, as noted above, it relates to slightly different populations and definitions of intellectual disability in each country. Data are drawn from a review of key government and nongovernment sector policy and discussion documents in each country, the peer reviewed literature and commentaries between 1995 and 2007. It is acknowledged that less data were found about policies in Canada and Ireland. The commonality of welfare regime and disability policy, and difference in population size were reasons for selection of countries. Selection was also serendipitously shaped by participants in the Annual Roundtable of the Special Interest Research Group on Aging and Intellectual Disability (SIRGAID) of the International Association for the Scientific Study of Intellectual Disability (IASSID) held in Toronto, Canada, in March 2006 from which this article grew.

CONTEXTS FOR SPECIFIC POLICIES ABOUT AGING

In each country, the welfare regimes that provide the context of disability policy are broadly similar and using Esping-

Andersen's (1990) typology can be categorized as "liberal." All countries have been influenced by neoliberal policies that have fostered the use of market mechanisms and an increasing focus on individualized and flexible provision of support (Anttonen et al., 2003). A wide range of policies relating to income support, health, human rights, antidiscrimination and equal opportunity provide a platform for those more specifically about services for people with a disability or intellectual disability. In all countries, these underpinning policies reflect a social model of disability, and have a clear intent that people with intellectual disabilities are to be treated as equal citizens, with the same rights as other citizens to access societal infrastructure, community facilities and services. These countries also have similar broad national policy directions for provision of specialist support, which reflect the types of principles articulated in the UK's *Valuing People* white paper—inclusion, independence, rights, and choice (Department of Health, 2001b).

Table 1 provides an overview of the demographic characteristics and welfare expenditure of each country, which shows the differences in the scale of the task each confronts. For example, Australia has an estimated 9,237 people with intellectual disability aged over 60 years, while in the U.S. the estimate is 641,161 people (Heller & Factor, 2004; Wen, 1997).

AGED-CARE POLICIES

In common with most developed economies, since the 1980s these countries have had strong policy directions that support aging in place for the general population. This term, originally used by urban geographers to refer to the aging of neighborhoods, is generally taken to refer to opportunities for people to remain in their own home (however defined), regardless of their increasing care needs (Chappell, 2001; Chaput, 2002; Forbat, 2006). It is seen as enabling a person to remain in familiar surroundings, close to family and friends, and retaining personal belongings and avoiding institutionalization, and suggests that continuity of residence is important as well as quality. This policy direction led to the expansion of support for older people to remain in their own homes and controlled access to residential aged-care facilities (Australian Institute of Health and Welfare [AIHW], 2005; Chappell, 2001; Conroy & Mangan, 2006; Means, 2007; Walker, Walker, & Ryan, 1995). Means (2007) suggests that this reflects not only economic imperatives, but also the priorities and preferences of older people themselves. As Table 1 shows, in all five countries, the proportion of the population aged over 65 years in residential aged care is less than 10%, though this increases quite significantly with age, as most residents are aged over 80 years.

In both Australia and Canada, aging in place policies are applied to people living in residential aged-care settings as well as in private homes (AIHW, 2005; Chappell, 2001). For example, in Australia, if a person enters a residential aged-care facility at a time when their needs are classified as low, the level of support (and funding) is expected to adapt as their needs change enabling them to remain in same facility rather than having to move (AIHW, 2005).

References to older people with life-long disabilities or sometimes, more specifically, intellectual disabilities are found in mainstream national or regional documents or legislation about

TABLE 1
Population aging

	UK	Australia	Canada	U.S.	Ireland
Population (in 000s) (OECD, 2005)	60,209	20,339	32,299	296,940	4,130
Population age 65+ (%) (OECD, 2005)	16%	13.1%	13.1%	12.4%	11%
Annual growth: Age group 65+ (%) (OECD, 2005)	1.3%	3.2%	3.4%	2.6%	n.a.
Welfare expenditure % of GDP (OECD, 2005)	21.82%	18%	17.81%	14.73%	13.75%
Population age 65+ in some form of residential "aged care"	5.5% (Anttonen et al., 2003)	8% (AIHW, 2005)	9.2% women 4.9% men (Statistics Canada, 2002)	7.3% (Anttonen et al., 2003)	n.a.
Approximate population of people with ID	210,000 (England; DoH, 2001b) 12,000 (Scotland; Scottish Executive, 2000)	103,000 (Wen, 1997)	n.a.	4,323,877 (Braddock, 2002)	25,613 (Kelly et al., 2007)
Estimated population of people with ID age 60+	25,000 (England; DoH, 2001b)	9,237 (Wen, 1997)	11,080 (65–75 years) (Government of Canada National Advisory Council on Aging, 2004)	641,161 (Heller & Factor, 2004)	2,844 (age 55+; Kelly et al., 2007)

GDP, gross domestic product; ID, intellectual disabilities; n.a., not available.

aged-care service provision. These are summarized in Table 2. In all countries, the difficulties faced by this group in accessing and having their needs met by mainstream aged-care services are acknowledged and noted as an issue that should be tackled. The documents indicate recognition that special or particular policies or programs will be required to ensure that the needs of older people with an intellectual disability are addressed. Responses, either suggested or enacted, are avoidance of inappropriate admission to residential aged-care facilities, supporting integration into health, leisure and day support programs for older people through joint planning and partnerships or the development of specialist programs. Ireland however, is the only country where it is specifically suggested that specialist programs should be the responsibility of the disability services system.

