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POLICY ANALYSIS PAPER

Beset by obstacles: A review of Australian policy development to support ageing in place for people with intellectual disability

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Abstract

Background Australian government policy regards people with intellectual disability (ID) as citizens with equal rights, which means that they should have access to the same opportunities as the wider community. Ageing in place is central to aged care policy in Australia for the general population.

Method This paper reviews policy to support the provision of similar opportunities to age in place for people with ID, and the reasons for its slow development.

Results Due to lifestyle patterns earlier in the life course, many people with ID experience a mid-life disruption to their accommodation, and may live in a group home as they age or may move prematurely to residential aged care. The absence of mechanisms to adjust disability funding as needs change, and the existence of policy that denies residents in group homes access to community-based aged care, forces disability services to "go it alone" to support ageing in place.

Conclusion Despite a national priority to improve the interface between the disability and aged care sectors, administrative and funding characteristics continue to obstruct the development of implementation strategies to support ageing in place for people with ID, which remain at the stage of an exploration of the issues.

Keywords: *Ageing, ageing policy, intellectual disability and ageing, ageing in place*

Introduction

Increases in the life expectancy of people with intellectual disability (ID) have followed similar but more pronounced trends to those found in the general population. With the exception of people with severe and multiple disabilities or Down syndrome, the life expectancy of this group now closely approximates that of the general population (Australian Institute of Health and Welfare [AIHW], 2000). Middle and old age, which until 30 years ago were not recognised in this population, are now important parts of the life course of these individuals. Older adults with ID form a small but significant and growing proportion of older people in the community (Bigby, 2004), comprising an estimated 0.13% of the total population aged over 55 years (AIHW, 2000).

Parmenter's chapter in a 1993 monograph (Moss, 1993) noted that Australian governments had just begun to recognise and study the issue of ageing with ID, and that no specific service provision had yet been made. The monograph concluded that across nine countries, an increased awareness of the growing numbers of older people with ID had "generally not been translated into policy" due to the paucity of knowledge about their needs (Moss, p. 87). In the intervening 15 years, this situation has to some degree been rectified, as knowledge about the health and social issues for this group has increased, and program models and policy responses have been developed (e.g., see Bigby, 2004; Davidson, Prasher, & Janicki, 2003; Janicki & Ansello, 2000; Janicki & Dalton, 1999).

Some groups of people with ID have distinctive patterns of ageing, and their needs reflect a complex combination of disability and age-related changes. For example, people with Down syndrome age prematurely and have an increased likelihood of early onset dementia, while people with cerebral palsy

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experience secondary disabilities associated with both ageing and the long-term impact of the impairment (Janicki & Dalton, 1999). Due to their life experiences, people with ID often age from a particularly disadvantageous position. For example, many will have used support services throughout their lives to access purposeful day and leisure activities and to assist with lifestyle planning, which they continue to require in later life. Many will not have married or had children, and will have very limited informal support networks as their parents age and die. Most will not have been in paid employment, and will have limited wealth or income to enable the exercise of choice and access to private health systems (Bigby, 2004). Just as in their younger years, some of the needs of older people with ID will be similar to those of the general population, while due to their pattern of ageing and life experiences, other needs will be different and not easily met by services designed for the general population.

During the 15 years since Parmenter reviewed policies on ageing, Australia's disability policy has shifted towards a rights-based perspective that recognises the equal citizenship of people with disability and their right to participate in all aspects of community life (Ward, 2006). This paper explores the issues that have arisen in formulating and implementing policy on ageing in place for people with ID, which has been a key area of aged care policy development for the general population.

