

A survey of people with intellectual disabilities living in residential aged care facilities in Victoria

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Abstract

Background Australia's national ageing policy recognises that people ageing with intellectual disability (ID) require particular attention, yet there is no policy framework concerning this population. This study describes the distribution and characteristics of people with ID in residential aged care in Victoria, provides insights into the pathways they take into aged care, and gives some indications of how facilities adapt to their needs.

Method A postal survey was sent to 826 residential aged care facilities in Victoria, seeking information from directors about their residents with ID. Facilities that responded were fairly representative of all facilities in Victoria.

Findings Residents with ID were younger, had entered at an earlier age and remained longer than other residents. Their reported dependency profile was similar to the general aged care population, although the incidence of dementia was lower. Primary areas of concern identified by providers were: inability to fit into the resident community,

lack of participation in activities and lack of meaningful relationships.

Conclusion This study provides a first glimpse into how older people with ID find their way into aged care and how others view their experiences once there. It suggests that further investigation is required into the accuracy of assessment undertaken prior to entry to more clearly understand whether residents with ID are inappropriately placed in residential aged care as a result of a shortage of disability accommodation and inadequate resources to support aging in place for those in such accommodation.

Keywords ageing and intellectual disability, residential aged care, ageing in place

The World Health Organisation's active ageing framework is reflected in *A National Strategy for an Ageing Australia* (Andrews, 2001). It seeks to achieve infrastructure to support; continued participation in the life of the community, opportunities to maximise physical, social and mental health, and an affordable, accessible and appropriate world-class system of care for older Australians. The Strategy emphasises that not all the frail aged use aged care services, but those who do will increasingly demand good-quality services and choice. It identifies people

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with lifelong disabilities as one group that faces particular barriers to obtaining the levels and types of services they need or prefer, and who require 'specific or special arrangements' to meet their needs (Andrews, 2001, p. 58). However, neither the Disability nor Aged Care system in Australia has a policy framework in relation to older people with intellectual disability (ID), nor is it clear which sector has the appropriate expertise or primary responsibility to provide care and services for this group of older adults (Bigby 2002; SCARC 2007). This absence of clear responsibility by either of the two sectors, their separate funding streams, the primary funding role of the Federal Government for Aged Care and State Governments for Disability, and the high unmet need for housing and support by people with disabilities potentially combine to encourage state-funded disability accommodation providers to shift older residents into aged care to save additional costs associated with ageing and to create vacancies for younger people (Bigby 2008).

Older people with ID differ from other older adults in respect of having poorer health, greater reliance on formal services, poorer informal support networks, more limited choices, and limited access to private wealth (Bigby 1997; Janicki *et al.* 2002; Haveman 2004). Subgroups such as people with Down syndrome, cerebral palsy or multiple disabilities, are likely to experience premature ageing, effectively lowering the age at which individuals may require ageing-related services (Janicki & Dalton 2000). Thus, the usual demarcation point of 65 years, which determines access to age-related services, may be inappropriate for at least a subset of older adults with ID and may effectively block their access to needed services. There is little research to inform policy development about appropriate pathways into or use of residential aged care for this population. Nor is there much research on the nature of adaptations required to meet the needs of this particular group when they are living in residential care. Existing research does, however, highlight concerns about these issues, warranting further investigation. Studies from Australia and other nations suggest that people with ID experience considerable residential mobility in their middle years and beyond (Hogg & Moss 1993; Bigby 2000), and a disproportionately high number live in aged care facilities, many at a relatively

young age (Bigby 2000; Thompson *et al.* 2004). Moving people to an aged care facility before it is either necessary for health reasons and/or without considering the effect on social and community participation is starting to be raised as an important issue of equity. Concern has been raised about the appropriateness and quality of residential aged care for people in this group. For example, the Nursing Home Reform Act, enacted by the US Congress in 1987, called for a preliminary assessment of appropriateness for admission by state authorities before someone with an ID could be admitted to a nursing facility. If the facility failed to obtain such an assessment prior to admission, all federal reimbursement for the cost of care would be denied. This Act also required all residents with an ID have an individually tailored plan of care to ensure that they were engaged in meaningful activities while residing in the nursing home. The UK White Paper *Valuing People* concluded that many people with ID were inappropriately placed in aged care, among residents who were older and more incapacitated than them (Department of Health 2001). This has implications for their ability to relate to others socially and to be able to maintain friendship and community activities which were previously enjoyed when they were still in place. In the UK, Thompson *et al.* (2004) found that less than one-third of people with ID who moved from the family home to aged care facilities did so for reasons associated with age. In Victoria, Australia, Bigby (2000) found that decisions initiated by disability service providers to place a resident in residential aged care were often contested by family members.