GOVERNMENT POLICIES ABOUT AGING AND INTELLECTUAL DISABILITY

As Table 3 demonstrates, the proportion of people with intellectual disability living in private homes with their families diminishes significantly with increasing age. The problems associated with this trend and the provision of accommodation support for older people with intellectual disability have been conceived by researchers and advocacy groups alike as the need to replace the primary care previously provided by families through the provision of in-home support, supported accommodation, or group homes; the adaptation of support to residents' changing needs as they age; and the avoidance of inappropriate placement in residential aged-care or nursing settings (Bigby, 2008b; McCallion & McCarron, 2004; Roeher Institute, 2000; Sutton et al., 1993; Thompson, 2003).

In all countries, stakeholders outside of government, such as peak industry bodies, professional associations, parents' organizations, charitable trusts and parliamentary committees, have been strong advocates around issues of aging. They have formulated specific policy positions, formed advocacy alliances and agreed sector positions, fostered research and service development, developed educational materials and lobbied bureaucratic, government and service providers. The broad position adopted most commonly by such initiatives is that, like other members of the community, people with intellectual disability should have the right to age in place, through the combination of existing disability support and additional aged-care services. As one Canadian commentator suggests, "[a]gencies need to be clear in terms of policy and practices about whether they will stand by individuals to the end of life and will accommodate these transitions" (Crawford, 2004). While in Australia, the Senate Community Affairs Reference Committee (2007) on Commonwealth State/Territory Funding Agreement (in section 5.50 of its report) recommended: "[t]hat funding arrangements and eligibility requirements should be made to allow supplemental aged care services to be made available to people with disabilities who are ageing, allowing them to age in place"; and that "[A]dministrative funding arrangements should not impede access to aged care services for people with a disability who are ageing".

Residential aged care has been frequently perceived as inappropriate and ill equipped to cater for people with intellectual disability, a perspective that has been echoed by research findings

(Chaput, 2002; Janicki & Ansello, 2000; Moss, Hogg, & Horne, 1992; Walker & Walker, 1998). Significant policy development work has also occurred among the international research community which has clearly articulated policy directions and principles (British Institute of Learning Disabilities, 2001; Hogg, Lucchino, Wang, & Janicki, 2001; Weber & Wolfmayr, 2006; Wilkinson & Janicki, 2002). For example, paragraph k of the Graz Declaration on Disability and Aging declares: "that home care and independent living measures should be promoted and segregating residential arrangements (e.g., institutions with no respect for options and choices) be replaced by community living in small groups, fostering social participation and citizenship, through adequate incentives and reform of social protection systems" (Weber & Wolfmayr, 2006).

References to the need to address issues associated with aging of people with intellectual disability are found in national disability policy documents or reports from government bodies in four of the five countries (the exception being Canada). The issues mentioned are summarized in Table 2. With the exception of the U.S., these documents only point to the importance of addressing the problem, and give broad hints of policy directions rather than detailing specific policies and implementation strategies. Common directions suggested are access to mainstream health and aging services, cross sector planning and partnerships, and avoidance of inappropriate admission to restrictive environments. The U.S. has the longest standing and most specific disability policy directions, mirrored in its aged-care policy which mandates joint planning between the two sectors and aims to ensure the least restrictive residential environment for people with intellectual disability. Policy documents in Scotland, which forms part of the UK, specifically mention aging in place as a policy direction, and suggest the need for flexible design and provision of accommodation support to meet changing needs across the lifespan (Scottish Executive, 2000).

The interpretation and implementation of national disability policy in each of the five countries is the responsibility of either state or local governments or regional bodies. The situation is particularly complex in federal countries, like Australia, Canada, and the U.S., where state, provincial or territorial governments have power to make their own policies and can supplement federal funding with their own. This can lead to significant variation in both policy and service systems, which makes tracing the formulation of more specific policies and implementation strategies about accommodation support for aging people very difficult. At best a small snapshot of policy and programs at the state, regional or local program level can be gained. However, this can be compared with other sources such as research findings and views of policy commentators.