Policies of ageing in place for the general community

The centrality of ageing in place to aged care policy in Australia reflects not only economic imperatives, but also the priorities and preferences of older people (Means, 2007). Ageing in place generally refers to opportunities for people to remain in their own home regardless of their increasing care needs (Chappell, 2001; Cohen & Day, 1993, cited in Chaput, 2002; Forbat, 2006). People are enabled to remain in familiar surroundings, close to family and friends, to retain personal belongings, and avoid institutionalisation. Ideas around ageing in place suggest that continuity and attachment to residence are important factors, as are the quality and nature of available support. The coordinated effort required to support ageing in place and to adapt the physical and social environment as needs change is reliant on financial resources, an adaptable environment, and the proximity of health services (Bigby, 2004; Chappell, 2001).

In Australia over the last decade, community and aged care services have expanded to support older people to age in place, in their own home in the community. The Home and Community Care program provides low levels of in-home support, while programs such as the Community Aged Care Package provide the equivalent of low care residential support to people in their home. Population-based targets have been set for the provision of residential aged care, and access is controlled through Aged Care Assessment Services (ACAS) (AIHW, 2005a, 2006a). The greater targeting of residential aged care to the frail aged is reflected in the increasing age and higher level of dependency of residents. Reforms to aged care in 1997 provided opportunities for residents in aged care facilities, as well as those in private homes, to age in place, by introducing mechanisms to adjust the level of funding as residents' needs change (AIHW, 2005a).

Ageing in place for minority groups

Policies that support ageing in place are problematic for disadvantaged minorities who have poor or unstable housing conditions or high support needs (Chappell, 2001; Means, 2007). People with ID are one group for whom the application of such policies is complex and fraught. The issues for this group extend beyond just having a place to live, to a lack of choice or control over housing and support options. They arise from the inherent need of people with ID for support as well as housing, their pattern of support and housing in young adulthood, the high level of unmet need for accommodation services, and the unresolved tensions of the interface between disability and aged care service systems which are explored below.

Midlife housing disruptions

In Australia as in the UK, adults with ID most commonly remain in the family home with parents until a transition occurs, in middle age or beyond, to some form of group home as a result of parental death or incapacity (AIHW, 2005b; Emerson, Hatton, Felce, & Murphy, 2001). Many adults with ID experience disruption in midlife, which is characterised by dislocation from familiar locality, possessions, friends or family (Bigby, 2000). Few therefore have the opportunity to age in place in their family home, or the choice of other independent supported accommodation options. In Australia, for a large proportion of middle-aged and older people with ID, their "home" will be a group home managed by a government or non-government accommodation service and funded by the government. For example, the median age of the estimated 8,274 residents with ID in group homes in Australia is increasing (AIHW, 2005b). As new policy directions seek to broaden housing and support options, this situation may change, however current policy suggests that group homes will continue to be the only option available to people with high support needs (Bigby & Fyffe, 2007).

Impact of unmet need

Like other developed countries, Australia has a high level of unmet need for disability accommodation support (Senate Community Affairs Reference Committee [SCARC], 2007). Middle-aged and older adults with ID living at home with elderly parents form a significant proportion of the estimated 23,800 people with disabilities with an unmet need for accommodation and respite services (Australian Bureau of Statistics, 2003; AIHW, 2007). This gross shortfall in availability of accommodation compounds the already emotionally difficult task faced by older families in planning for their family member's future (Bigby, 2000). Rather than exercising choice about the location, type of accommodation, and selection of co-residents, adults with ID leaving the family home in mid-life may be forced to take the only option available. Some are likely therefore to be ageing not only in a group home, but one which they have not chosen and which is a poor match to their needs.

Some adults with ID are unable to access disability accommodation support at all, and move from the family home to residential aged care, which may not be a good match to their needs. For example, a survey of aged care facilities in the Australian State of Victoria found that 31% of residents with ID in residential aged care facilities had been admitted directly from the family home (Bigby, Webber, McKenzie-Green, & Bowers, in press). Other groups who are likely to be ageing in less than optimal circumstances are residents of large institutional facilities, or residents in the poor quality accommodation offered by the private for-profit sector (such as boarding houses and pension-only supported residential services). For example, it is estimated that 4,687 people with ID continue to live in large institutions in Australia (AIHW, 2005b), while 9% of residents in pension-only supported residential services in Victoria are people with ID (Green, 2004).