Notions of inappropriate placement are inevitably tied to questions about the experiences and type of support provided to older people with ID who are living in residential aged care. Thompson *et al.* (2004) in their survey of UK aged care facilities found that residents with ID did not 'fit in' well, had a low level of participation in recreational activities and that staff lacked specific knowledge about them. Despite this, however, most providers in their study reported that they adequately met the needs of residents with ID. Earlier work by Hogg & Moss (1993) found that people with ID living in aged care received less individualised support and participated less in leisure activities than did their peers in disability accommodation. Consistent with

these concerns, a substantial advocacy campaign in Australia has focussed attention on the unsuitability of residential aged care for younger people with disabilities (<http://www.ypinh.org.au>; SCARC 2005; Winkler *et al.* 2006). However, this campaign has concentrated on residents under 50 years of age and remained largely silent on the position of the 'younger old' aged over 50 years but younger than the average resident age of 84.3 years (AIHW 2006).

Concern about younger people with disabilities in aged care in Australia, has led to a shift in Aged Care Assessment Service guidelines, which now require that all less restrictive options must be explored for a person under 65 years before residential aged care is considered. There have been reports that this new policy has led to refusals to assess 'younger older' people, which may, paradoxically, prevent older adults who experience premature ageing from receiving the services that are most appropriate (SCARC 2007). Thus, a situation can occur where some people are inappropriately placed in an aged care facility, while others with serious health issues are refused entry because of their age. Consequently, while evidence points to the inappropriately early placement of some people with ID in residential aged care, those who experience premature aging or early onset dementia (such as people with Down syndrome) may find access to be a problem.

This paper reports on the first phase of a 4-year study that aims to explore the pathways by which older adults with ID come to residential aged care, the type of care and support provided to this group, and the circumstances in which it may be an appropriate option. The first phase, reported here, mapped the population of people with ID in residential aged care facilities in Victoria, asking specifically: (1) how many and what are the characteristics of people with ID living in residential aged care in Victoria; (2) why do they move to residential aged care and where do they move from; (3) what type of support do they receive in residential aged care; and (4) what do residential aged care providers see as the issues in providing support for people with ID.

Method

A survey was mailed to the Nursing Director of all residential aged care services listed on the

Commonwealth Department of Health and Ageing web site for Victoria 2005(826). The survey was in two parts. The first sought information about the location and resident capacity of the facility, whether they had any residents with ID, and the main issues arising regarding care for this resident group. The second part sought de-identified information about the characteristics of each resident with ID, including gender, age and length of residence, reason for entry, activities, level of functional need [Resident Classification level (RCS)] and frequency of contact with family and friends.

Surveys were mailed in July 2006. Four weeks later follow-up phone calls were made to non-responding facilities, and offers were made to complete the surveys by phone. If this option was taken up, the phone call was treated as a structured interview and the format of the survey was closely followed. Responses were received from 286 facilities, with approximately half of the surveys being completed on the phone. Taking account of undeliverable surveys and a small number of facilities that had closed, this represented a 35.0% response rate. Ethics approval was given by Human Research Ethics Committees of the Australian Catholic University and La Trobe University.

The data were analysed statistically with the aid of the Statistical Package for the Social Sciences. Answers to open-ended questions were analysed thematically by coding them into separate categories.

Sample limitations

While this was a relatively low response rate, the sample was fairly representative of Victorian aged care facilities, in respect of location and resident capacity; 55.0% of facilities in the sample were in the metropolitan area compared with 55.0% of all Victorian facilities, and 72.0% of the sample had a bed capacity of 60 or less compared with 78.0% of all Victorian facilities. One hundred and fourteen (40%) aged care facilities identified a total of 207 residents with ID. Most of these facilities (71, 62.0%) had only one resident with ID, 26.0% had two residents, and 8% had three residents. Two facilities stood out with 17 and 23 residents with ID respectively. Comparison of the data from these two

facilities with those that had small numbers showed a different resident profile on almost all dimensions. Both of these facilities had a high proportion of residents with ID, most of whom had been transferred together following the closure of small institutions. These differences suggest that the two facilities with a high concentration of residents with ID are indeed exceptional, the result of a particular constellation of events. It was, therefore, decided that data from the facilities with a small number of residents with ID were more likely to be a representative snapshot of the profile and experiences of people with ID in residential aged care. Accordingly, data for facilities with a small number of residents are presented separately from the two exceptional facilities that had a high number. Wherever possible, characteristics of residents with ID are compared with aggregate data on all residential aged care residents in Victoria, collected by the AIHW (2006).

