MAPPING THE TERRAIN:

Ageing people with lifelong intellectual disability living in residential aged care facilities in Victoria

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Joan Donoghue, Catholic Homes for the Elderly

Christine Cornish, Brotherhood of St Lawrence

Frances Exell, Friends of L'Arche Melbourne

Ian Hazeldine, Council of Intellectual Disabilities Agencies (CIDA)

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Contents

CONTENTS	**V**
TABLES AND FIGURES	**VII**
EXECUTIVE SUMMARY	**IX**
1. THE CONTEXT AND THE STUDY	**1**
Introduction	1
Research aims	3
Methodology	3
Profile of the residential aged care facilities	4
Facilities with residents with lifelong intellectual disability	5
Strengths and limitations of the sample	5
2. AGED CARE RESIDENTS WITH LIFELONG INTELLECTUAL DISABILITY	**7**
Profile of residents with intellectual disability	8
Current age	10
Summary	13
3. PATHWAYS INTO RESIDENTIAL AGED CARE	**15**
Where residents were admitted from	15
Reasons for admission	16
Aged care: Preferred option, best option, only option?	18
Services from the disability sector	20
Summary	21
4. RESIDENT CARE AND ACTIVITIES	**23**
Onsite activities	23
Offsite activities	24
Religious activities	25
Relationships with others in the facility	25
Facility support for residents' outside contacts	26
Practical support from others	27
Care and activity issues	28
Pastoral care programs	33
Factors contributing to positive experiences	34
Summary	35
5. DISCUSSION OF THE FINDINGS	**37**
Estimating the total number of residents	37
Issues raised by the present study	37
Further research: Australian Research Council Grant	39
Implications of the Research for the ARC linkage project	40
REFERENCES	**41**

Tables and figures

Table 1 Geographic location of responding residential aged care services, n=286 5

Table 2 Resident capacity of responding RACS and all Victorian RACS 5

Table 3 Number of residents with lifelong intellectual disability in responding facilities 7

Table 4 Distribution of residents according to capacity of facilities (total number of beds) 8

Table 5 RCS levels of residents with lifelong intellectual disability, n=198 9

Table 6 High and low RCS levels of residents with lifelong intellectual disability, n=198 10

Table 7 Percentage of residents with intellectual disability in various age categories, n=193 11

Table 8 Length of residence in an aged care facility, n=195 11

Table 9 Residents' age at entry into aged care, n=193 12

Table 10 Where residents were admitted from, n=197 15

Table 11 Reasons for admission, n=199 16

Table 12 Frequency of onsite activities, n=195 23

Table 13 Frequency of offsite activities, n=190 25

Table 14 Positive relationships with other residents, n=197 26

Table 15 Frequency of contact with family, friends and others, n=192 27

Table 16 Practical support from others, n=195 28

Executive summary

This report presents findings from a survey of residential aged care facilities in Victoria. The survey sought to: a) understand the number, distribution and characteristics of ageing people with intellectual disability living in such facilities, b) gain a sense of their pathways into residential aged care and c) gather preliminary information about the ways facilities adapt to their needs. This project is part of a larger project, now funded by an ARC Linkage grant, that aims to:

- Understand existing partnerships and working relationships between disability services and residential aged care and Aged Care Assessment Teams.
- Investigate the different pathways into residential aged care for older people with intellectual disability living in different forms of accommodation.
- Investigate the quality of care experiences of older people with intellectual disability in residential aged care, and analyse their relationships between family and other informal support network members and examine the roles that informal support plays in decision making and monitoring their quality of care.

Just over one in three of all Victorian aged care facilities responded to the survey on which this report is based. They are representative of all Victoria facilities as far as metropolitan and non-metropolitan location and resident capacity is concerned. We are reasonably confident that the circumstances of residents living in these facilities and the issues concerning care of residents with intellectual disability adequately reflect and are indicative of the overall picture. The study's ability to draw definitive conclusions about the total number of residents with intellectual disability living in residential aged care in Victoria is limited. However, estimates from the findings suggest that there may be 400-500.

Forty percent of responding facilities (114) had at least one resident with intellectual disability and together they had 207 such residents. People with intellectual disability were in large and small facilities. The most common pattern was for facilities with a bed capacity of between 30 and 60 to have one or two residents with intellectual disability. Fifty-three percent of the facilities with residents with intellectual disability were in a metropolitan area, although the percentage of residents in the metropolitan area was higher (62 percent).

Overall, females outnumbered males by approximately two to one. While this is quite consistent with the total permanent residential aged care population in Australia, it does not reflect the greater percentage of males than females in the general population of people with intellectual disability.

The survey suggests that intellectually disabled adults living in residential aged care are, on average, considerably younger than the general aged care population. Significantly, there were small numbers of residents with intellectual disability in their thirties and forties, and in their eighties and nineties, with the majority between these two extremes. The average age reported for residents with intellectual disability was 64.8 years, their length of stay in aged care ranged from less than one year to over thirty years, with the median being five years and the average of 8.2 years. This pattern differs from the general aged care population among whom the average length of stay is much shorter.

Two facilities stood out as different from the other 112, housing both a larger number and greater percentage of residents with intellectual disability than other facilities Residents with intellectual

disability in these two facilities were almost exclusively female , were older and had spent longer periods of time in the facility than their peers in the other facilities.

Based on the Resident Classification Scale (RCS), fifty-eight percent of residents with intellectual disability had been rated at a high level of dependency. This parallels the percentage of high care residents in the general resident population.

Pathways into aged care are quite varied in the 112 facilities. The largest proportion of residents were living with family prior to their move into residential aged care, and were generally admitted when their carer became ill or died, when their own health deteriorated or when family members could no longer provide the level of care and support they required. Residents who were not intellectually disabled followed similar patterns with ill-health, behavioural management issues and the need for a higher level of care than was previously available, the main reasons for admission into aged care.

A substantial majority of the residents in the two facilities with a large number of residents (72 percent) were admitted from supported accommodation other than a Community Residential Unit (CRU), Supported Residential Service (SRS), or training institution, either because of closure of the previous institution or inability of the previous supported accommodation to provide the level of care needed. A small proportion of residents in these two facilities (10 percent), admitted more recently than other residents, have been admitted from living with family.

Respondents reported that moving into aged care was the preferred option for 69 percent of residents; it was not the preferred option for nine percent. However, the 'preferred' option is often the only option. Sometimes, it is preferred in the sense that the particular facility is located close to family members. For residents in the two facilities with a large number of residents, admission to the facility was preferred as it kept friends together and maintained previous close associations.

Only 16 percent of residents currently receive services from the disability sector. Those who do receive these services tend to be younger residents who attend a day centre or other support group.

A large majority of residents were reported as participating in onsite activities daily or weekly, although it appears that in some case they are passive rather than active participants in activities designed for the general body of ageing residents. Residents in facilities with a larger bed capacity are more likely to participate in offsite group activities organised by the facility.

Residents in facilities with a large number of residents with intellectual disability are significantly more likely to have positive relationships with other residents and special friendships within the facility, compared to sole residents or those who are one of a small number. However, some of the latter do have positive relationships and some have close associations with staff members. Facilities reported that they try to find and organise appropriate activities for their residents with varying degrees of success and that sometimes the resources were not available to do the best job possible for such residents.

Care and activity issues identified by the respondents included general care issues, the need for appropriate and individualised activities, difficulties with providing for younger residents in an environment where their needs are often different from those of other residents; a high level of 'one to one' interaction required for many residents with intellectual disability; difficulties with managing inappropriate behaviour especially when staff time and resources are limited or stretched, gaining access to support services; the need for staff training and sometimes having insufficient staff resources.

While this study provides an understanding of some characteristics of residents with an intellectual disability residing in aged care and identifies some major life and care issues it also raises further questions, some of which will be investigated over the next three years via an ARC Linkage grant funded project. The questions and issues include: why are residents with intellectual disability so much younger than other residents? Why is there a comparatively large proportion of these

residents admitted from the family home? Given what we know of the distribution of intellectual disability in the general population, why are there not more males with intellectual disability in the residential aged care population?

The study also indicates the need for a more finely grained understanding, to explore the impact of the diversity of impairments, care and support needs that are subsumed within the general category of intellectual disability on care issues for individual residents. RCS levels indicate levels of dependency. They do not, however, provide a full picture of the diversity of residents with intellectual disability in aged care. Some residents have mild intellectual disabilities while others are severely disabled and are unable to communicate. What are the implications of this wide diversity for staff and for residents? The distinction between residents with an intellectual disability who have good communication skills and those who do not is likely to be crucial in their care and points to the importance of having a variety of means by which people's history goes with them into residential aged care. Current funding arrangements for residential aged care do not take account of the variability of special needs of this group of residents.

There is no common way that facilities adapt to the needs of their residents with an intellectual disability. In general, facilities with a larger number of people with an intellectual disability have a greater capacity to provide appropriate group activities. At present, in facilities with one or a small number of intellectually disabled residents, there are some indications that, in the absence of training, quality care is sometimes 'hit and miss' and may depend on whether staff in the facility has some knowledge, understanding or experience of intellectual disability, either in an aged care environment, the community or their own family. Nevertheless, some facilities use what resources they have to provide a stimulating and appropriate environment. The task is made easier when there is support from family members, adequate physical resources and, for some younger people, support from at least some disability services.