Ageing in place in group homes

Most research on ageing in place for people with ID has focused on residents in group homes, particularly those with dementia. Ageing in place has been conceptualised as either remaining in the same group home, or moving to another home within the same disability service (Janicki, 2004). The adaptation of formal support to enable ageing in place in group homes is mediated by the service provider and their funding body, and by policies that govern access to potential additional services, as well as consideration of the impact on co-residents. The absence of formalised partnerships between the disability and aged care systems to provide supplementary support means that disability service providers must "go it alone". Research suggests that it is primarily service provider organisations that support ageing in place within the limits of their existing resources, through their in-house policies, informal organisational practices, and staff culture (Wilkinson, Kerr, Cunningham, & Rae, 2004). For example, a cross-national study of group homes in five countries (Japan, Australia, Sweden, Canada and the US), where one or more residents had dementia, found no increase in funding to provider organisations to take account of the residents' changed support needs (Janicki, Dalton, McCallion, Baxley, & Zendell, 2005).

The inadequacy of this approach is suggested by research from both the UK and the US, which shows that despite a strong commitment by staff to retaining residents in their own homes, the most common model of service for people with ID and dementia is referral to residential aged care (Janicki & Dalton, 2000; Wilkinson et al., 2004). Limited Australian data are available to indicate the proportion of older residents with ID who move from group homes to residential aged care. In 2000, Bigby found a pattern of relocation from group homes to residential aged care in Victoria (Bigby, 2000), but this pattern may be changing. A 2006 survey of Victorian aged care facilities found only a small proportion of residents with ID who had been admitted directly from group homes (6%), although actual numbers may be higher as some of the 9% of residents admitted from hospital care are likely to have previously lived in group homes (Bigby et al., in press).

The approach of drawing on the existing resources of provider organisations is unlikely to be sustainable as the number of older people with ID increases. For example, one large disability organisation in Australia has reported a growing deficit as it absorbs the ongoing costs of supporting its ageing residents (Cooke, 2007). Such an approach will also lead to inconsistent and unpredictable responses across the service system, given the differing size of provider organisations and their capacity to absorb increased costs.

Arguments for ageing in place in group homes

In Australia, the primary alternative to aging in place for residents in group homes is to move into a residential aged care facility. These facilities are much larger than group homes, with an average of 54.4 beds; average length of stay for permanent residents is 2.75 years; and 52% of residents are over 85 years (AIHW, 2006a). It seems likely that people with ID are often misplaced in residential aged care. Compared to other residents, they are younger, enter at an earlier age, stay for a longer period, and are less likely to have dementia; and their different profile is not explained by a high number of residents with Down syndrome or early onset dementia (Bigby et al., in press; Thompson, Ryrie, & Wright, 2004). Studies that have sought the views of family members or staff, or examined the quality of care and experiences of residents with ID in residential aged care, conclude that the needs of these individuals are met less effectively in such facilities than by group homes in the disability sector, especially with regard to individualised support and participation (Moss, Hogg, & Horne, 1992; Walker & Walker, 1998).

Advocacy groups have voiced strong support for policies which enable ageing in place within group homes or more broadly within the disability sector (British Institute of Learning Disabilities, 2005; Crawford, 2004; National Disability Authority & National Council on Ageing and Older People, 2006). In Australia, two enquiries by Senate Standing Committees on Community Affairs – "Access and Equity in Aged Care" (SCARC, 2005) and "Funding of the Commonwealth States/Territories Disability Agreement" (SCARC, 2007) – have generated debate about ageing in place for individuals with ID. Submissions from the Commonwealth government, most State governments, disability service providers, and advocacy groups have articulated strong support for the right of this group to age in place, as has been accorded to other older people in the community. For example, the Commonwealth government stated:

> The principle of "ageing in place" should apply to the disability community, just as it does to the general community, so that people with disability are encouraged to age in place and, where they choose to do so, are able to access appropriate support services. (SCARC, 2007, p. 117)

While this debate has highlighted the differing positions on the most appropriate strategies to achieve this goal, it has remained at a very generalised level. Little attention has been paid to the varying interpretations of ageing in place; to its problematic application for older people who live in inappropriate or sub-optimal accommodation; to differentiating between the needs of the younger old and the frail aged; or to considering the quality of care that group homes and residential aged care can offer to people with ID at various stages of the ageing process.