With a 35.0% response rate, generalisations to Victorian residential aged care should be made with some caution. There is some reason to believe that our study may actually reflect an over-sampling of facilities where individuals with ID were living, as telephone follow-up revealed that facilities with no such residents were less likely to respond the survey, believing that it was not relevant to them.

Findings

Characteristics of residents with intellectual disability

Of the 207 residents identified, 40 lived in the two exceptional settings (17 and 23 residents) with the remaining 167 being from facilities with 1–3 such residents. Detailed data were available for 158 of the 167. Females outnumbered males by more than two to one (69.0% to 31.0%), which is similar to the general population of residents (72.0% female) in residential aged care. As Table 1 shows, reported ages of residents with ID ranged from less than 30 to over 90 years, with an average of 64.8 years. Almost half (46.8%) were aged less than 65 years and only a few (7, 4.4%) aged over 85 years. This age profile is considerably younger than the general population of residents in aged care, of whom only 4.1% are aged less than 65 years while 52.0% are aged over 85 years (AIHW 2005, 2006).

Since it is well documented that care needs generally rise with age, the relatively young age of individuals with ID raises questions about likelihood that these residents would need a high level of care. However, in this study, 60.7% of residents (96) with ID were classified as high care (RCS 1–4), with 24.1% (38) classified as low care (RCS 5–7) (data were missing for 24, 15.2%). If those for whom data are missing are excluded, 71.6% of residents with

Age group	Residents with ID		All permanent residents in residential aged care in Victoria* %
	N	%	
<45	10	6.3	} 4.1
45–54	15	9.5	
55–64	49	31.0	
65–74	43	27.2	8.7
75–84	31	19.6	35.2
85–94	7	4.4	44.6
95+	–	–	7.4
Missing data	3	1.9	–
Total	158	100.0	100.0

Table 1 Age of residents with intellectual disability (ID) in 112 residential aged care facilities in Victoria compared with all permanent residents in Victorian residential aged care facilities

* Source AIHW (2006).

ID were classified as high care and 28.4% as low care. Significantly, the percentage of low-care residents was less than that found in the general population (33%), while the percentage of high-care residents with ID was somewhat higher than that of the general population in residential aged care (67%).

Some insight into the relatively high-care needs of people with ID was gained by examining their health conditions as reported by providers completing the survey. These included a very wide range of medical and psychiatric conditions, most frequently, epilepsy, diabetes, asthma, osteoarthritis, osteoporosis, cerebral vascular accident, depression, anxiety, schizophrenia, sensory impairments, cancer, heart disease, hypertension and gout. Other less frequent diagnoses included dementia, obesity, incontinence, behavioural disorders, brain lesions and anaemia. These are similar to conditions that affect all older people (AIHW 2005, 2006). There was no attempt to assess the severity of these conditions, or the level of resulting disability.

The prevalence of dementia was, however, much lower in the group with ID than is found in the general residential aged care population. Just over 10.0% of residents with ID (17) were reported as having dementia compared with an estimated 60.0% in the general resident population (AIHW 2006). There was no difference in the mean age of residents in this study with and without dementia. Twenty residents were reported to have Down syn-

drome, of whom half were also reported to have dementia. Residents with Down syndrome tended to be younger at 60 years than those without this condition at 66 years [$t(148) = -1.87, P = 0.06$], while residents with Down syndrome *and* dementia were significantly younger, at 61, than residents with dementia without Down syndrome at 74 years [$t(15) = -3.91, P = 0.001$].

Length of stay

The average age of older Australians moving to residential aged care is 84.3 years, and their average completed length of stay is 2.7 years (AIHW 2006). In contrast, the average age of residents with ID in this study moving to residential aged care was 59.4 years, and their average length of stay (at the time of the study) was 5.6 years, more than double that of other residents. It must be noted that the figures for the general aged care population are completed length of stay, while the survey was only able to determine length of stay to date, which means that for residents with ID their completed length of stay will be longer than the figures reported here. As Table 2 shows, at the time of data collection, 44.0% of residents with ID had lived in residential aged care for more than 8 years.