Funding for the aged care sector is generally regarded as fairly inflexible. The different levels of disability, the variety of individual resident care needs, as well as the recurring theme in the study findings of the need for 'one-to-one' interaction between staff and residents with intellectual disability, has implications for funding. It may be that intellectual disability could be considered a 'special needs group' and be funded as a specific category in residential aged care.

1. The context and the study

Introduction

Changes in the life expectancy of people with intellectual disability have followed similar, but more dramatic trends, to those found in the general population. For example, a study of residents in an institution in the United Kingdom found that between 1930-1955 just under 10 percent of residents survived to age 50 compared to just over 50 percent between 1955-1980 (Carter & Jancar, 1983). More recently, a US study of people with Down Syndrome found their average life expectancy to be 25 years in 1983 compared to 49 years in 1997, demonstrating almost a doubling of life expectancy during this period (Yang, Rasmussen & Friedman 2002). With the exception of people with Down Syndrome and those with profound and multiple disabilities, the life expectancy of people with intellectual disability is now more similar to that of the general population (Janicki et al., 1999).

The increased longevity of people with intellectual disability together with population increases as a result of the baby boom generation means that the number of older people with intellectual disability will increase significantly over the next decade (Yang, Rassmussen & Friedman, 2002; Bigby, 2004). These trends are illustrated by figures from the database of clients registered with intellectual disability in Victoria. In 1982, 321 clients (3 percent) were aged over 60 years; the number increased to 559 (4 percent) in 1990 and again to 1327 (6.7 percent) in 2000 (Bigby et al., 2001). The current cohort of older people with intellectual disabilities is the first sizeable group to have survived into later life. They form the largest sub group of ageing people with lifelong disability and are a small but significant and increasing group of older people in the community. It is estimated they comprise, 0.13 percent of the population over 55 years (Wen, 1997).

The characteristics and lifelong marginalisation of older people with intellectual disability mean they differ from the general population in respect of having poorer health, greater reliance on formal services, poorer informal support networks and limited access to private wealth (Haveman, 2004; Janicki et al., 2002; Bigby, 1997). These factors put them at a disadvantage in terms of care and support for age related problems. Their lifelong disability also means that some, particularly people with Down Syndrome, cerebral palsy or multiple disabilities, experience premature ageing (Janicki & Dalton, 2000). Neither the Disability or Aged Care system in Australia is prepared for or has a policy framework in relation to this minority group (Bigby, 2002; Fyffe, Bigby & McCubbery, 2006).

The World Health Organisation's active ageing policy framework promotes strategies for 'optimising opportunities for health, participation and security to enhance quality of life for people as they age' (2002). This vision is reflected in *A National Strategy for an Ageing Australia* (Andrews, 2001), which seeks to achieve: sustainable retirement income; positive attitudes towards older people; 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. People with lifelong disabilities are identified as one of the groups in the community that face particular barriers in obtaining the levels and types of services they need and the suggestion is made that they will require 'specific or special arrangements' to meet their needs (Andrews, 2001 p. 58). There is little research to inform policy on appropriate pathways and

decision-making processes by which people with intellectual disability should access residential aged care, the nature of adaptations that may be required to meet their particular needs, or the partnerships that may be necessary between the two sectors. Existing research does however, highlight concerns about these issues that warrant further investigation.

Studies from both Australia and overseas suggest that people with intellectual disability experience considerable residential mobility in their middle years and beyond. In Victoria, Bigby (2000) found that 53 of 62 people with intellectual disability who had lived with parents until middle age had moved at least once since they left parental care and 50 percent had done so twice or more by the age of 65 years. Hogg and Moss (1993) in the UK found that 37 percent of people with intellectual disability over the age of 50 years had moved in the last five years. Research suggests that a disproportionately high number of older people with intellectual disability live in aged care facilities although there is no certainty about the actual numbers of this group in such facilities (Bigby, 2000; Thompson, Ryrie & Wright, 2004, Scottish Executive, 2000). For example, at the time of Bigby's Victorian study (2000), two-thirds of the sample, whose average age was 65 years, lived in an aged care facility.

Research has raised concern about the appropriateness and quality of this type of care for people with intellectual disabilities. For example, the UK white paper *Valuing People*, concluded that many people with intellectual disability were misplaced in aged care amongst residents who were older and more incapacitated than they (Department of Health, 2001). Thompson, Ryrie and Wright (2004) in the UK found that less than one-third of people with intellectual disabilities moving from family home to aged care facilities did so due to age related reasons. In Victoria, Bigby (2000) found placement in residential aged care was often contested by family members, and that people with intellectual disability in aged care facilities were often younger than other residents, with an average age of 65 years compared to 81 years for all residents at that time.

Notions of inappropriate placement are inevitably tied to questions about the experiences and type of support provided to older people with intellectual disability in residential aged care. Thompson, Ryrie and Wright (2004) in their survey of UK aged care facilities, found residents with intellectual disabilities had a low level of participation in recreational or social activities; that staff lacked specific knowledge about this group; they did not 'fit in' and were relatively younger than other residents. They suggest there is limited recognition by aged care providers of issues of adapting care, most of whom, despite indicators to the contrary, suggested they adequately met the needs of residents with intellectual disability. Earlier work by Hogg and Moss (1980), comparing older residents with intellectual disability in aged care and those in disability accommodation, found those in aged care received poorer quality of care, as additional needs related to their disability were not taken into account; there was less individualised support and they participated less in leisure activities than those resident in aged care.

In Australia a substantial advocacy campaign has focussed attention on the suitability of residential aged care for younger people with disabilities,[1] although it has been largely concerned with 'younger' rather than 'younger older adults'. A recent survey of residents aged under 60 years in Victorian aged care facilities concluded this group were socially isolated and had limited opportunities for recreation (Winkler, Farnworth & Sloan, 2006). However, although residents with intellectual disability made up 15 percent of those surveyed, it is difficult to draw conclusions about their experiences and consequently about the suitability of this accommodation type because the findings did not differentiate by age or diagnostic groupings.

Whilst evidence suggests inappropriate placement of some people with intellectual disability in aged care may occur, there appears to be consensus that access may be the most appropriate option for some of this population at some stage in their life, with the question remaining of how to make

[1] see *Young People in Nursing Homes National Alliance*, http://www.ypinh.org.au

their experience of care better (Fyffe, Bigby & McCubbery, 2006, Senate Community Affairs Reference Committee (SCARC), 2005). However, recent developments in Australia may obstruct such access. For example, advocacy about the situation of younger people with disabilities in nursing homes has questioned the applicability of aged care facilities to people with disabilities aged less than 65 years (SCARC, 2005; Winkler, Farnsworth & Sloan, 2006). Aged Care Assessment Team guidelines indicate that all other less restrictive options must be explored for people under 65 years before they should be considered for residential aged care, and some evidence (Fyffe, Bigby & McCubbery, 2006) suggests this has led to their refusal to assess 'younger older people'. All these factors have the potential to make access to aged care difficult for people with Down Syndrome who age prematurely, and among whom a high proportion are likely to experience early onset dementia (Janicki & Dalton, 2000). There appears to be a pressing need to consider entry pathways into residential aged care that differentiate between groups and which are not based on chronological age.

Research aims

The study reported in this paper is the first stage of a larger project now funded by an ARC Linkage grant that seeks to:

- Understand existing partnerships and working relationships between disability services and residential aged care and Aged Care Assessment Teams.
- Investigate the different pathways into residential aged care for older people with intellectual disability living in different forms of accommodation.
- Investigate the quality of care experiences of older people with intellectual disability in residential aged care, and analyse their relationships between family and other informal support network members and examine the roles that informal support plays in decision making and monitoring their quality of care.

This first stage aimed to map the population of people with intellectual disability living in residential aged care in Victoria. The study sought to understand the number, distribution and characteristics of this group, gain a sense of their pathways into residential aged care and the way in which facilities adapted to their needs.

Methodology

A mailed survey was sent to all residential aged care services listed on the Commonwealth Department of Health and Ageing website for 2005, the latest listing available at the time the survey was distributed. 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 lifelong intellectual disability, and the main issues arising regarding care and activities for this resident group. The second sought information about each resident with lifelong intellectual disability — their gender, age and length of residence, their pathway into the aged care facility, their onsite and offsite activities, the frequency of contact with family and friends outside of the facility and any other support they received from others. A Project Reference Group, comprised of representatives from the disability and aged care sectors, provided advice to the research team about the scope and content of the survey.

A total of 826 surveys were distributed in July 2006. The initial return of 147 completed surveys by mail was quite low and an extensive telephone follow up of facilities who had not responded was therefore undertaken. In selecting facilities for follow up, some account was taken of the need to

include rural, urban and regional facilities and not-for-profit and privately-run facilities. The telephone follow-up calls ultimately led to responses from a total of 286 facilities, a response rate of 35 percent, taking account of undeliverable surveys and a further small number of facilities discovered through the telephone follow up calls to be not currently operating or not contactable after repeated phone calls. Advice from the Project Reference Group indicated that a number of facilities on the 2005 list had closed, reducing the total number of facilities which could potentially respond.