Australian housing and support policies for older people with ID

The formulation of government policies and associated strategies to address questions of ageing in place specifically for people with ID, such as "How is it to be funded?" (posed by Senator Patterson: SCARC, 2007), has been slow to develop. Too often, the emphasis has been on broader State and Commonwealth disability policies, which assert the principles of choice, inclusion, participation, and the right of people with ID to be treated as equal citizens (Bigby, 2002). However the absence of an upper age limit to these policies signals the continued reliance of ageing people with disabilities on disability services that are unrelated to ageing.

Since the early 1990s, disability service providers and State governments have developed various initiatives, particularly around issues of retirement and adapting services to allow more flexibility in residents' daytime occupations. These have included: education and training, joint service planning and cross-sector partnerships at a local level, small-scale pilot programs, and organisational policies in non-government organisations (e.g., see Bigby, 1999, 2002; Bigby, Balandin, Fyffe, McCubbery, & Gordon, 2004; Dew & Griffin, 2002). Most initiatives have been locally based, small in scale, short-term, and usually funded from the organisation's existing resources, rather than a long-term systemic change. Ansello (2004) has suggested that initiatives of this type are responses to matters "not yet sufficiently addressed in public policy".

Policy in the disability sector

The first major policy step towards addressing the issue of ageing in place for the disability sector in Australia was the priority given in the multilateral Commonwealth/States and Territories Disability Agreement (CSTDA) (2002–2007) to the strengthening of access to generic services and cross-government linkages for people with disability (Department of Family and Community Services, 2003a). However although the bilateral agreements between the States and the Commonwealth were framed in terms of an intention to improve the interface between the aged care and disability sectors, there was no specific mention of the key interface between disability and health. An examination of the publicly available strategy planning documents of the State and Territory disability agencies, as well as the Annual Reports of the National Disability Administrators, suggests that the areas pinpointed for action are: improving Aged Care Assessment Services procedures and protocols; developing or evaluating flexible funding programs and mixed models of service provision; and addressing both workforce training and the transition from work to retirement. However this remains largely at the stage of an exploration of the issues (Australian Health Care Associates, 2006). South Australia is the only State to make an explicit commitment to ageing in place for the disability sector (Department of Family and Communities, 2004). In other States, there is little expectation of ageing in place for people with disability, as shown in the policy statement on group homes in Victoria, which suggests that residents cannot regard a group home as their permanent home and that they may be expected to move:

> The duration of stay in a particular SSA [Shared Supported Accommodation, i.e., group home] may vary. For example, where an individual's support needs change to such an extent that their existing service can no longer provide adequate support within existing resources, there may be a requirement to move to another service. (Department of Human Services, 2006, p. 5)

Policy in the aged care sector

The difficulties faced by people ageing with life-long disabilities in obtaining the level and type of services they need was noted in the National Strategy for an Ageing Australia, which suggested that specific or special arrangements will be required to meet the needs of this group (Andrews, 2001, p. 58). Yet no systematic development of specific arrangements for people ageing with ID has eventuated, although some ad hoc provisions and pilot programs have taken place.

Significant advocacy in 2005/2006 on behalf of "younger people with disabilities in nursing homes" has tightened access to residential aged care and attracted new funds to provide alternative housing and support options for younger people (primarily those aged under 50 years) living in aged care facilities. The spin-off of these policies has been reduced access to Aged Care Assessment Services (ACAS) and restrictions on entry to residential aged care for people under 65 years (SCARC, 2007). This may in turn have the effect of supporting ageing in place in group homes.