Pathways to residential aged care

The largest group of residents with ID (37.0%) came to residential aged care directly from the

Length of stay	Residents with ID		All Victoria residents in residential aged care* %
	n	%	
<1 year	15	9.5	38.2
1–<2 years	21	13.3	16.6
2–<3 years	23	14.6	12.1
3–<4 years	18	11.4	8.6
4–<5 years	12	7.6	6.3
5–<8 years	22	13.9	11.0
8 plus	44	27.8	7.0
missing	3	1.9	–
Total	158	100.0	100.0

Table 2 Length of stay of residents with intellectual disability (ID) in 112 residential aged care facilities in Victoria compared with all permanent residents in Victorian residential aged care facilities

* Source AIHW (2006).

Table 3 Previous accommodation of residents with intellectual disability in 112 residential aged care facilities in Victoria

Previous accommodation	Residents	
	<i>n</i>	%
Community residential unit (group home)	10	6.3
Other supported accommodation	40	19.0
Living with family	58	36.7
Living alone or with unrelated others	12	7.6
High-care aged care facility	10	6.3
Low-care aged care facility	11	7.0
Hospital	14	8.9
Don't know	3	1.9
Psychiatric hospital	2	1.3
Total	158	100.0

family home, a much higher proportion in non-metropolitan facilities (34.0%) than that in metropolitan facilities (23.0%). As Table 3 shows, a high proportion of residents (25.3%) had previously lived in some form of supported accommodation. The number of residents admitted directly from disability funded group homes (6.3%) may be artificially low, masked by an admission to hospital occurring prior to the move to aged care. The pattern of previous accommodation is quite different for the general population in residential aged care of whom 49% lived alone prior to their admission, 45% lived with family and 6% lived with others (AIHW 2006). This difference reflects the greater reliance of people with ID on formal accommodation services at an earlier stage in the life cycle.

For residents with ID who were admitted from supported accommodation, the main reason given for their admission was the inability of the facility to provide adequate support. The main reason residents were admitted directly from the family home was the death or ill health of their primary carer. At admission, 30.4% of residents were aged under 55 years, and 31.0% were between 51 and 60, while only 9.5% were over 65 years. People with Down syndrome (with or out without dementia) did not enter residential aged care at a significantly earlier age than other residents with ID. These profiles

differs markedly from the general population of aged care, of whom only 4% are aged under 65 years while 96% are over 65 years at the time of admission. (Table 4)

Respondents reported that, for 69.0% of the residents, the move to residential aged care had been the residents' preferred option, while it was reported as not the preferred option for only 9.0% of residents (data were missing for 22.0%). In cases where residential aged care was reported as not the preferred option, the reasons given for selecting residential aged care were related either to the health needs of the resident or a desire for greater proximity of friends and/or family.

The high percentage reporting that residential aged care was the resident's preferred option must be interpreted cautiously as this was reported by the residential aged care provider, not the resident. Respondents also suggested that for many residents residential aged care was the only option available or which had been considered. For example, respondents said:

He probably could have gone somewhere else because he is fairly independent. It seems to me that families hit a crisis (when the person has to be hospitalized). They don't know what to do so they decide on aged care as the only option but with good care the person often starts to feel better.

Lived here in the town all her life and familiar with our facility

[The resident's] mother comes for respite periodically. No community option available.

Appropriateness of residential aged care

Although there are many ways to approach the question of appropriateness, two important issues are the participation of residents in community activities and the development of meaningful relationships. The survey responses indicated that a substantial majority of residents with ID (94%) took part in onsite activities at least weekly, with 73% participating daily. While no comparable data are available concerning similar rates of engagement for the general aged care population, anecdotal evidence suggests that the rate is higher than this for both weekly and daily take-up.

Age group	Residents with ID		All permanent residents in residential aged care in Victoria* %
	<i>n</i>	%	
<45	18	11.4	} 4.0
45–54	30	19.0	
55–64	49	31.0	
65–74	42	26.6	9.9
75–84	15	9.5	40.7
85–94	–	–	41.2
95 over	–	–	4.2
Missing data	4	2.5	–
Total	158	100.0	100

* source AIHW (2006).