Examples of the range of initiatives developed and funded by various levels of government in each of the five countries are given in Table 2. Many of these are locally based, time-limited pilot or demonstration projects rather than long-term programs driven by a clear policy framework. The common features are their short-term *ad hoc* nature, and patchy development across services systems, leading to little program consistency within countries or even within administrative units. Initiatives include education and training, joint service planning, cross-sector partnerships, program development seeded by government funds and the development of organizational policies and programs

TABLE 2
Policy and older people with intellectual disability

	UK	Australia	Canada	U.S.	Ireland
Mention of older people with ID in aged-care policy documents	<i>National Service Framework for Older People</i> identified issues for older people with ID, such as premature aging and different needs to be taken into account in developing services; singles out partnerships with mental health services in particular and the importance of specific health problems being addressed locally (DoH, 2001a)	<i>National Strategy for an Aging Australia</i> identified people with ID as one of the groups facing particular barriers to obtaining the level and type of services they need; suggests they will require specific or special arrangements to meet needs (Andrews, 2001).	<i>National Advisory Committee on Aging</i> identified aging with ID as an issue and commissioned a paper on aging and developmental disabilities as one of series on "Seniors on Margins" (Government of Canada National Advisory Council on Aging, 2004).	Early recognition of age-related issues: Many U.S. states developed state activity plans targeting older clientele with ID during 1980s (Janicki, Ackerman, & Jacobson, 1986); 1987 amendments to Older Americans Act enabled older adults with developmental disabilities to receive mainstream aging services, enable funding of specialist services, encourage state units on aging and area agencies on aging and state and community ID agencies to jointly plan and develop services for older adults with ID; amendments to the Nursing Home Reform Act 1987 addressed inappropriate placements through procedures to restrict admission and provided for specialized services for those who remained (Janicki, 1999; Janicki & Dalton, 2000)	<i>Action Plan for Services for Older Persons 1999-2008</i> (Eastern Health Board) recognized challenges posed by people with Down syndrome and dementia; action plan for dementia recommended specially designed care for people with Down syndrome and dementia delivered in ID system, with training facilitated by old-age psychiatry or geriatric medicine (McCarron & Lawlor, 2003; O'Shea & O'Reilly 1999).
Mention of issues for older people with ID in national ID policy frameworks	National policy mentions the need to address aging issues, notes older people may be "misplaced" in "aged care"; suggests partnerships between different care sectors (such as ID, mental health, and older people); suggests age-related health issues can be tackled through person-centered planning (DoH, 2001b). Suggests the need for flexible design and provision of accommodation support (Scottish Executive, 2000).	State and federal disability legislation has no upper age limit; two of the 19 priorities in the 2002-07 Commonwealth/State agreements relate to aging and aim to strengthen access to generic services and improve cross sector linkages; envisaged that links between sectors would improve access health other services and improve collaborative work (Australian Health Care Associates, 2006).	No mention at national policy level.	National advocacy by and documents of concern issued from President's Committee on Mental Retardation; Developmental Disabilities Assistance and Bill of Rights Act and other legislative framework mandated sharing ID planning and partnerships with "aged-care" sector dating back to mid-1980s (Ansello & Rose, 1989).	Attention drawn to aging in reports of National Intellectual Disability Database; joint report by National Council Aging and National Disability Authority 2006 identified ID and aging as priority needs (Conroy & Mangam, 2006).
Examples of strategies used to implement policy directions on aging	Specific funding for housing initiatives as part of "Extra Care Housing" (King, 2004); the Foundation for People with Learning Disabilities (2002) through its GOLD project funded a range of innovative projects between 1998-2002 that provided a series of program exemplars as well as, in some cases, leading to longer term service development (e.g., the Birmingham Psychological Service for Older Adults).	Action to restrict entry to residential "aged care" for younger people with disabilities, particularly those age less than 50 and not the least restrictive option; entry to residential "aged care" must be assessed and approved by Aged Care Assessment Service; national pilot initiatives examined interface of disability and "aged care"; pilot "top up" model of aging in place, assessing those as eligible for residential "aged care" (AIHW, 2006).	Various collaborations between agencies, for example, the Ontario Partnership on Aging and Developmental Disabilities, (2005).	U.S. Administration on Developmental Disabilities in the 1980s funded a number of University Affiliated Programs (UAPs) to include training on aging issues; NIDRR funded Rehabilitation Research and Training Center on aging and developmental disabilities at University of Illinois at Chicago; the Administration on Aging and the Center for Medicare and Medicaid Services jointly funded 24 state units on aging to develop Aging and Disability Resource Centers as the single point of entry for all "consumers," including individuals with developmental disabilities, seeking long-term care services (Sutton et al., 1993; Bigby, 2004).	Development of specialist memory clinic for people with Down syndrome, agency specific responses, by for example, Sisters of Charity and St. Michael's House, (McCarron & Lawlor, 2003; McCausland et al., 2006).