However policy has been silent on the situation for "younger old people" with ID (i.e., those aged less than 65 years) who experience premature ageing or early onset dementia, and whose needs might be better met in residential aged care. ACAS undertake a two-step process for the general population, first assessing eligibility for aged care services and then considering the most appropriate option. Many of those "eligible" for residential aged care choose to remain in their own home with community-based aged care supports. A similar process cannot be reproduced for residents in group homes, as they cannot access community-based aged care services while living in their group "home", and those under 65 years will find it increasingly difficult to gain access to residential aged care (for the reasons mentioned above).

A significant cross-sector pilot program was established in 2003/2004 by the Department of Health and Ageing as part of their Innovative Pool Disability Aged Care Pilot initiative (AIHW, 2006b). Nine projects across Australia were established to explore the provision of community-based aged care services for ageing residents in group homes. Objectives were to identify age-related needs and to test whether the addition of aged care services would reduce inappropriate entry to residential aged care. The programs were targeted at residents assessed as eligible for residential aged care. State governments, in partnership with disability provider organisations, maintained existing disability supports while project funds purchased additional services through partner aged care providers. The projects demonstrated improved quality of life for older residents and the feasibility of supporting them to age in place largely through additional health planning, access to allied health care, and day-time community support. Furthermore, the projects demonstrated the potential of cross-sector partnerships when resources are made available to support them. Highlighted also was the complexity of distinguishing age-related from disability-related needs, and the importance of joint assessment processes by ACAS and disability services (AIHW, 2006b). Despite advocacy from the disability sector in support of these pilot programs, they were not continued, and the Commonwealth government has indicated that further work is required to develop an acceptable approach to people ageing with a disability in group homes (SCARC, 2007). This response suggests that the Commonwealth has significant problems with this service model.[1]

Policy intention without implementation strategies

Though fairly general in nature, the CSTDA bilateral agreements indicate a policy intention to include older people with ID in aged care services and to support cross-sector planning and partnerships. Despite this, no firm policies exist that actually provide mechanisms to support ageing in place, define reasonable expectations, or stipulate which system or systems – aged care, community care, disability, or health – has responsibility for funding this strategy. Rigid program boundaries and policy definitions restrict access to aged care programs by residents in group homes, as well as partnerships between disability organisations and aged care services to provide supplementary support for ageing in place. In addition, there are few mechanisms available to ensure that ageing people with disabilities can gain access to quality primary and hospital health care which is responsive to their unique combination of disability- and age-related needs, nor have initiatives been taken to improve their access to specialist geriatric services. No measures have been introduced to develop the expertise of ACAS in assessing younger old people with ID, or to give policy guidance about the circumstances when entry to residential aged care might be the preferred option for this group. Strategies to support ageing in place remain localised, inconsistent, ad hoc and resourced by pilot programs or from existing resources. The limited evidence suggests that although some people under 65 with ID continue to enter residential aged care, gaining access to an ACAS assessment is increasingly difficult for this group (Bigby et al., in press; SCARC, 2007). The following section considers some of the reasons why policy development in this area has been so slow.

Competing interests and unresolved policy issues

Some theorists regard policy as evolutionary, a set of goals and hypotheses to be tested and adjusted over time (Bridgman & Davis, 2004). From this viewpoint, the refinement of policies to support ageing in place will gradually evolve as pilots and other initiatives form "laboratories for emerging public policies" (Ansello, 2004). However Putnam (2004) warns that few attempts have been made to sort out the issues that lie at the heart of this policy. The combination of unresolved tensions that stem from the organisational and political characteristics of the aged care and disability systems in Australia, a lack of clarity about the veracity of the goal of ageing in place, and the unmet need in the disability sector, may account for the slow development and implementation of policy.