Table 4 Age of entry of residents with intellectual disability (ID) in 112 residential aged care facilities in Victoria compared with all permanent residents in Victorian residential aged care facilities

Some residents did not participate in activities either within or outside the care homes. Reasons given for this included: their health, cognitive incapacity, and emotional or behavioural difficulties. For example, comments about why residents did not participate in activities included: increased frailty, (resident is) asleep most the day; poor motivation and chronic pain; and disruptive, unable to concentrate.

Some facilities had either designed a specific programme for the residents with ID, or encouraged the resident to become involved in the facility by adopting a helping role or taking on small jobs. For example, respondents said:

We have found activities she is interested in – a large TV screen, pet therapy, massage. Local school children visit and volunteers take her for walks in her wheelchair.

He doesn't enjoy onsite activities but has several roles – he collects mail and bread, and sets up the room with chairs and equipment. Relationships are with staff rather than residents.

Residents with dementia participated in daily activities at a lower level (41.2%) than did those without dementia (73.0%).

Just under 50% of residents with ID participated in off-site activities at least weekly. This included

regular attendance at some type of disability day programme and outings with staff or friends and family. Sixteen per cent of residents, mostly those under 60 years, continued to use disability services to maintain engagement in activities. For some, the partnership between Aged Care and Disability services appeared to work well, e.g. one respondent remarked:

We have been working in cooperation with disability services since the resident's admission. Resident has enjoyed tailored activities.

Notably respondents from several facilities commented that their resident with ID had been unable to access disability services, on the grounds that this would be double-dipping (i.e. accessing funding from both disability and aged care sectors). However, the absence of a policy framework discussed earlier means that there are no firm policies regarding concurrent access by people with ID to both residential aged care and disability services.

A further question related to the appropriateness of residential aged care is whether facilities offer sufficient opportunity for meaningful relationships. Our survey revealed that just over a quarter of residents were reported as having no positive relationships with other residents (28.0%). Significantly, in the 'exceptional' facilities (those with large numbers

of ID residents), only 5% of residents were reported as not having any positive relationships with other residents, compared with 28.7% in the smaller facilities. Furthermore, residents in the two exceptional facilities were twice as likely to have a close or 'special' friendship with another resident than those in facilities with a smaller number (65.0% compared with 33.0%).

A large majority of facilities reported that they supported contact between residents and their informal network of family and friends, reporting that 50.0% of all residents with ID had contact with an informal network member at least weekly. It was not unusual for residents with ID to find friends among the staff, rather than other residents. Existing relationships were of support for a small group of residents who had been admitted with a relative, either a mother or sister (seven, 10% of residents admitted from the family home).

Perceptions by residential aged care providers

To further explore the appropriateness of residential aged care for people with ID, the survey included an open-ended question about the issues that arose in providing care to people with ID. Of the 97 responses to this question, three-quarters (73) pointed to a range of difficulties.

The most common issue identified by aged care providers (48%) were the difficulties associated with residents with ID 'fitting in' to the type of activities and support provided by the facility to other residents. This was seen as primarily owing to their younger age, different interests, difficult behaviours or different care needs. Other issues identified were the need for more individualised attention (24%), their social isolation (11%), negative attitudes of other residents (6%), lack of appropriate staff training (6%), and shortage of resources to adapt to their particular needs (10%). For example, respondents said:

The main issue is that most of the time, people are misplaced as they are usually younger than other residents. They have nothing in common with aged residents except that they can't look after themselves. It would be good if there were services outside for these people.

Group activities tend to be age specific and beyond the comprehension of those with intellectual disability.

Boredom – there are not enough hours given for lifestyle programs to spend extra time with this resident. Lack of companions. All other residents are considerably older than her.

As the majority of our high care residents have dementia we cater for short attention spans. Both residents [with intellectual disability] have aggressive behaviour problems that limit their participation in group activities and more time is spent with them one to one.

We have one (intellectually disabled) resident out of ten. This requires one to one attention mostly from staff. There is also resistance from other residents regarding (her) integrating into group activities.

She is much younger than other residents; however as she has lived with her mother for years she tends to fit in OK. She has trouble understanding dementia and older people but has her own way of coping.

The remaining quarter (24) of responses indicated that the care for this group was not dissimilar from that of other older people or that differences had been easily accommodated sometimes in conjunction with specialist disability services. For example,

Diversionary therapy is available and very good. We work out a specific program for the resident who is very pleasant and integrates well; we are a good facility.