TABLE 3
Place of residence people with intellectual disability

	UK	Australia	Canada	U.S.	Ireland
Place of residence of younger people with intellectual disability	70% in family home supported accommodation age 20–24 years (Emerson, Hatton, Felce, & Murphy, 2001)	51% in group homes all ages and 29% in institutions (all ages) (AIHW, 2005).	n.a.	40% in family home (age under 40); 35% in family home (age 41–49) (Braddock, 1999).	63.9% in family home (all ages); 27% in disability accommodation (age 20–34 years); 55.1% in disability accommodation (age 35–54 years) (Kelly et al., 2007).
Place of residence of older people with intellectual disability	30% in family and supported accommodation for adults age 55+ years (Emerson et al., 2001); less than 15% within family age 60+ years (King, 2004).	Victoria study of age 62+ adults found 26% living with family or independently, and 74% using formal services (64% in residential aged care and 10% in group homes) (Bigby, 1998).	n.a.	25% with family (age 60+) (Braddock, 1999); 8% of those in out-of-home care are in residential “aged-care” facilities with significant variation among states, e.g., Kansas has less than 1%, Georgia has 24% (Rizzolo, 2004).	75.4% in disability accommodation (age 55+ years); 0.6% in nursing care (Kelly et al., 2007).

internally funded by nongovernment organizations. The available evidence suggests that the U.S. has taken more systematic approaches through, for example, funding infrastructure support for the disability service system in the form of a national Rehabilitation Research Training Center on Aging with Developmental Disabilities and a myriad of state-based University Centers of Excellence on Disabilities that have a focus on aging (Ansello, 2004; Janicki, 1999). However, it also suggests that program development is very variable across the country.

RESEARCH EVIDENCE AND COMMENTATOR VIEWS ON POLICY IMPLEMENTATION

Ansello (2004) suggests that issues associated with aging for people with intellectual disability are “not yet sufficiently addressed in public policy.” The preceding review of policy documents suggests national governments in these five countries have recognized problems of providing appropriate accommodation support, accessing health and other services, and the potential for inappropriate placement in nursing homes. Despite the strong positions taken by groups outside of government that support aging in place, there is an absence of specific policy frameworks on how best to meet accommodation needs or guide program development. Primary policy directions are either vague, such as developing partnerships between sectors or involve the curtailment of options such as entry to residential aged care without complementary strategies to enable more positive alternative accommodation options.

Further evidence of the absence of specific policies and implementation strategies is found in commentaries by advocacy groups, peak bodies, and other stakeholders based on their experiences of what is happening on the ground. As the summary in Table 4 shows, a similar picture emerges in all five countries of the failure to turn broad policy intentions into systematic strategies. Cross sector partnerships and collaboration have not occurred, which may be due more to a lack of government funding than willingness to work together, issues of aging in place are not high on the agenda of aged-care or disability sectors and have not been incorporated into sector planning mechanisms. Perhaps most remarkable is the situation in the U.S. where very few state disability agencies have policies on dementia care, and aging issues are not a “hot topic” despite it being seen to be leading the way in the last two decades of the 20th century and having the most clearly articulated national policy position (Ansello, 2004). The views of policy commentators and advocacy groups are remarkably similar across these five countries supporting Ansello’s contention that the issue is not sufficiently addressed in policy.

Evidence from research about the operation of services and the experiences of older people with intellectual disability also gives some indication of the clarity of policy frameworks and nature of implementation strategies. Table 4 summarizes the research in each country that has considered the pattern of housing and support for older people with intellectual disability. In all countries, it suggests that some residents shift from group homes to residential aged care, and in some, a disproportionate number of older people with intellectual disabilities live in residential aged care. The research suggests that when residents are