Aged care for the general community in Australia is a uniform national population-based system, characterised by rigid program boundaries, and is largely the responsibility of the Commonwealth government. By contrast, the bulk of disability funding comes from the States, and the service system is less uniform, more discretionary, and without national population-based targets, which means that the overall budget can more easily be capped than the universal aged care system. There is considerable overlap between the two systems in terms of the types of services delivered and the eligibility of clients. These organisational characteristics create the potential for partnership across the sectors, but also for costs to be shifted from one sector to the other (and so from one level of government to the other), and thereby for clients to be perceived as unfairly dipping into both systems ("double dipping"). This structure fosters in each sector quite different stances on achieving ageing in place, which consequently impedes cross-sector agreement on strategies. The division of responsibility for disability policy and aged care into different levels of government and administrative departments undermines the Commonwealth's espoused all-of-government approach to disability policy, and further compounds the division between the two sectors.

Partnership between the sectors?

State governments and disability providers have framed the core issue of ageing in place as: (i) access to aged care services by people using disability services, and (ii) the need for partnerships and joint responsibility between the sectors. Proposed strategies are premised on the need for additional support to be provided by the aged care sector. For example, the enquiry into Access and Equity in Aged Care recommended:

> That the Commonwealth respond to the growing needs of people ageing with disabilities by consulting with the States and Territories and stakeholders to identify ways to improve access by people ageing with a disability to appropriate aged care services including service provision in supported accommodation. (SCARC, 2005, p. 150)

The CSTDA enquiry recommended:

> That 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. Administrative funding arrangements should not impede access to aged care services

> for people with a disability who are ageing. (SCARC, 2007, p. xii)

The logic that the increased costs associated with ageing should be borne by the aged care sector is supported by a human rights perspective which regards people with a disability as citizens with equal rights. The special needs of a person with a disability do not disappear as that person ages, and continued access to disability services is required. Such specialist services must complement, rather than replace, services that are available to other older people, such as allied health, rehabilitation, or hospital services. For example, early onset dementia in a person with Down syndrome living in a group home is a problem associated with ageing, and this means that the person will require access to aged care expertise (such as memory clinics) in addition to the breadth of existing disability supports (such as support with decision-making or participation in the community). In other words, aged care dementia-specific services should be made available over and above disability services. If this were the case, the result would be a partnership between the two sectors rather than "double dipping", as each sector would be providing something the other does not. This stance is also cognisant of the situation of unmet need and waiting-lists which exist for disability services, and of the potential impact if the disability sector is to face increasing costs associated with an ageing population.

The Commonwealth government has argued against this position of a mix of services from different sectors, suggesting that either one sector or the other is able to provide appropriate care:

> 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. (SCARC, 2005, p. 147)

> If a person is receiving an accommodation support service or a nursing home service, those service providers are meeting that person's need. (SCARC, 2005, p. 120)

This position is based on the perspective that disability is a primary characteristic and that disability services are comprehensive. Thus, for example, problems such as early onset dementia, a chronic illness, or hearing loss for an older resident in a group home should be dealt with by the group home service in conjunction with the health system. The argument is that the person already has substantial support from the disability system, which costs much more per capita than the aged care services available to other older people (SCARC, 2007). Following this logic, the Commonwealth government goes on to suggest that the States have the discretion to organise their disability services and expenditure as they see fit to take account of changed needs. This position suggests that people are either disabled or aged, but not both. It also relies on the assumption that residential aged care can replicate and simply replace disability services. Thus a person with ID should either remain in a group home and have their needs met there, or move to residential aged care which will alone be sufficient to meet their needs without additional input from disability services. On the one hand, this position ignores the lack of expertise in the disability sector regarding age-related issues, while on the other, it ignores the very narrow focus of residential aged care on personal or nursing care, its lack of expertise in working with people with ID, and the need of people with ID for broader support to assist with issues such as life planning, maintaining contact with family, advocacy and community access.