The high care resident has an individually tailored care and activity plan with strategies to help address behaviours caused by her intellectual disability. The low care residents also have behavioural care plan strategies. All three residents access external services to help meet their care needs. Training has been sourced to help staff understand the special needs of these two residents.

She just fits in I think a lot of it is because she just looks normal. In another facility I worked, we had a person who looked different and the older residents didn't accept him.

Discussion

This survey provides a broad brush view of how residential aged care providers describe the characteristics and experiences of residents with ID in residential aged care in Victoria. The findings suggest that people with ID are thinly scattered across 40% of the aged care facilities in the sample, with most facilities having between one and three residents. A concentration of a higher number of residents has occurred in two facilities owing to particular historic circumstances such as the closure of small institutions and the en masse transfer of their residents to one facility. The reasons for this transfer were not investigated, but funding was unlikely to be a reason as in Australia; government per capita subsidies are higher in the Disability sector than that in Aged Care (Bigby 2007).

The profile of residents is similar to what was found in a UK survey (Thompson *et al.* 2004); people with ID are admitted at an earlier age, are younger and stay for longer than other residents. The findings also suggest that the majority of residents with ID are the 'younger old' aged between 60 and 80 years. They neither fall into the group of younger people with disabilities targeted by the 'Younger People in Nursing Homes Campaign' for whom aged care is considered inappropriate nor fall into the very old or frail aged for whom residential aged care is designed. Rather they are the group about whom both Aged Care and Disability policies are silent.

The findings suggest that residents with ID have similar levels of assessed dependency as the general population of residential aged care even though they are considerably younger, apparently healthier and have a much lower rate of dementia. Further exploration is required to understand their dependency profile, which could be an artefact of assessment tools and processes that are not attuned to people with lifelong disabilities. Some support for this proposition is found in the evaluation of recent pilot projects that drew attention to the limited expertise of Aged Care Assessment Teams with people with lifelong disabilities and the advantages of a collaborative approach towards assessments involving both Disability and Aged Care professionals (Hales *et al.* 2006). Further research is required to explore the process by which assessments are

made for this group, the reliability of the assessments made and the instruments used.

Another proposition is that the similar dependency profile, and indeed the younger age profile of residents with ID is a reflection of the premature onset of age-related conditions or the onset of secondary disabilities found in some subgroups of people with ID. However, in this survey groups known to experience premature aging and early onset dementia such as those with Down syndrome formed only a small proportion of all residents with ID, and no significant age differences were found between residents with and without dementia. If a significant proportion of admissions were related to early onset dementia, it would be expected that those with dementia would be younger than those without. Much more finely grained research is required to understand the association between premature aging or the onset secondary disabilities and the admission of people with ID to residential aged care.

These findings indicate that entry to residential aged care for most residents with ID from other forms of supported accommodation is associated with organisational capacity and the inability of services to provide the level of support required. However, further exploration is required to determine whether this reflects an inability of the service providers to adapt to changing resident needs, resource shortages or the severity of residents health problems. The evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot (Hales *et al.* 2006) suggests that it is due to resource shortages, as the pilot programmes demonstrated, the capacity of supported accommodation services to continue to support these residents when additional resources and expertise around aging issues were provided. Such findings support the notion that initiatives to support ageing in place in supported accommodation may delay the admission of younger older people with ID to residential aged care, reducing their length of stay and providing continuity of social relationships for as long as possible.

Provider comments regarding resident preferences suggest that older families may lack information about potential options or assistance in planning for alternative housing. Recent Federal programmes have targeted respite for older carers of people with disabilities often in the absence of more

comprehensive support to assist planning about the future, other than the very targeted financial planning initiative in the form of special trusts for people with severe disabilities (Commonwealth of Australia 2007). This study suggests the need for a greater emphasis on support and information to enable families to make informed decisions as they plan for the future. However, it is estimated that, across Australia, 23 800 people with disabilities had an unmet need for either supported accommodation or respite services (AIHW 2007). This chronic shortage of supported accommodation which limits available options may also help to explain the high proportion of residents that entered residential aged care directly from the family home.