As well as substantially raising the response rate, the telephone follow-up calls proved useful in identifying reasons why facilities did not respond and in providing more detailed information in some cases.

Reasons for an initial non-response were varied. A number of respondents said they did not have any residents with intellectual disability and therefore did not consider the survey relevant to them, although the letter accompanying the survey was careful to explain the reasons for the research and emphasised that the research team was interested in everyone's views about care and activity issues, even if they did not have any residents in the category.

There was also a strong sense from respondents' comments that staff in aged care facilities have heavy administrative and 'paperwork' requirements. Some said they regarded the survey as just another task asked of them, with little hope of further resources resulting from responding. The survey asked for quite detailed information about residents with lifelong intellectual disability, which would generally require taking time to consult resident files. In the circumstances, this may well have dissuaded busy staff from completing the survey. Changes of staff were also cited as a possible reason for the survey being overlooked or neglected.

On the other hand, respondents in many of the facilities were extremely cooperative and helpful in responding to questions and giving additional information about the difficulties and the successes of caring for residents with lifelong intellectual disability. The research team is very appreciative of their assistance.

Finally, the telephone calls to approximately half of the total number of survey respondents provide a richer picture of both general care and activity issues and the circumstances of individual residents than is possible with a mailed survey. The follow-up calls were treated as a structured interview and the format of the survey was closely followed. However, additional comments inevitably occur during a telephone interview and the qualitative responses asked for in relation to some questions can be clarified and amplified, so more information is generally available than in a mailed survey.

Profile of the residential aged care facilities

Table 1 shows the geographic location of responding facilities. Fifty-five percent are in a metropolitan area, 12 percent in a regional centre, 33 percent in a rural town and less than one percent in a remote area.

This compares relatively well with the geographic location of the total population of Victorian residential aged care services. Figures supplied by the Victorian Department of Human Services show that 60 percent of Residential Aged Care Services (RACS) Victoria in 2005 were in a metropolitan area and 40 percent in a rural area.

Table 1 Geographic location of responding residential aged care services, n=286

	No.	%
Metropolitan Melbourne	157	55
Regional city	34	12
Rural town	94	33
Remote area	1	<1
Total	286	100

The match between the responding facilities and the total population of Victorian Residential Aged Care Services in regard to resident capacity is also relatively close. Table 2 shows comparative percentages for resident capacity.

Table 2 Resident capacity of responding RACS and all Victorian RACS

Resident capacity (number of beds)	Facilities responding to survey	All Victorian RACS %
30 or less	30	34
31-60	42	44
61-90	18	16
91+	10	6

Facilities with residents with lifelong intellectual disability

Of the 286 facilities which responded to the survey, 114 (40 percent) have at least one resident with lifelong intellectual disability. The total number of residents with intellectual disability in the 114 facilities is 207. It is worth noting that, although the survey did not ask whether facilities had ever had a resident with lifelong intellectual disability, the telephone follow-up calls indicated that at least nine additional facilities had had such residents in the past but did not currently have any. Therefore, the picture of facilities and residents represented in this report should be regarded as a snapshot at a particular time.

Facilities catering for a specific ethnic community

Eleven facilities catered primarily for a specific non-Anglo ethnic community. They covered nine different cultural background communities. None of the eleven currently has a resident with lifelong intellectual disability, although several had had such a resident in the past and several others said that they would have no difficulty in catering for intellectual disabled residents if they were approached to do so.

Strengths and limitations of the sample

While the sample of responding facilities is not large, it is nevertheless just over one in three of all Victorian facilities. Responding facilities are representative of all residential aged care facilities in Victoria as far as metropolitan and non-metropolitan location and resident capacity is concerned. We can therefore be reasonably confident that the circumstances of residents living in these

facilities and the issues concerning care of residents with intellectual disability adequately reflect and are indicative of the overall picture.

The study has limitations for drawing any conclusions about the total number of residents with intellectual disability living in residential aged care in Victoria. We cannot make a direct extrapolation from the proportion of responding facilities that had at least one resident with intellectual disability because we cannot know whether this proportion is reflected across all facilities. However, some extrapolations from the findings, based on different sets of assumptions, are made in the discussion section of the report, taking account of findings concerning the distribution and profile of residents with lifelong intellectual disability.

2. Aged care residents with lifelong intellectual disability

Of the 114 facilities with residents with lifelong intellectual disability, 53 percent are in a metropolitan area, 11 percent in a regional city, 36 percent in a rural town and 1 percent in a remote area. This distribution reflects quite closely the metropolitan, regional and rural spread of the total sample of 286 facilities shown in Table 1 (55 percent in a metropolitan area, 12 percent in a regional city, 33 percent in a rural town and less than 1 percent in a remote area).

As already indicated, the total number of residents with lifelong intellectual disability in the facilities is 207. We have information about 199 of them.[2]

Table 3 shows the distribution of numbers of residents with intellectual disability in the responding facilities. Sixty percent of responding facilities had none (column three) and 40 percent had at least one.

The final column of Table 3 shows that 62 percent of facilities with a resident with lifelong intellectual disability have only one; a further 26 percent have two and eight percent have three (Table 3). Overall, 96 percent of facilities with residents with intellectual disability have between one and three such residents. We can say then that out of those facilities that responded to the survey, most of those who have intellectually disabled residents, have a small number only and 62 percent have one only.

Table 3 Number of residents with lifelong intellectual disability in responding facilities

No. of residents	No. of facilities	% of all responding facilities	% of all facilities with residents with an ID
0	172	60	
1	71	25	62
2	30	9	26
3	9	3	8
4	1	<1	1
5	1	<1	1
*5+	2*	1	2
	286		100

** one of the facilities has 17 residents; the other has 23 residents*

[2] One facility refused to give information about two residents, despite assurances of anonymity, although the manager had many comments to make about care and activity issues. Another respondent said that she had sent in the survey although there was no record of it being received; a decision was made not to pursue details of the three residents she spoke of. A third said that the facility had a resident but she did not have the time to give details; offers of another interview time and/or a further form to complete at leisure were refused. Two others facilities did not provide details of residents.

Table 4 shows the distribution of residents with intellectual disability according to the total bed capacity of the facilities they were living in. Single residents were in both small and large facilities, with the largest number in facilities with between 31-60 residents. Thirty-four percent of 'single' residents (that is, the only intellectually disabled resident in a facility) were in facilities with a total capacity of 30-40 residents and 18 percent were in a facility with a total capacity of 60 residents. The rest were spread across the range (10 to over 100).

Table 4 Distribution of residents according to capacity of facilities (total number of beds)

Facility bed capacity	No. of residents with intellectual disability in a facility						
	1	2	3	4	5	6+	Total
10 or less	1	1					2
11-30	21	5					26
31-60	29	16	4	1		2	52
61-90	15	4	1		1		21
91+	5	4	4				13
Total no. of facilities	71	30	9	1	1	2	114

Two facilities stood out from the rest in the number and percentage of residents with an intellectual disability, having 17and 23 respectively. Because they differ significantly from the others they are, in some cases analysed separately. Both of these facilities are located in metropolitan Melbourne.

Overall 62 percent of the residents are living in the Melbourne metropolitan area, ten percent in a regional area, 28 percent in a rural town, and less than one percent in remote areas. (While 53 percent of the facilities with at least one resident with intellectual disability are located in the Melbourne metropolitan area, the two facilities with higher proportions of residents are both located in metropolitan Melbourne.)

Profile of residents with intellectual disability

This section summarises the overall profile of residents with intellectual disability.

Gender

Female residents with lifelong intellectual disability in the 114 facilities outnumber males by more than two to one; 69 percent to 31 percent. The predominance of females reflects the general pattern of gender breakdown in permanent residential aged care. The Australian Institute of Health and Welfare (AIHW) 2004-2005 report on residential aged care in Australia (AIHW, 2006b) indicated that females made up 72 percent of permanent residents in aged care in that year.

However, while the predominance of female compared to male residents with intellectual disability found in the survey reflects the overall pattern in aged care, it is at odds with what is known about the gender distribution of intellectual disability in the general population, where males outnumber females.

The residents in the two facilities with a large number of residents are almost exclusively females. If we exclude these two facilities from the analysis, the proportion of females to males in the remaining 112 facilities is somewhat less — 61 percent to 39 percent — although females still heavily outnumber males.

High and low care and levels of dependency

Residential aged care facilities in Australia can be either high care or low care facilities. High care facilities cater for residents who are assessed as requiring both skilled clinical care as well as personal care. High care facilities are required to have registered nurses on site for all shifts. Residents in low care facilities are, in the main, assessed as requiring, personal care which can be provided by unregistered staff. Low care facilities are required to ensure that personal care staff has access to a registered nurse over 24 hours but, in contrast to high care facilities, are not required to have 24 hour onsite registered nurse coverage.