TABLE 4
Commentary on policy implementation progress

Aging in place	UK	Australia	Canada	U.S.	Ireland
<p>Characterization and commentary on approach and progress</p>	<p><i>Ad hoc</i> wide variation across regions in models of service development; little evidence of local systematic planning; few partnerships boards have developed plans to address the needs of older people, they are marginalized from benefits of strategic planning; dislocated from policy intent (Forbat, 2006). Reactive, and no underpinning principles or framework; "service provision characterized by fragmentation and limited choice of resources and specialist care" (Hatzidimitriadou & Milne, 2005). Scotland lacks specialist policy and aims are variously met (Fitzgerald, 1998).</p>	<p>Still at stage of scoping, examining changing needs and expectations and developing framework to guide the development of provision of services (Australian Health Care Associates, 2006). <i>Ad hoc</i> pilot initiatives not funded programmatically or recurrently (AIHW, 2006). Limited effectiveness in dealing with cross-portfolio issues, particularly the interface of aging and disability; problem in dealing with federal government where responsibilities cut across another government (NSW Government, 2007).</p>	<p>Survey of agencies in Toronto, Ontario, area in 2000 found 54% believed services inadequate to meet needs of older people with developmental disabilities (Sparks & Temple, 2000).</p>	<p>Seen to be leading the way in 1980s and 1990s by UK researchers (Robertson et al., 1996; Walker & Walker, 1998), but impetus not continued. "Challenges noted but few attempts to sort out issues lying at the heart of these" (Putnam, 2004). National survey of state units on aging and developmental disability systems found older people with intellectual disabilities were often ignored by these service systems, and few state developmental disability agencies had policies on dementia care or assessment (Janicki, 1996; Coogler, Anselmo, Wood & Cotter, 1997, cited in Janicki & Anselmo, 2000). Aging not a hot issue for either system, service systems were reactive, to specific problems and noisy advocacy issues, rather than taking proactive stances (Anselmo, 2004).</p>	<p>Joint working is rare between the "aged-care" and disability systems, with little evidence of an integrated approach, and this population is regarded as a homogenous group (Conroy & Mangano, 2006).</p>
<p>Research on policy in action</p>	<p>Qualitative study of six facilities, most common model is "referral-out" for residents with dementia; no access to external resources to assist organizations to support aging in place; staff committed to keeping an older person in place (Wilkinson, Kerr, Cunningham, & Rae, 2004). National survey of residential "aged care" found older people with ID placed in residential "aged care" but not due to own needs; they were significantly younger than other residents and placed earlier than age 65 (Thompson et al., 2004). Cost differential found—disability shared supported accommodation cost approx. UK£43 and residential "aged-care" cost approx UK£14–20 (Thompson et al., 2004). Disproportionately high number of older people in residential aged care; estimated as 1 in 10 of those in out-of-home care in Scotland (Scottish Executive, 2002—cited in Thompson et al., 2004). Staff assumption is that a move from shared supported accommodation will occur (Bland et al., 2003; Hatzidimitriadou & Milne, 2005).</p>	<p>National study of group homes found staff want to retain and let adults with ID age in disability system; only 3.4% of residents aged 50+ years moved to residential "aged care" over 2 years; 30% of respondents thought such a move inevitable; respondents reported difficulty in accessing "aged care" services or additional resources to support changing needs of aging residents; agencies absorbed increased costs from own organizational resources (Hyffe et al., 2007). Large disability organizations are absorbing costs associated with aging (<i>The Age</i>, Feb. 13, 2007). Victoria survey of people with intellectual disability in residential aged care found 40% had at least one person with ID; these residents were younger, stayed longer and were less likely to have dementia than other residents; half had moved from home (Bigby et al., 2008); cost differential found residential "aged care" costs \$44,000, disability housing costs \$84,000 (Senate Community Affairs Reference Committee, 2005).</p>	<p>Older people seen as at-risk of moving to long term residential "aged care" and numbers in this type of care are increasing (Pedlar, Hutchinson, Arai, & Dunn, 2000; Roeher Institute, 2000). Group home residents often relocated to long term care settings (and sometimes to special care units) when dementia begins to present care management difficulties (Chaput, 2002).</p>	<p>When home care no longer viable for adults in mid- to late stage dementia the most common solution is transfer to long-term care facilities or specialist care units (Janicki & Dalton, 2000). No infusion of new resources to pay for dementia care or programmatic or environmental adaptations; more time and staff resources need to be budgeted (Janicki et al., 2002). Most states do not take into account increased needs for 24h staffing for residents who have retired or for aging in place, as system expects either static or continued development; staff tolerance and threshold for moving has shifted up upward over time (Janicki & Dalton, 2000). Many older families are forced to seek admission to nursing facilities, as there are no other alternatives; residents with ID in residential "aged care" are younger than other residents, average age is 64 years compared to other residents' average age of 80 years; less likely to be diagnosed with Alzheimer's disease (Rizzolo, 2004)</p>	<p>Anecdotal evidence that people with ID and dementia go to generic memory clinics; may be more likely to be referred to institutional care due to the lack of experience of staff with this group (McCarron & Lawlor, 2003). 15% of adults with ID in group homes predicted they would have a change of accommodation, while over 50% of carers thought a change would be necessary as people aged (O'Rourke, Grey, Fuller, & McClean, 2004).</p>
	<p>Multi-national study of group homes in 5 countries, including U.S., found no increase in funding to organizations to take account of increased support needs of people with dementia, residents were able to age in place by <i>ad hoc</i> actions of organizations using their own resources, which cannot be sustained for large numbers predicted in the future (Janicki et al., 2005)</p>				