Complexity of "top up" models

The Innovative Pool Pilot initiative demonstrated that "topping up" disability services with aged care funding was feasible and could have good outcomes for residents, at a relatively low cost (AIHW, 2006b). However, it also demonstrated the complexities of designing and funding such a program that stem from the difficulty of separating aged-related from disability-related needs, as well as the potential duplication of existing disability services.

The characteristics of the Australian funding system create an imperative to prevent the total cost of supporting an older resident in a group home (including costs previously met by the disability service) from being shifted to the aged care sector. In turn, this means that a top up model must identify the additional needs and costs associated with ageing. Separating age-related needs from existing disability needs is a complex proposition. Age-related needs are not necessarily uniform, and can be acquired from very different starting-points in different people. For example, age-related changes to a person's mobility and balance may mean that they require additional support. However, if that person had low support needs and good mobility when younger, their need for support when older may still be lower than someone with pre-existing mobility problems and high support needs but no age-related additional needs. The degree of change – referenced to each individual – is important in identifying age-related needs rather than an objective measure of need. This makes it difficult to apply a uniform, standardised group-based approach to measuring age-related needs.

It is argued that top up models lead to program duplication, and thereby compound the difficulties of identifying age-related needs. This was illustrated in the Innovative Pool Pilot program, when older residents who had retired from supported employment needed support and supervision during the day to participate in meaningful activity. This could be viewed as a result of both ageing (no longer being able to work) and disability (requiring support to access activities). However, the type of support provided by the Innovative Pool Pilot program closely resembled the disability program (i.e., community support) provided to younger people with disabilities who are unable to undertake employment. The key difference was that for the younger people the need was solely related to their disability, while for the older people, it was related to both disability and age.

There are also difficulties in identifying the target population for top up programs. Age is not a useful criterion given that premature ageing is experienced by some people with ID – nor is changing needs, as younger and middle-aged as well as older people with ID experience changes in their support needs. The absence of mechanisms in the disability sector to adjust funding according to changed support needs creates a tendency for all changed needs to be put down to ageing, which effectively excises middle age as part of the life course for people with ID, and shifts perceptions of ageing to a younger age than is warranted. Examples of this tendency are found in day programs where more flexible programs for older people often include much younger people as well (Bigby et al., 2004).

The inherent complexities of targeting, identifying, and measuring age-related as opposed to disability-related needs, combined with issues about the overlap of programs, create significant obstacles to the development of a top up model. The work of Baldock (1997) on community care highlights similar complexities. He refers to "product and consumer complexity", which together "conspire to make very difficult, and probably impossible, the project of constructing a body of evidence-based knowledge that would allow a more informed allocation of social care services" (p. 82). Such appears to be the case for the top up model.

Alternative strategies

The necessity to tackle some of these perhaps insoluble complexities is largely a product of the Australian funding system, which creates the imperative to avoid shifting costs from one sector to the other, while the extent of unmet need creates the imperative to shift costs. One way of dealing with this dilemma is to remove the need to solve it, by adopting a different policy strategy to deal with ageing in place for people with ID. This could take the form of a program of additional earmarked funding from the Commonwealth to the States, based on the demographic profile of their populations with ID, to enable them to create and fund mechanisms to support ageing in place – in other words, a block transfer to the States to compensate for additional age-related needs of people with ID. Such a strategy would provide a new stream of specific funding for the States to tackle housing and support for this group, which would be comparable to the funding provisions made for alternative accommodation support for younger people with disabilities in nursing homes (SCARC, 2007). This strategy is in keeping with the position adopted by the Commonwealth government in its submission to the Senate Enquiry on "Access and Equity in Aged Care", where it acknowledged that the needs of ageing people with ID will not fit easily into existing aged care programs, and so will require the development of new programs (Department of Family and Community Services, 2003b).