To add to the complexity of residential aged care, low care facilities can cater for people with a high level of dependency. It is possible then that residents who are assessed as requiring high care can be residing in a low care facility. There are many constructions of aged care facilities. As well as 'stand alone' high and low care facilities, there are co located sites where some licensed beds are for high care and others are for low care. In some instances, the low and high care beds will be situated in different buildings on the same site. In others, they may be under one roof but divided within the building. All residents in government funded aged care facilities are categorised according to one of seven RCS categories. It should be noted that the RCS does not consider all of a resident's care needs but considers those factors that have been identified as contributing the most to differences in the total cost of relative care needs. The RCS category is arrived through an assessment of each resident's clinical and personal self care needs, as well as their needs for social and emotional support. Residents who are assessed between RCS level one to four are considered to have high levels of care need. Residents below level 4 are considered to have low levels of care need. The level of Australian Government subsidy for each resident is determined by their RCS category[3]. Fifty-eight percent of the residents in this survey were in high care and 42 percent in low care. Table 5 shows that 58 percent of residents with intellectual disability have a high level of dependency (RCS levels of 1-4). There is then a close match between the percentage in high care (see above) and the percentage assessed as having high dependency needs.

Table 5 RCS levels of residents with lifelong intellectual disability, n=198

RCS level	Number of residents	% of residents
1	37	19
2	31	16
3	25	13
4	20	10
5	35	18
6	13	7
7	11	6
missing	26	13
	198	100

Table 5 shows that RCS level is missing for 13 percent of residents. [4] This is quite a high proportion, so some caution is needed in comparing the percentage of residents in a high care situation and the percentage assessed as having high dependency needs through the RCS.

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[3] See http://www.health.gov.au/internet/wcms/publishing.nsf/Content/ageing-manuals-rcm-rcmindx1.htm~ageing-manuals-rcm-rcmindx106.htm).

[4] Around half of the missing RCS values were in surveys returned by mail and the remainder where information was collected through telephone follow-up calls. We can only speculate as to why the values are missing from the surveys returned by mail. It is known that in at least some of the telephone interviews, the respondents did not have access to the resident's file at the time.

As explained previously, the picture regarding high and low care places is complicated by ageing-in-place. In the overall aged care system, a substantial proportion of low care places are occupied by a high care resident. The latest data from the Commonwealth Department of Health and Ageing indicates that 31 percent of low care places have high care residents.

For confidentiality reasons the format of the survey questions regarding RCS level and number of high and low care places in facilities does not allow a direct comparison of the number of residents with high and low RCS scores in high and low care places in the facilities.

Table 6 compares high (1-4) and low (5-7) RCS levels for residents in the main group of 112 facilities and the two facilities which have large numbers of residents Compared with facilities which have between one and five residents with intellectual disability, the two facilities with a large number of such residents have a higher proportion of residents assessed as having low dependency needs.

Table 6 also shows that most of the missing data for RCS levels are amongst the 112 facilities with a small number of residents with intellectual disability.

Table 6 High and low RCS levels of residents with lifelong intellectual disability, n=198

	Facilities (112) with a small number of residents		**Facilities (2) with a large number of residents**	
RCS level	*No .of residents*	*% of residents*	*No. of residents.*	*%of residents*
high	92	50	17	28
low	40	33	21	67
missing	26	17	2	5
	158	100	40	100

Current age

Table 7 shows that residents with lifelong intellectual disability are a very mixed group as far as their age is concerned. The average age is 64.8 years. The final column shows that around a half of them (49 percent) are between 51 and 70 years; 42 percent are 71 or older; and 11 percent are 50 or younger. This spread of ages reflects both the earlier ageing of some people with intellectual disability and the lack of alternative options when they reach the stage of needing a high level of care.

Columns two and three of Table 7 show differences between the age profile of residents in the 112 facilities with a small number of residents and the two facilities with a large number of residents. In the former, there is a wider spread of ages and around 78 percent are evenly spread between those in the fifties, sixties and seventies.

In contrast, residents in the other two facilities are on average older and there is less of a spread of ages. The largest proportion of residents (45 percent) is in their seventies and there are currently no residents aged 40 or younger in the two facilities. There is likely to be related partly (but only partly) to the greater number of females in these facilities, as females in permanent residential aged care are on average older than males. Across Australia, 57 percent of female residents are 85 or more compared with 38 percent of male residents in this age group (AIHW, 2006b).

Table 7 Percentage of residents with intellectual disability in various age categories, n=193

age group	facilities (112) with a small number of residents % of residents	facilities (2) with a large number of residents % of residents	all facilities % of residents
30 or less	1	0	1
31-40	3	0	3
41-50	8	3	7
51-60	26	13	24
61-70	26	18	25
71-80	26	45	30
81-90	9	18	11
91+	1	3	1
	100	100	100

Table 7 shows that 11 percent of residents with intellectual disability are 50 or younger, considerably younger than the overall average of 64.8 years. The group of residents currently aged 50 or younger comprises 11 females and 6 males, which is roughly in proportion to the total number of female and male residents with intellectual disability. Nine are in metropolitan facilities and 8 in non-metropolitan facilities, also matching quite closely the 55 percent/45 percent proportion of metropolitan and non-metropolitan facilities overall in the sample. Their RCS levels are varied. Seven of them are assessed as having a high level of dependency and five as having a low level of dependency. The RCS levels of the remaining five are missing.

Years of residence

The picture regarding the length of time residents have spent in residential aged care is as varied as that for residents' age (Table 8). The final column shows that 68 percent of all residents with intellectual disability have spent between one and ten years in a facility; eight percent have spent less than one year and 11 percent more than 15 years. The median is five years and the average is 8.2 years.

Table 8 Length of residence in an aged care facility, n=195

age group	facilities (112) with a small number of residents % of residents	facilities (2) with a large number of residents % of residents	all facilities % of residents
<1 year	10	0	8
1-2 yrs	28	15	26
3-5 yrs	22	10	19
6-10 yrs	25	20	23
11-15 yrs	10	27	13
16-20 yrs	4	20	8
21-30 yrs	>1	5	2
more than 30 yrs	>1	3	1
	100	100	100

The findings in Table 8 vary somewhat from the general Australian pattern of length of residence in residential aged care. At June 2005, 27 percent of the existing permanent residents in aged care

had spent less than one year in care (AIHW, 2006b) compared with 8 percent of our sample of residents with intellectual disability. Only 21 percent of the total population of permanent residents in aged care had spent five years or more, whereas in our sample, the proportion is 47 percent.

The profile of residents in the two facilities with a large number of residents in this special needs group accentuates the difference between the research group and the general permanent residential aged care population in Australia. Twenty-eight percent of residents in these two facilities have spent more than 15 years in the facility compared with 5-6 percent of residents in the other 112 facilities. The median length of time spent by residents in these facilities is 11 years, compared with four years in the other facilities.

However, even with the two facilities excluded from the analysis, the overall pattern of difference between the general Australian residential aged care population and the research sample remains. There are fewer residents who have been there for less than one year (10 percent compared with 27 percent) and considerably more who have been in residence for more than five years (around 40 percent compared with 21 percent).

Age at entry into aged care

The findings presented in Tables 7 and 8 imply that there is a wide range of ages at which people with lifelong intellectual disability enter aged care. Table 9 shows that overall, 20 percent are aged 50 years or less and around the same percentage (22 percent) are 71 years or older. The largest proportion (34 percent) came into aged care between the ages of 51-60.

Table 9 also shows some differences between the pattern of age of entry of residents in the 112 facilities with a small number of residents and the two facilities with a large number of residents. In the facilities with a small number of residents, a somewhat larger proportion of residents came into aged care aged 50 or younger (21 percent compared with 15-16 percent) and a smaller proportion came in during their fifties (31 percent compared with 44 percent). However, the proportions entering at older ages — in their sixties, seventies and eighties — are quite similar.

Table 9 Residents' age at entry into aged care, n=193

age group	facilities (112) with a small number of residents % of residents	facilities (2) with a large number of residents % of residents	all facilities % of residents
30 or less	3	2.5	3
31-40	6	0	5
41-50	12	13	12
51-60	31	44	34
61-70	24	23	24
71-80	19	15	18
81-90	5	2.5	4
30 or less	0	0	3
		100	100

The 39 residents admitted at age 50 or younger closely reflect both the gender distribution and the location of all of the residents in our sample. It is difficult to make a definitive statement about whether the dependency levels of this group are higher than for the total group of residents. RCS levels are missing for one in five of them. Of the 'early entry' residents whose RCS level is known, 65 percent have a high level of dependency, compared with 54 percent of the total group.

The purpose of this research was to examine the situation of people with life long intellectual disability who are ageing, rather than younger people with complex disabilities placed in residential aged care. This latter group have been the subject of considerable advocacy for change during recent years which has led to initiatives by the Council of Australian Governments (COAG) to create alternative housing and support options and address such inappropriate placement.

Range of diagnoses

Residents with intellectual disability had a very wide range of other diagnoses. A large majority listed at least one diagnosis in addition to intellectual disability; many listed considerably more than one. The most frequent (not necessarily listed in order of frequency) were epilepsy, insulin dependent or non-insulin dependent diabetes, Down Syndrome, cerebral palsy, asthma, osteoarthritis, osteoporosis, cerebral vascular accident (CVA or stroke), depression, anxiety, schizophrenia, various hearing and sight defects or degeneration including myopia and macular degeneration, various forms of cancer, heart disease, hypertension and gout. Other less frequent diagnoses included obesity, incontinence, behavioural disorders, brain lesions and anaemia. These are similar to conditions those that affect all older people and are quite common in residents in aged care. The most common health conditions of people aged 65 and over who have a health condition include arthritis, hearing disorders, hypertension, heart disease, diabetes and osteoporosis (AIHW, 2006a).