TABLE 4 Continued

Aging in place	UK	Australia	Canada	U.S.	Ireland
Advocacy and policy position taken by the non government or informal sectors	Foundation for Learning Disabilities' GOLD project funded range of research, service development and training initiatives. Positions taken by major national organizations, such as Mencap and BILD. Training materials produced by BILD. Down Syndrome Association of Scotland undertook advocacy stance, policy information, and training.	Major national industry body (NDS)'s national committee on aging and disability instrumental in building cross sector coalition of provider organizations and a securing memorandum of understanding on aging issues (Fyffe et al., 2007). Recommendation by Senate Community Affairs Reference Committee, 2005 on Quality and Equity in Aged Care and Senate Community Affairs Reference Committee (2007) on Commonwealth State/Territory Funding Agreement for aging in place and joint funding by disability and "aged-care" system.	Strongly articulated positions on aging in place, the need for clarity and clarity of policy from families and providers involved people with ID (Crawford, 2004). Strong policy position on aging in place, and need development of national principles and policy framework to inform program guidelines in British Columbia by Association for Community Living (2009b).	The Arc of the United States' position statement on aging. Political forces, such as The Arc of the United States, the Joseph P. Kennedy, Jr. Foundation, and the former AAMR, attempts to keep support for aging alive at federal level and push agenda with states (Janicki & Dalton, 2000). National organization—the AAIDD—has produced information and guidelines for care of older people.	Commission on Nursing Report (Government of Ireland, 1998) pointed to gap in services for aging people with ID and urged the nursing discipline to respond.

AAMR, American Association on Mental Retardation; AAIDD, American Association on Intellectual and Developmental Disabilities; BILD, British Institute on Learning Disabilities; ID, intellectual disabilities; n.a., not available; n.d., no date.

enabled to age in place, it is due to specific “in-house” policies of the service organization, or informal staff practices that strongly support this approach rather than more formalized partnerships between the disability and aged-care systems, or government policy. For example, a cross-national study of group homes, in five countries (Australia, Canada, Japan, Sweden, and the U.S.) where one or more residents had dementia, found no increase in funding to provider organizations to take account of the changed support needs of people with dementia (Janicki, Dalton, McCallion, Baxley, & Zendell, 2005). Residents were enabled to age in place by *ad hoc* actions of organizations using their own resources. A survey by Fyffe, Bigby, and Mccubbery (2007) in Australia made similar findings.

Data from all countries suggest that broad policy intentions have not reached as far as program development or funding policies. Supporting residents to remain in their own homes which are often group homes appears to be feasible but hampered by the absence of firm policy commitment and defined programmatic strategies such as provision of flexible funding. Also, in the absence of other alternatives, some people with intellectual disability go directly into residential aged care from their family home when parents die. Surveys about the admission of people with intellectual disability to residential aged care in Australia, the UK, and the U.S. indicate that people are placed in residential aged care because of the absence of other alternatives, rather than it being the best or preferred option (Bigby, Webber, McKenzie-green, & Bowers, 2008; Janicki, 1994; 1999; Thompson, Ryrie, & Wright, 2004). For example, Janicki (1999) suggests that in the U.S., “. . . often referral is not based on need for nursing care but age or lack of available alternatives.” A similar finding was made in respect of people moving directly from the family home into residential aged care in Victoria Australia (Bigby et al., 2008). Studies in Australia, Ireland, and the UK indicate a high proportion of staff in group homes perceive the transfer to residential aged care as an inevitability for older residents (Bland, Hutchinson, Oakes, & Yates, 2003; Fyffe et al., 2007; Hatzidimitriadou & Milne, 2005)

As referred to earlier, the extant research that has sought the views of family or staff or examined the quality of care and experiences of residents with intellectual disability in residential aged care, in Australia, Canada, the UK, and the U.S. has concluded that their needs are met less effectively than by supported accommodation in the disability sector. Evidence from all countries suggests that aging people with intellectual disability are poorly matched to other residents in residential aged care, they do not fit the average resident profile, and are likely to be younger, less likely to have dementia, and to stay for a much longer period of time. The absence of policies to avert admission or, more positively, to ensure alternatives to residential aged care are available, may mean that aging poses a significant threat to the quality of support received by older people with intellectual disability.

FACTORS CONTRIBUTING TO ABSENCE OF SYSTEMIC POLICY AND IMPLEMENTATION STRATEGIES

What emerges from the data is a pattern that while the specificity of direction about accommodation support or aging in place varies across these five countries, nowhere are systematic mid-level policy frameworks or implementation strategies in place to

support general policy directions. From the viewpoint that policy is evolutionary, a set of goals and hypotheses to be tested and adjusted over time, the refinement and implementation of broad national policy directions will evolve over time. The spectrum of local initiatives discussed earlier, form “laboratories for emerging public policies” (Ansello, 2004) and the processes of experimentation, and feedback around strategies will clarify policy intentions, and inform the development of mid-level goals and strategies. However, pilot and demonstration projects have been occurring for more than 15 years and as Putnam (2004) suggests, few attempts have been made to sort out the underlying issues. It may be then that a lack of clarity about policy goals, the needs that exist and where responsibility for the resources necessary to meet these lies, as well as unresolved tensions about goals, account for the slow development and implementation of policy about accommodation support for older people with intellectual disability.