A strategy such as this may provide a springboard for State governments to develop funding mechanisms for disability providers that take account of changes in residents' support needs, whether or not they are associated with ageing. It would also avoid the tendency to label all changed needs as due to ageing, which may help providers to focus on middle age as part of the life course for people with ID. In addition, such a strategy fits current market-based models of purchasing individualised support, and would potentially provide funds for disability services to reconfigure their staff skills or to purchase external aged care expertise as and when required. Alternatively, given the relatively small number of older people in each provider organisation, a regionally based service could be established to provide consultancy on age-related issues and a pool of skilled support staff to be drawn on by a network of provider organisations. This approach would also provide resources to foster partnerships between the two sectors.

This type of strategy has the potential to broaden the focus beyond ageing in place for residents in group homes, and to provide resources to improve the quality of support provided to older people who may be in inappropriate or less than optimal housing. It could, for example, provide funds for disability services to work in partnership with residential aged care or other facilities such as private supported residential services.

Another strand of policy must be to develop greater clarity about the advantages or otherwise of ageing in place for different sub-groups, or for people at different stages of the ageing process. This will help to clarify if, when, and in what circumstances residential aged care may be considered as the most appropriate option for younger old people with ID, as well as for those over 65 years. If it is accepted that for some older people, residential aged care may at some stage be the most appropriate option, then another potential strategy is to include people with ID as a "special needs group" under Section 11.3 of the Aged Care Act (1997). This would mean that their particular needs would be taken into account in the planning, allocation, and funding of aged care places. Such a move would perhaps support the development of expertise and the designation of earmarked places for people with ID in selected residential aged care facilities.

One danger of the allocation of funds to State disability authorities to compensate for the additional costs associated with ageing of people with a disability is the perception that the disability system will therefore assume total responsibility for all age-related needs of this group. However clearly, disability services, even with additional aged care funding, cannot take on the role of the health care system. The strategy must therefore be complemented by others aimed at improving access to allied health, hospital, and specialist geriatric services to underpin support by accommodation services. These strategies could include the establishment of hospital disability liaison positions to facilitate appropriate inpatient care and rehabilitation for people with ID, and the adaptation of specialist geriatric health services (such as memory or falls clinic) for this group.

Conclusion

The competition among disadvantaged groups for government resources, as well as between competing priorities within the disability sector, is becoming fiercer, and so requires strong advocacy and powerful allies, as well as a compelling case — all of which pose problems in the case of older people with ID. The high level of unmet demand for accommodation and other disability services for these individuals perhaps attests to this sector's limited political power to influence government decisions on resource allocation.

The strength of the case for ageing in place, and for the funding strategies to achieve this, is potentially weakened by what Baldock (1997) refers to as the "plasticity" of community care. This refers to the ease with which different sources of care can be substituted for one another, and is normally discussed in the context of informal care taking up shortfalls in the availability of formal care for people living at home. In the case of people with ID, it may be suggested that care provided by group homes in the disability sector can be replaced with care provided by facilities in the aged care sector. What may be seen to be of principal importance is that care is provided – who provides the care and the nature of that care are largely invisible, and of little concern to those disconnected from the issues. This means that the case for policy and strategies to support ageing in place, and the differences in care required by people at different stages of the ageing process, must be more clearly argued, and the assumptions underpinning the counterarguments confronted.

It is no longer tenable (as Moss did in 1993) to argue that a lack of policy is the result of a lack of knowledge about the particular needs of ageing people with ID. The fact that policy has not progressed past an acknowledgement of the issues and a broad direction for going forward is due to a failure to agree on implementation strategies, to the creation of obstacles as a consequence of the administrative arrangements in place for the aged care and disability service systems, to the unmet need for resources in the disability sector, and to a climate in which advocacy and political power, rather than need, drives policy developments.

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Note

1 However the new Commonwealth Labour Government elected on 24 November 2007 has signalled a different and more supportive position on "top up" models in its "Disability and Carers Policy" released during the election campaign (McLucas, 2007).

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