This survey suggests that a majority of aged care facilities have difficulty adapting to the social and recreational needs of residents with ID, although some demonstrated their capacity to do so. What is not clear from the findings are the factors influencing the capacity of those facilities that do adapt. Early indications are that a partnership with disability services has the potential for positive outcomes, which significantly is another issue on which policy is silent. That residents with ID were less likely to be socially isolated in the two facilities where they formed a larger group, suggests that consideration should be given to some form of specialisation to enable small groups of residents with ID to be clustered in facilities. This might enable both a more amenable social environment and the development of staff expertise within facilities. The potential benefits, however, must be weighed against potential disadvantages caused by the large catchments area, and consequent dislocation from local communities, required to make specialisation viable in the context of Australia's small and scattered population of people with ID.

The findings from this survey are congruent with the resident profile and pattern of residential aged care admission reported in research from the UK (Thompson *et al.* 2004). Both studies highlight that many residents with an ID could be misplaced in residential aged care facilities. However, an in-depth examination of the factors influencing their entry to aged care, their level of care need and the impact of coexisting medical conditions is required before such a conclusion can be reached with any certainty.

Acknowledgement

This project was funded by Peter and Margaret Gill.

References

- Andrews K. (2001) *National Strategy for an Ageing Australia: An Older Australia, Challenges and Opportunities for All*. Commonwealth of Australia, Canberra.
- Australian Institute of Health and Welfare (AIHW) (2005) *Current and Future Demand for Specialist Disability Services*. Disability series. Cat. no. DIS 50. AIHW, Canberra.
- Australian Institute of Health and Welfare (AIHW) (2006) *Residential Aged Care in Australia 2004–05: A Statistical Overview*. AIHW cat. no. AGE 45. AIHW, Canberra. (Aged Care Statistics Series no. 22).
- Australian Institute of Health and Welfare (AIHW) (2007) *Current and Future Demand for Specialist Disability Services*. Disability series. Cat. no. DIS 50. AIHW, Canberra.
- Bigby C. (1997) When parents relinquish care: informal support networks of older people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities* **10**, 333–44.
- Bigby C. (2000) *Moving on without Parents: Planning, Transitions and Sources of Support for Older Adults with Intellectual Disabilities*. McLennan+Petty/P. H. Brookes, New South Wales/Baltimore.
- Bigby C. (2002) Aging with a life long disability: challenges for the aged care and disability sectors. *Journal of Intellectual and Developmental Disabilities* **24**, 231–41.
- Bigby C. (2008) Beset by obstacles: a review of Australian policy development to support aging in place for people with intellectual disability. *Journal of Intellectual and Developmental Disabilities* **33**, 1–11.
- Commonwealth of Australia (2007). *Special Disability Trusts: Getting Things Sorted*. Department of Families, Community Services and Indigenous Affairs, Canberra.
- Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. (CM 5068). TSO, London.
- Hales C., Ross L. & Ryan C. (2006) *National Evaluation of the Aged Care Innovative Pool Disability Aged Care Interface Pilot: Final Report*. Australian Institute of Health and Welfare, Canberra. Aged care series no 12, Cat no Age 50.
- Haveman M. (2004) Disease epidemiology and ageing people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities* **1**, 16–23.
- Hogg J. & Moss S. (1993) The characteristics of older people with intellectual disabilities in England. In: *Inter-*

- national Review of Research in Mental Retardation*, Vol. 19 (ed. N. Bray), pp. 71–96. Academic Press, New York.
- Janicki M. & Dalton A. (2000) Prevalence of dementia and impact on intellectual disability services. *Mental Retardation* **38**, 276–88.
- Janicki M., Davidson P., Henderson C., McCallion P., Taets J., Force L. *et al.* (2002) Health characteristics and health service utilisation in older adults with intellectual disability living in community residences. *Journal of Intellectual Disability Research* **46**, 287–98.
- Senate Community Affairs Reference Committee (SCARC) (2005) *Quality and Equity in Aged Care*. Commonwealth of Australia, Canberra.
- Senate Community Affairs Reference Committee (SCARC) (2007) *The Commonwealth State/Territory Disability Agreement*. Commonwealth of Australia, Canberra.
- Thompson D. J., Ryrie I. & Wright S. (2004) People with intellectual disabilities living in generic residential services for older people in the UK. *Journal of Applied Research in Intellectual Disabilities* **17**, 101–8.
- Winkler D., Farnworth L. & Sloan S. (2006) People under 60 living in aged care facilities in Victoria. *Australian Health Review* **30**, 100–8.

Accepted 17 December 2007