Lack of Clarity about Policy Goals

As the figures in Table 3 suggest, few people with intellectual disability have the opportunity to age in place in their long-term family home and, for a large proportion, “home” will be a group home managed by a government or nongovernment accommodation service, funded by government. Consequently, the bulk of research and debate has focused on these residents whose right to age in place has been strongly asserted by commentators. However, for group home residents, “aging in place” has been variously interpreted. For example, in the U.S. context, it can mean either remaining in the same group home or moving to another within the same disability service (Janicki, McCallion, & Dalton, 2002). An Irish discussion paper on aging and disability suggests its means remaining in disability services (Conroy & Mangan, 2006). In Australia, a survey of service providers found its meaning varied widely including: staying within the disability sector, but moving house to “be with like people”; staying at home until death or palliative care is required regardless of the cost, or staying at home until a certain level of medical or complex care is needed, or until the service provider cannot or will not continue to provide support (e.g., due to resource shortfalls, occupational health and safety, lack of staff training) (Fyffe et al., 2007). These various interpretations of aging in place reflect quite different program directions. It is not clear, for example, what is intended by “moving but staying within the disability sector” and whether in this case, such an interpretation of aging in place actually sanctions the establishment of medium or larger scale congregate care designed specifically for older people within the disability sector. Also raised are the largely unanswered questions about why and when it might be considered appropriate for an older person with intellectual disability to move to residential aged care or indeed another form of disability supported accommodation. Policies found in Australia and the U.S. to divert people from residential aged care similarly lack clarity, referring to inappropriate or premature admission without defining what this means. Research has shown, however, that such notions are extremely hard to codify as they stem from various possible combinations of multiple factors (Fyffe et al., 2007; Janicki et al., 2002).

Debate about aging in place draws a parallel between people with intellectual disability and the general population. It is often

assumed that the strategies already in place to support aging in place for the general community could simply include people with intellectual disability. However, enabling aging in place in a funded disability service is much more complex and requires different strategies than those required for a person living in a private home with others with whom they chose to live and, who also, in many cases provide significant unpaid care. The issues are quite different and include, for example, consideration of the impact on co-residents and the adaptation of formal support—staff and infrastructure resources, which have to be mediated both by the policies of the service provider and funding body. Competing principles will also give rise to a range of difficult dilemmas. Older people, whose health and independence are declining, fit poorly with the values of participation, independence, and provision of support rather than care that underpin the operation of group homes. This raises questions about the extent to which such values can be compromised in adapting to age-related changes without fundamentally changing the nature of the service. Existing tensions between meeting group and individual needs in group homes may be exacerbated by the changed needs of an aging resident, raising questions about whose needs take priority, other members of the group or the aging individual. Such dilemmas may be compounded by lack of access to resources, or pressure from staff or families. Aging in place in group homes is more complex than partnerships between disability service providers and aged-care providers who service the general population; it requires internal organizational change, as well as resolution of a range of dilemmas that are not easily codified in policy.

Aging in place has been identified as problematic for disadvantaged minorities who have poor or unstable housing conditions and high support needs (Chappell, 2001; Means, 2007). Yet issues about its applicability for people with intellectual disability living in inappropriate or suboptimal environments are seldom raised in the literature or policy documents. Survey research from Australia and the UK, indicates a sizeable proportion of adults with intellectual disabilities in residential aged care are admitted directly from the family home, not from choice but as the only available option (Bigby et al., 2008; Thompson & Wright, 2001; Thompson et al., 2004). Aging in place for this group may not be a good option or for those who continue to live in large scale institutional psychiatric or intellectual disability facilities.

A much clearer conceptualization of aging in place, which has been main focus of advocacy, is required. Multiple policy goals and strategies are needed to take account of the diversity of the persons who are aging with intellectual disability, many of whom live in inappropriate accommodation due to their history or difficulty in accessing disability supported accommodation when they lose primary carers in midlife. This later group is potentially sizeable given the high level of unmet need for supported accommodation in the countries considered (AIHW, 2006; British Columbia Association for Community Living, 2009a; Kelly, Kelly, & Craig, 2007; Stancliffe, 2002)

Conceptualising the Problem and Questions of Equity

The policy and other documents reviewed for this study commonly conceptualize the problem of accommodation support for older people with intellectual disability as being the

shared responsibility of aged-care and disability service systems. Responses are frequently couched in terms of the need for partnerships between the two sectors, avoidance of residential aged care or the development of specialist or separate programs. They can be characterized as being dual track, suggesting both inclusion and use of mainstream services and development of specialist disability services. Ireland is the only country that appears to lean more in favor of specialist services. The dual track approach locates policy and thus fiscal responsibility for its implementation with both disability and aged-care sectors. Reliance on the support and actions of multiple stakeholders as is the case here makes policy much harder to formulate and implement (Bridgman & Davis, 2004). Ansello (2004), for example, suggests the difficulty of partnership formation and joint working in the absence of dedicated additional resources. The commitment required from both sectors and other problems that stem from this conceptualization of the problem as a shared cross sector responsibility may account for the limited progress in policy development.