A separate question was asked concerning how many of the residents with intellectual disability also had dementia. Twenty-two percent of all residents were reported as having dementia. This may, however, be an under-estimation of the total number. Some respondents were uncertain and thought that a resident may have mild dementia. It is not possible to know whether a full screening process had been gone through in order to rule out other diagnoses.

Summary

Forty percent of responding facilities (114) had at least one resident with intellectual disability. The location of these facilities closely matches the location of all responding facilities. The facilities included 207 residents with intellectual disability. Almost all facilities had between one and three residents and around 60 percent had only one. Single residents with intellectual disability are found in facilities with both a small and a large bed capacity, although the largest numbers are in facilities with between 31 and 60 beds. Overall, females outnumbered males by approximately two to one. While this is quite consistent with the total permanent residential aged care population in Australia, it does not reflect the greater percentage of males than females in the general population of people with intellectual disability.

The population of intellectually disabled residents is on average considerably younger than the general aged care population. However, it is very varied, ranging from a small number of people in their thirties and forties to residents in their eighties and nineties. The average age is 64.8 years. Around 11 percent are aged 50 or younger. Residents have been in an aged care facility from less than one year to over thirty years. The median length of stay is five years and the average is 8.2 years. Overall, there is quite a different pattern of length of stay compared with the general aged care population. In the latter, fewer residents spend long periods of time in care.

Two facilities stood out as different from the other 112 because they had a large number of residents with intellectual disability. Residents in the two facilities were almost exclusively females. On average, they were older and had spent longer periods of time in the facility than residents in the other facilities. Nevertheless, they tended to follow the general pattern of being admitted at earlier or later ages, although more of them were admitted in their fifties compared to residents in other facilities.

Fifty-eight percent of residents with intellectual disability have a high level of dependency (RCS levels of 1-4). This matches the percentage of residents reported as being in high care places across the facilities. However, the overall picture regarding RCS levels is complicated by the fact that RCS levels for 13 percent of residents are missing. There is a significantly higher proportion of residents assessed as having low dependency needs in the two facilities with a large number of residents compared to facilities with a small number of residents.

3. Pathways into residential aged care

This section discusses findings concerning the ways in which people with lifelong intellectual disability enter residential aged care – where they were before they came into a facility, the often multiple reasons they enter into aged care and whether or not residential aged care was the preferred option.

Where residents were admitted from

The relatively wide variety of pathways into residential aged care for residents in most facilities is apparent from Table 10, which lists where residents were admitted from. The Table also shows quite different patterns for facilities with a small number of residents and the two facilities with a large number of residents.

In the majority of facilities, the largest proportion of residents with intellectual disability (37 percent) was admitted directly from living at home with family. (We know from the telephone follow-up calls that several of those admitted from hospital were living at home before they went into hospital.) Six percent were previously in a Community Residential Unit (CRU). Around the same proportion was admitted from a Supported Residential Service (SRS), from hospital and from transfer between aged care facilities. A somewhat smaller proportion was admitted from a training centre or other institution.

Table 10 Where residents were admitted from, n=197

Where resident was admitted from	facilities (112) with a small number of residents % of residents	facilities (2) with a large number of residents % of residents	all facilities % of residents
Community residential unit	6	2.5	6
Supported residential service	8	0	7
Training Centre or other institution	5	0	4
Other supported accommodation	9	72.5	22
Living with family	37	10	31
Boarding house	2	2.5	2
Living alone or with unrelated others	8	2.5	7
Transfer from aged care facility, high care	6	0	5
Transfer from aged care facility, low care	7	5	7
Hospital	9	0	7
Rehabilitation unit	0	0	0
Don't know	2	5	3
Other	1	0	<1

Ten percent of residents were living alone, with unrelated others or in a boarding house before being admitted to a facility; 13 percent came from other aged care facilities, either high or low care, and nine percent directly from a hospital.

Table 10 shows that most of the 22 percent of residents admitted from 'other supported accommodation' are in the two facilities with a large number of residents. They are by far the largest percentage of such residents. We know from the findings concerning reasons for admission (Table 11) that some of the 'other' supported accommodation places residents were admitted from are institutions which have since closed. Ten percent of residents in the two facilities were admitted from living with family, compared with the 37 percent in other facilities. All are recent admissions (1-6 years), in contrast to the much longer period of residence for most others in the two facilities.

Reasons for admission

Respondents were asked to select all the reasons that each resident was admitted from a predetermined list. Multiple reasons were identified for approximately 10 percent of residents with intellectual disability. It should be noted that this information is based on facility records, which can sometimes be augmented by staff knowledge of the person's circumstances and previous life.

Overall, the most common reasons for admission are the inability of previous supported accommodation to provide the degree of support and/or care required (25 percent of residents), ill-health or death of a primary carer (20 percent of residents). Next most common are the resident's behavioural management issues (13 percent), 24 hour nursing or personal care required and not available (13 percent), closure of the previous facility (12 percent) and ill-health of the resident (11 percent). Four percent of residents enter aged care to accompany a relative. Table 11 sets out these details.

Table 11 Reasons for admission, n=199

Reason for admission	% of residents
Ill health of the resident	11
Death or ill health of primary carer	20
Behavioural management issues	13
Inability of previous supported accommodation to provide degree of care/support required	25
24-hr nursing/personal care required and not available	13
Closure of previous facility	12
To accompany a relative	4
Don't know	9
Other	10

The residents in the two facilities with a large number of residents with intellectual disability do not show the same wide variability of reasons for admission as do those in the other 112 facilities. Inability of the previous supported accommodation to provide the degree of care and support needed was cited as a reason for admission for 30 percent of residents; closure of the previous facility for 25 percent and the need for 24 hour care for 10 percent of residents. For 15 percent of residents, the reason for admission was not known.

As we might expect, there are some patterns of relationship between reasons for admission and where residents were before they come into residential aged care.

Previously living with family

The principle reason for admission for those admitted directly from living with family was the death or ill health of their primary carer (55 percent). Other reasons for admission are quite widely spread. Some are likely to be a consequence of the ill health or death of the primary carer — to accompany a relative (10 percent), inability of their previous supported accommodation (home with family) to provide the degree of care or support required (5 percent) and the fact that 24 hour nursing or personal care was required and not available (5 percent). Other reasons relate to the health and behaviour of the person with intellectual disability themselves, that is, ill health of the resident (10 percent) and behavioural management issues (6 percent).

Additional comments and the telephone follow-up calls indicate that in some instances, it was not so much ill health or death of the primary carer, but a general realisation that for various reasons, family members were no longer able to cope with the demands of caring, for example: 'it got to the point where the father was no longer able to do the heavy lifting required' and 'the family were just not coping'.

Mothers and daughters and mothers and sons were admitted together, when the health of the mother deteriorated. However, in one instance, it was an older and younger sister who came into the facility at the same time.

Fifty-eight percent of the residents admitted from living with family had a high RCS level, leaving 42 percent who did not. The proportion with a high level of dependency is the same as that for the total survey group of residents with intellectual disability.

Residents are more likely to have been admitted from living with family if they are in a facility in a non-metropolitan area, compared to a metropolitan area. Fifty-one percent of residents from a non-metropolitan area, by far the largest proportion of admissions, were admitted from home, compared with 23 percent of residents in a metropolitan area. If the 40 residents from the two facilities with a large number of residents are excluded from the analysis (because we know that a large majority were admitted from 'other supported accommodation'), the proportion of residents in metropolitan facilities admitted from living with family rises to 34 percent, still considerably less than the proportion in non-metropolitan facilities.

Living in supported accommodation

The most common reason for admission for those previously in Community Residential Units, Supported Residential Services and training centres or other institutions was inability of the previous supported accommodation to provide the degree of care or support required. The spread of reasons was wider for those in 'other supported accommodation'. It will be remembered that a large proportion of these residents were in the two facilities with a large number of residents. Reasons given for the admission of this group included inability of the previous supported accommodation to provide the level of care needed (35 percent), closure of the facility they previously lived in 28 percent), the person's behavioural management issues (14 percent) and the need for 24-hour nursing or personal care (11 percent).

Living alone or with unrelated others

Those who were living alone or with unrelated others were admitted because they had reached the point of requiring 24 hour care and support, because of their own ill health or behaviour management issues, in one instance because of the ill health of their primary carer, and for a small number of 'other' reasons.

Transfer between aged care facilities

For those admitted from a low care aged care facility, it was the need for 24 hour care and/or support or the closure of the previous facility that most frequently triggered their admission to the current facility. Reasons for transfer between facilities were quite mixed and included ill health of the resident, behavioural management issues, inability of the previous facility to provide the level of care needed, closure of the facility and a small number of 'other' reasons. It is worth noting that in two instances, a general improvement in the health status of the person allowed a transfer from high to low care, and in another, the resident's sister advocated for her to be transferred to a low care facility.