Though administrative arrangements differ between and even within these five countries, a common feature is the separation of responsibility for the aged-care and disability sectors, with each located in different administrative structures or even level of government. There are few reasons why either sector should have a strong commitment to policy about accommodation support for aging people with intellectual disability or to funding partnerships with the other sector. There is little incentive for disability sectors to take the lead, for example, in maintaining older people in its funded accommodation if additional resources are required, especially given the high level of unmet demand for accommodation services in all these countries. Indeed the possibility of transferring aging residents of group homes to residential aged care, which would free up resources for unmet need, or avoiding entry into disability accommodation of older people on waiting lists are potentially a disincentive to take any positive action about aging issues.

Similarly, there are few incentives for the aged-care sector to invest in partnerships with the disability sector. Although only indicative, figures from Australia and the UK that compare cost and size of facilities in each sector suggests those in the disability sector are smaller and better resourced (Bigby, 2008a; Thompson et al., 2004). In these contexts, use of aged-care funding to “top up” disability services could be perceived as iniquitous or “double dipping” by people with disabilities. A much clearer rationale, than simply that of poor quality, would be needed to support the proposition that unlike other older people, those with intellectual disability should not be expected to use residential aged care. Policy analysts have challenged the “welfarist” approach of aged care, suggesting that it has much to learn from the disability sector around issues of rights and provision of support that increases access and independence (Priestly & Rabiee, 2002). Combined, the cost differential and difference in approach of the disability sector challenges the quality of residential aged care more generally, thereby opening up a whole set of issues that governments may not want to confront. Such issues provide however, the basis for an alliance between advocates from both sectors aimed at improving the quality of residential aged care.

If, as surmised, part of the reason for the slow development of policy frameworks and implementation strategies has been the

conceptualization of the solution to accommodation support for older people with intellectual disability as a shared responsibility. Then, perhaps the “specialist” approach that Ireland appears to be adopting may be a way forward worthy of more consideration. This locates responsibility to adapt accommodation and develop associated support services much more firmly with the disability sector. This may mean the disability service system will have to reorient to incorporate knowledge and expertise around age-related support needs, as was suggested by O’Shea and O’Reilly (1999) and take responsibility for the development of specialist age-related services. It may also give the disability sector a much clearer mandate to lead and adequately resource partnerships with existing services or organizations (Bigby, 2004). Alongside the clearer location of responsibility, however, the challenge will remain to develop policy directions and frameworks that reflect the values of inclusion, independence, choice and rights to inform program development. This will require the articulation of unequivocal outcomes sought for older people and the resolution of some of the unresolved issues discussed earlier.

Given the complexities involved in aging in place in group homes, aiming for simple across the board outcomes such as remaining in a group home may not be feasible. However, importantly, outcomes may also include the adherence to transparent and rights-based decision making processes should any type of move be contemplated.

In the absence of clearer policy frameworks that incorporate ways to resolve tensions, and in the context of scarce resources, a danger of the disability sector taking responsibility for aging is that the right to age in place may be interpreted in the way suggested earlier, not as the right to remain in one’s own home but within the disability sector. Evidence of such implicit policies is found in the development of larger congregate facilities for older people with intellectual disability that has occurred or been foreshadowed in various states in Australia (Government of South Australia, 2005; NSW Government, 2007). There is little reason to think that such developments, by being placed in the disability rather than aged-care sector, will avoid the institutionalization and poor quality of care experienced by many older people in the general population.

Attracting additional resources to the disability sector for policy and program development is difficult as increasingly costs of social programs are capped and social needs balanced with economic imperatives (Baldock & Evers, 1991). Disability services, like other community-care programs are localized, selective, and highly variable, making costs easily containable. The competition for resources from government among disadvantaged groups as well as within the intellectual disability sector between competing priorities is fierce, requiring strong advocacy and powerful allies, as well as a compelling case. The high level of unmet demand for accommodation services in all these countries attests perhaps to the sector’s limited political power to influence government resource decisions. The case for resources may also be hampered by the difficulties of articulating clearly policy goals and outcomes and the ease with which different sources of care may be perceived as a substitute for each other. In the case of older people with intellectual disability, governments may see care in large residential facilities, be they in the disability or aged-care sector, to be a direct substitute for care in small group homes or more individualized options. What matters to those disconnected

from the more complex issues is that care is provided somewhere. It must be argued, however, that what is important for people with intellectual disability as they age is the quality of support that is provided. This is best guaranteed by programs that are built on the principles that apply to earlier parts of their life course, so that old age is not a threat to well-being. There is still a long way to go in adapting these principles to the particular challenges of aging and designing strong policy frameworks to guide program development, but these tasks remain as urgent now as when Moss first raised their urgency in 1993, almost 20 years ago.

ACKNOWLEDGMENTS

I would like to acknowledge the contributions of Frode Larsen, Britt-Evy Westgaard, Nancy Jokinen, Lesley Udell, Jenny Overender, and Karen Watchman for the development of this article.

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