Admission from hospital

The ill health of the resident and the need for 24 hour care and support were the main reasons for admission from a hospital. As noted before, at least some of these residents had lived at home prior to their hospital admission.

Other reasons

The 'other' category was sometimes used to further explain the resident's circumstances. However, some of the other reasons for admission identified included the following:

- A mother who lived in a rural area had been regularly visiting her son who lived in a metropolitan facility. The regular visiting became difficult; she was concerned about the care her son was receiving and wanted him closer, so he was admitted to a more local facility.
- Aged care facility staff described 'rural isolation' as the reason for one resident being admitted and another said: 'He (the resident) was unable to cope. His family were socially isolated'.

Aged care: Preferred option, best option, only option?

The survey asked respondents whether the move to an aged care facility was the preferred option for the person or his/her carer. Again, it needs to be said that it is facility staff who are responding to this question. While resident files may well include relevant information and staff in the facility may know the person's circumstances and history well, this is not always the case. A substantial minority of respondents (22 percent) said that they did not know whether or not it was the preferred option.

In relation to a substantial majority of residents with intellectual disability (69 percent), facility staff said that entry into aged care was the preferred option. Only in relation to nine percent of residents did they say it was not the preferred option. The large majority of responses indicating that aged care was the preferred option has to be seen in light of the fact that in most cases, it is the only option available. Respondents were asked why the decision was the preferred option or not. Our next study will also delve into whether this is preferred option for the older person. Their comments both reflect varying perspectives and suggest that they took varying account of the reality that there is very little choice about being admitted to residential aged care for many people.

The preferred option

The largest proportion of comments concerning the person's entry into residential aged care being the preferred option generally refer to the (high) care needs of the resident, the need for

management of difficult behaviours, the resident's degree of disability, or the circumstances of the previous carer which made it not possible for them to continue in the caring role.

Some specifically referred to admission being the best available option, saying or implying that it was not necessarily the preferred option, for example:

> Best option for the mother who was caring for her.
>
> Best option for the mother; there was nowhere else for her to go.
>
> Probably not ideal but the family was looking for somewhere where he would get high level care. He has improved since being here.
>
> Best option for the sister as she was very frail and could no longer look after (resident).

In offering an explanation for why residential aged care was the preferred option, other respondents referred specifically to the facility — its location, the fact that it was known to the family, or what it could provide. Some examples, with the location of the facility, are below. Mention of proximity and being local is almost always in relation to a facility in a rural town.

> Local community (facility); death of carer. (rural town)
>
> The family live one block away. (rural town)
>
> Mother and brother live close by. (rural town)
>
> Lived here (in the town) all her life and familiar with our facility. (rural town)
>
> Mother came for respite periodically. No community option available; considered by family as appropriate for his needs. (rural town)
>
> Son, who manages his affairs, lives locally. (regional city)
>
> Family lives close; better care for the resident (rural town)
>
> Because of our activity program. (metropolitan area)

The following comment was made by a respondent in a metropolitan facility. The resident she is referring to was admitted from a hospital because he required 24 hour care and support. As well as intellectual disability, his diagnoses include depression, hypertension and challenging behaviours. The staff member did not know whether residential aged care was the preferred option for the family. However, she reflected:

> 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 hospitalised). 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.

The respondents believed that admission to the residential aged care facility was the preferred option for 20 of the 23 residents in one of the facilities with a large number of intellectually disabled residents. They believed that for the majority in this facility, admission to the aged care facility was the preferred option because it maintained ongoing and long term relationships between residents, indicating that they had been together in the previous facility, which had closed or could no longer provide for their level of need. Aged care was believed to be the preferred option for another person because she already had friends in the facility and for several others because their families knew of the organisation.

For most of the residents in the other facility with a large number of residents with intellectual disability, the respondent did not know whether it was the preferred option.

Not the preferred option

For nine percent of residents, facility staff reported that residential aged care was not the preferred option. The reasons were varied and included the absence of any other option, the inevitability of deteriorating health and the need for high levels of care, and the reluctance of some (now) residents to move away from family and friends. Examples are below:

> It was the last resort for the family; parents were divorced and the mother in a RACS.
>
> (The resident) wanted to stay at home.
>
> She missed all her friends but it was necessary healthwise
>
> It was not preferred given the type of disability but nothing else was available.
>
> Not 60 at time of admission and he wanted to stay at home but his needs were too high.
>
> Not really the best option but the closest.
>
> Not really (preferred) but he needed high care immediately. Family were happy for him to come here.
>
> Parents would have preferred her to stay home. They tried several options but they didn't work. Now content that their daughter is in the facility. We feel honoured that they are satisfied.
>
> Not really (preferred). Previous carers didn't want it but there was nowhere else.
>
> Would have preferred her to stay at home but necessary because of death of mother and the father couldn't cope.

Services from the disability sector

Respondents reported that 44 percent of residents with lifelong intellectual disability had services from the disability sector in the past; 31 percent did not have such services. For 25 percent of the residents, use of disabilty sector services was unknown. Residents in facilities with a small number of residents were significantly more likely than residents in the two facilities with a large number of residents to have had services from the disability sector in the past. This is likely to be related to the fact that they are on average younger and have been in the facilities for less time.

Only 16 percent of residents currently receive services from the disability sector. They vary in age; however, just under half of this group are people attending a day centre, generally for between two and five days per week. As expected, most are under 60 years of age; however several are in their sixties and one 83 year old, living in a facility in a remote area, goes to what is described as a day care centre. Residents in facilities with a small number of residents are more likely than those in the two facilities with a large number to be currently receiving services form the disability sector (18 percent compared with 8 percent).

Other services or support accessed by between one and three people include disability pension, sheltered workshop, SCOPE services, Outreach services, an activity group in the community and volunteer work.

There were instances too of facilities trying to get such services for their residents but being unable to do so because they are in an aged care facility, for example: 'We've tried to get services for her but we can't access disability services because she is in an aged care facility' (facility in a metropolitan area).

Residents currently receiving services from the disability sector are equally as likely to live in a facility in a non-metropolitan area, as in a metropolitan area. One person in a rural town is driven 50 kilometres to attend a centre several times a week. Nevertheless, a number of respondents in rural towns commented on the scarcity of services in their area.

Summary

In the 112 facilities which have a small number of residents with intellectual disability, pathways into aged care are quite varied. The largest proportion of residents (around 37 percent) is people previously living with family. They are generally admitted when their carer becomes ill or dies, when their own health deteriorates or when family members can no longer provide the level of care and support they require. The remaining residents in these facilities are admitted in roughly similar proportions (6-10 percent) from a community residential unit, a supported accommodation service, from hospital or transfer between aged care facilities and from living with unrelated others. Ill-health, behavioural management issues and the need for a higher level of care than was previously available, are the main reasons for admission into aged care for residents admitted from these places.

A substantial majority of the residents in the two facilities with a large number of residents (72 percent) were admitted from supported accommodation other than a CRU, SRS, or training institution, either because of closure of the previous institution or inability of the previous supported accommodation to provide the level of care needed. A small proportion of residents in these two facilities (10 percent) have been admitted from living with family; all have been admitted relatively recently.

Respondents reported that moving into aged care was the preferred option for 69 percent of residents; it was not the preferred option for nine percent. Respondents did not know whether it was the preferred option or not for between one in four to five residents. The qualitative comments about preferred options for aged care support the observation that in many cases, residential aged care is the 'preferred' option because it is the only option. Sometimes, it is preferred in the sense that the particular facility is located close to family members. For residents in the two facilities with a large number of residents, admission to the facility was preferred as it kept friends together and maintained previous close associations.

Only 16 percent of residents currently receive services from the disability sector. They tend to be younger residents who attend a day centre or other support group.

4. Resident care and activities

The survey sought information about how frequently residents with lifelong intellectual disability participated in onsite activities, offsite activities (away from or outside the facility) and religious activities.

Onsite activities

A substantial majority of residents (94 percent) were reported as taking part in onsite activities daily or weekly, with 73 percent participating daily (Table 12). There were no significant differences between the daily and weekly participation rates of residents in facilities with a small number of residents and facilities with a large number, and the same proportion, five percent, either never participated or only a few times a year. However, additional information from the telephone calls clarifies the finding.

The telephone follow-up calls indicated that in the facilities with a small number of residents, some residents are described as passive rather than active participants in the general activities and lifestyle programs organised by the facility for all residents. It will be recalled from Section 2 that single residents with intellectual disability are found in facilities across the range of total capacity between 10 and 100 or more residents. In the facilities with 23 and 17 residents, residents with intellectual disability are a large part of the total facility population, with consequently much greater opportunities to organise activities around their specific needs.

Table 12 Frequency of onsite activities, n=195

	No. of residents	% of residents
Daily	142	73
Weekly	41	21
Monthly	2	1
Bi-monthly	0	0
A few times a times	6	3
Never	4	2
	195	100

The picture of onsite participation is therefore somewhat more complex than the findings in Table 12 indicate. Nevertheless, the figures suggest that a majority of facilities make efforts to involve residents with intellectual disability in the facility's activities programs if possible. Although the survey did not specifically ask about individually designed activities programs, the telephone calls and some of the written comments indicate that some of the facilities with a small number of residents have individually designed activities for residents. Planning and providing for appropriate activities for individuals is discussed further below under the heading of Care and Activity Issues.

Respondents reported that residents are passive rather than active participants in the general facility activities programs for a variety of reasons, including failing health and frailty, physical and cognitive incapacity to do so, and emotional and behavioural difficulties. Below is a selection of comments regarding why residents did not take part in activities.

> Increased frailty, (resident is) asleep most the day.
>
> He is very withdrawn and is more settled and relaxed in his own environment. Only participates in activities of his preference.
>
> Poor motivation and chronic pain.
>
> Disruptive, unable to concentrate.
>
> Physically and cognitively unable to do so. Very noisy at times.
>
> She is very passive and when not at the day centre observes rather than takes part on most occasions. She did have a close friend who died 2 years ago - no close friends since.
>
> She is intrusive and disruptive, has limited language skills, resists activities and is no longer able to walk. Tends to read, do some drawing and listen to music in her own room.
>
> She is quite passive but does take part in some activities.
>
> Resident is not interested. Doesn't join in with other residents. She's a passive participant.

Some facilities with a small number of residents had either designed a specific program, found activities which the resident is interested in, encouraged the resident to have a helping role in the facility or encouraged them to take responsibility for various small jobs. Some examples are below:

> Resident prefers not to (take part in facility activities program). ID is severe and we have a specific program designed to address this and provide enjoyable activity.
>
> 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.
>
> She enjoys knitting, watching TV and cutting and drawing on cardboard.
>
> 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 helps out with the exercise group. Tends to become very bossy and watches everyone. He goes offsite to the Senior Citizens' club.
>
> We have a good lifestyle program. He looks after his fish, plays bingo, is in the choir, involved in all of these activities.

However, the following comment indicates that staff time and resources are not available in some facilities: '([Resident] doesn't talk or interact with others much. No appropriate activities are available, except for music. The facility is waiting for someone to be employed for this purpose.'

Offsite activities

Overall, respondents reported that around 50 percent of residents with intellectual disability participate in some form of offsite activity weekly and 10 percent do so daily (Table 13). Significantly more residents in the two facilities with a large number of residents participate in off-site activities weekly than do residents in facilities with a small number (68 percent compared with 45 percent).

The survey did not ask about the nature of these activities; however, the telephone follow-up calls and some written comments, including those in relation to current services from the disability sector and care activity issues, give some indication of the types of offsite activities that take place.

Residents in the two facilities with a large number of residents with intellectual disability include regular outings in their activities program (see below). Offsite activities for residents in facilities with a small number of residents include regular attendance at a day centre or some other disability-related form of support and activity, and employment in a sheltered workshop. Offsite activities can also include staff members or volunteers taking residents out for walks, family members and friends taking residents out for outings and residents visiting friends and family (see below).

Table 13 Frequency of offsite activities, n=190

	facilities (112) with a small number of residents % of residents	facilities (2) with a large number of residents % of residents	all facilities % of residents
Daily	11	10	10
Weekly	45	68	49
Monthly	7	17	9
Bi-monthly	3	0	2
A few times a year	9	5	8
Never	25	0	21
	100	100	100

Around 30 percent of residents never participate in offsite activities or do so only a few times a year and it is likely that this is due in large part to their level of dependency and incapacity. Of the 40 residents who were recorded as never attending offsite activities, just over two-thirds had high levels of dependency (a RCS level of 1-4). The RCS levels of seven of these residents were missing.

Religious activities

Overall, almost half of the residents (48 percent) participate in religious activities at least weekly. One third never do so and a further eight percent do so only a few times a year. In contrast to the overall pattern, 82 percent of the residents in the two facilities with a large number of residents participate daily or weekly in religious activities. Religious activities play a major part in some residents' lives and are reported by staff to be a great comfort to them, especially in regard to dealing with the death of parents and other close relatives and friends.

Relationships with others in the facility

The survey asked whether residents with intellectual disability had positive relationships with other residents in the facility. Overall, half were recorded as having positive relationships and a further quarter as having somewhat positive relationships, leaving one in four not having positive relationships or positively avoiding other people (Table 14). The telephone follow-up calls indicated that some residents who do not have positive relationships with other residents do, however, have close associations and attachments to staff members.

A significantly greater percentage of residents in the two facilities with larger numbers of residents had positive relationships with others and fewer did not have positive relationships, compared with those in facilities with a small number of residents.

Table 14 Positive relationships with other residents, n=197

	facilities (112) with a small number of residents % of residents	facilities (2) with a large number of residents % of residents	all facilities % of residents
Positive relationships	47	68	50
No positive relationships	24	2.5	19
Somewhat positive relationships	24	27	26
Resident avoids other people	5	2.5	5
	100	100	100

We also asked whether residents had a special friendship or close association with other residents. Consistent with the other findings, residents in the two facilities with a large number of residents were more than twice as likely to have a special friendship or close association than were residents where they were the sole person with intellectual disability or one of a small number (65 percent compared with 31 percent). Overall, 40 percent of all residents were recorded as having a special friendship and 44 percent as not having one, with the remainder as 'somewhat' having a special friendship.

Facility support for residents' outside contacts

A large majority of facilities (90 percent) said that they support opportunities for residents to have contact with people from their previous life. They do so through a variety of means — encouraging visits from family and friends, helping with telephoning, trying to trace family members and friends, facilitating visits and providing a range of other supports for contacts to occur. In most cases where facilities said that they didn't support such opportunities, the reasons given were because the person had no or few contacts from the past, relatives were either absent from their lives or living far away, or the person's physical and mental condition was such that contacts were difficult or not possible.

There are strong arguments for considering that frequent contact with family and friends enhances the overall experience of living in a residential aged care facility and can contribute to general levels of emotional and physical and emotional health to a certain degree. Sixty percent of residents with intellectual disability were recorded as having daily or weekly contact with family, friends or others. One in five (20 percent) was recorded as never having contact with others from outside the facility or doing so only a few times a year (Table 15).

Table 15 Frequency of contact with family, friends and others, n=192

	facilities (112) with a small number of residents % of residents	facilities (2) with a large number of residents % of residents	all facilities % of residents
Daily	18	30	21
Weekly	41	35	39
Monthly	16	5	13
Bi-monthly	7	0	6
A few times a year	10	30	14
Never	8	0	7
	100	100	100

There is no significant relationship between gender and frequent contact with family, friends and others (defined as daily or weekly contact). Sixty percent of females had frequent contact compared with 61 percent of males.

There is however a significant relationship between being located in a metropolitan area and frequency of contact, despite the comment above that admission to a facility in a rural area is quite often preferred because it allows family members to be or remain geographically close to the resident. Sixty-two percent of residents living in a metropolitan area have frequent contact compared with 39 percent of those living in a non-metropolitan area. However, this may be the effect of the facilities with a large number of residents being located in the metropolitan area. The facilities have a larger proportion of residents who have frequent (daily or weekly) contact with family, friends or others (65 percent compared with 59 percent in all other facilities).

The particular circumstances of residents in the two facilities (a higher proportion of low dependency residents and a higher level of frequent contact with others) may also contribute to another significant relationship — that between lower levels of dependency and frequent contact with family, friends and others. Seventy percent of residents assessed as having a lower level of dependency (RCS levels 5-7) have daily or weekly contact with family, friends and others compared with 60 percent of those assessed as having high dependency needs (RCS levels 1-4). Again, however, the proportion of missing RCS values needs to be noted.

The factors which contribute to frequent contact of intellectually disabled residents with other people outside a residential aged care facility need further investigation.

Practical support from others

Family, friends, volunteers and institutional bodies such as the Guardianship Board and the State Trustees offer support for residents with intellectual disability. Table 16 shows the range of support offered and the percentage of residents reported as receiving such support. The most common are management of a resident's affairs and companionship and visiting, followed by general advocacy for the resident, additional personal care and being taken on outings. (Percentages add to more than 100 as respondents gave multiple responses.) The finding needs to be treated with some caution, as it was sometimes noted on the survey form, or apparent in a telephone interview, that the facility itself provided some of the forms of practical support listed.

Table 16 Practical support from others, n=195

	No.	%
management of affairs	168	86
advocacy	80	86
financial support	56	41
additional personal care	23	29
takes on outings	85	44
companionship/visiting	130	44
none of the above	20	67
other	7	10

Care and activity issues

All respondents were asked to draw on their experiences and to note what are the main issues regarding care and activities for residents with intellectual disability in aged care. Their responses show that they are commenting on the basis of varied experience. Some are currently working with residents with intellectual disability, some have worked with them in the past and others have no experience of people with intellectual disability in aged care. Their comments are both general and refer to characteristics of individual residents.

The following discussion focuses on care and activity issues identified by respondents in facilities which had at least one intellectually disabled resident, with occasional reference to issues identified by respondents whose facilities do not currently have any such residents. Eighty-six percent of the facilities with current residents listed some care and activity issues. Although their comments vary in style and the amount of detail included, there are a number of consistent and recurring themes. They are outlined below, with examples, under the following headings:

- General care issues
- Appropriate activities
- Providing for younger residents
- Need for 'one to one' interaction/ attention
- Management of challenging behaviours
- Access to other support services
- Staffing and staff training

The issues are discussed separately for convenience but respondents' comments, and common sense, show that they are often inter-related. Some of the inter-relationships are discussed.

General care issues

General care issues include maintaining residents' dignity and self-esteem, providing for their social, physical and emotional needs, understanding their past and recognising their specific needs. Examples of such broad comments are below.

> Enabling individuals to have need for intimacy and sexual expression met and dignity maintained.

> Understanding their past; they may have spent a significant time in sub-standard institutional 'care' which can determine certain behaviours and require specific approaches.

> Identifying resident individual preferences when family members are not available to provide this information.

Respondents referred to some residents needing a higher level of prompting, encouragement and assistance from staff to enable ADLs (Activities of Daily Living) to be completed.

> May require prompting for personal hygiene. May require assistance with personal hygiene. May need smaller groups per carer to supervise uninhibited behaviours.

> General care requires a higher level of prompting, encouragement and supervision form staff to enable to ADLS to be completed.

Other respondents tended not to differentiate between care issues for residents with lifelong intellectual disability and other ageing residents. One of the facilities with a large number of residents with intellectual disability noted: 'Basic care needs are consistent with those who do not have intellectual disability'.

Yet others implied that care issues for people with lifelong intellectual disability were little different from people with acquired brain injury (ABI), for example: 'There are no issues once they are in high care as they fit in with other ABIs etc.'

The two comments below are a reminder of individual differences and the sometimes complex interactions between intellectual disability and ageing. They also point to difficulties in generalising across a population, some (but not all) of whom are similar in some ways ('they can't look after themselves') but whose needs are very individualised in other ways, including the degree to which they are facing difficulties associated with ageing.

> 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.

> No issues really. Resident tends to fit in with others. She is quite positive, seems to be happy in herself. It doesn't change anything in the facility (having her here). She is still mobile. She's done incredibly well. Her issues are to do with ageing.

Appropriate activities

Respondents had concerns about the appropriateness for this group of residents, of activities which are generally provided for residents in aged care. Some of the concerns are related to the generally younger age of people with intellectual disability and the implications this has for their general interests and preferences, for example in music and other activities. Other concerns about activities relate to the behaviour of residents with intellectual disability, their level of disability, their physical and emotional ability (and inability) to enter into the activities, their clashes with older residents, and isolation because of behaviours which others see as challenging or disruptive.

The term 'passive' participation in some group activities has already been noted. This is again apparent in the activity issues identified. One respondent commented: 'Group activities tend to be age specific and beyond the comprehension of those with intellectual disability'. Another said:

> We have individualised programs and a daily program that is very extensive. Intellectually disabled residents are mostly passive participants in these programs but they enjoy some things, e.g. one does enjoy music and staff put (music) on for her. The most difficult thing is that there is nothing in the community that can be provided, e.g. specialised activities or community groups visiting.

The level of disability of the resident is clearly an important factor in participation in group activities. A facility which currently has two residents commented:

> Neither resident has severe disabilities and can join in with most activities. As the majority of our high care residents have dementia we cater for short attention spans. Both residents have aggressive behaviour problems that limit their participation in group activities and more time is spent with them one to one.

Difficulties are sometimes exacerbated when there is only one resident who has different needs from the others, as the following g comment indicates:

> 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.

Funding is also an issue in providing appropriate activities:

> There are not enough activities hours in the budget to be able to provide the one to one care he needs. (facility has only one resident).

The two facilities which have a large number of residents with intellectual disability do not have the problem of individuals isolated by age and 'difference' from other residents. In this regard, their care and activity issues are somewhat different from those in other facilities. Their comments indicate that both an understanding of individual differences and the need to tailor activities for this group of residents is necessary. One of the facilities which have a large number of residents commented:

> Basic care needs are consistent with those who do not have intellectual disability. For these residents, our activity program is simplistic and takes into account short concentration times. Activities often revolve around outings.

The other facility noted:

> Simple clear instructions and explanation of expectations is needed. There is a need to modify activities to accommodate lack of numeracy and literacy skills. Activities offered need to boost self-esteem and not set (people) up for failure. All activities offered need to focus on their abilities rather than disabilities. There is also a need to be aware of occupational health and safety as often (they) have poor insight and judgement.

Residents' degree of physical and cognitive disability has already been referred to as a significant factor in whether they are able to take part in the group activities organised for residents in general, and the degree to which they have positive relationships with others in the facility. This is evident in the issues identified by respondents and in comments such as the following:

> In the case of the current resident, there are no particular issues. She gets on well with everyone and everyone is willing to help her.

Facilities with one or two residents who have severe physical disabilities may not have access to appropriate means of transporting residents outside the facility. One facility had only recently gained access to a bus which could be used to transport the resident, who was wheelchair bound.

However, having a small number of residents need not necessarily lead to difficulties in finding appropriate activities, as the following comment illustrates:

> (The resident) prefers simple activities aimed at a younger age. This is frowned upon in residential aged care but our resident loves soft toys which make a noise. Also racing cars and tracks, ball games, some exercise classes, loves winning prizes at Bingo. Really enjoys receiving mail and have staff read it to him over and over. Loves collecting the eggs from the chooks and delivering the mail to me. Loves lots of attention and positive reinforcement.

On the other hand, some facilities appear not to have the resources to make offer an individualised program or appropriate activities:

> Nursing staff don't have time to do much with him. There are few activities for people with dementia, 'wanderers' or others requiring special activities. They are waiting for someone to be employed for this purpose.
>
> 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.

Providing for younger residents

The impact of residents with intellectual disability often being younger than other residents is implicit in many of the comments above. It is especially apparent in the following issues identified by respondents, some of which refer to difficulties of understanding between younger and older residents.

> Age of other residents is an issue. Residents with intellectual disability usually come in at a younger age. Difficulty in getting volunteers to help with activities. Ability of (older) residents to understand special needs of residents with intellectual disability.
>
> Staff are not fully equipped, nor is the facility, to deal with younger people, especially where there is a lack of communication. This makes it very difficult to assess their needs. If person is known to the staff and the community, it works better and needs are understood. This resident is very well known to other residents and accepted.
>
> Types of activities are limited. Age issue, resident is younger than others. She wants to be involved, needs more activity. We have tried to access activities for her off site but not been successful. She wants to stay active and involved and some facility activities not appropriate.
>
> Younger ones get bored. Music choices of younger ones are different too, so often (listening to music) has to be solitary. No other issues really. The younger resident accepts the rest of the community in the facility.
>
> No access to community programs. It's very difficult to have access to daily outings outside of the home. Activities in aged care are not suitable for young residents. If the resident is not financial, we can't have access to a private carer to organise outings.

Need for 'one to one' interaction and attention

Respondents from facilities with no current residents with intellectual disability, as well as those with such residents, frequently referred to this group of residents as needing 'one on one' attention. The reasons stated and implied include the range of often highly individualised physical and emotional needs of such residents, their range of challenging behaviours and sometimes their high levels of dependence on staff. Some examples are given below:

> Individualised needs and a variety of behavioural and physical disabilities.
>
> One to one supervision in ensuring privacy and dignity is protected during group or communal activities. In some cases behavioural issues impacting on other residents, requiring specialised monitoring and management strategies.
>
> High dependence on staff for physical/personal care, management of affairs, emotional support, friendship. Friendships mostly with staff, staff and volunteers from previous residential care service. Impaired communication and limited life experiences reduce the ability to establish friendships with other than staff members.

> Specific individual needs towards providing appropriate resources. Their emotional world from their perspective is small - leads to difficulties in groups of older people. Tend to be self focused, and often need one on one attention.

> Lots of one-on one-time listening and reassuring (is needed) and assistance with ADLS due to lack of insight.

Managing challenging behaviours

The challenge of managing and dealing with behaviours which are described as difficult, intrusive, attention seeking, and sometimes inappropriate, was a recurring theme. The challenge is made more difficult when staff in some facilities do not have specific training in working with this resident group. The following comment indicates additional factors which can contribute to making this a difficult issue for facilities:

> Behaviours: care plan interventions are not consistent with changes of shifts and (at times) lack of staff genuine interest. There is the potential for social isolation for such residents. (We need to) provide more opportunities for one to one and small group interaction in social and leisure time.

Access to other support services

The identification of issues included examples where the facility had access to other support services, used them as much as they could and appreciated that they were available. Services specifically mentioned included SCOPE and Nexus, for example: 'Depending on the age group, the facility may need to access SCOPE Services for 'special' education and more appropriate stimulation. There were also examples of such services not being available and being sorely needed. The two comments below are about positive use of other services.

> No issues really because we outsource, we use whatever is available in the area.

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

Staffing and staff training

The need for adequate training for staff working with residents with intellectual disability was listed as an issue by some respondents. However, not everyone appeared to agree that specific training was necessary. Some comments implied that general guidelines concerning attention to the social, emotional and physical needs of (all) residents were sufficient. Others were more specific, for example, 'personal care issues are similar to anyone requiring such care, including behaviour management'.

It is worth noting that respondents in facilities which did not currently have a resident with intellectual disability quite frequently mentioned staff training as an issue, as something that would be necessary if facilities were to admit residents with intellectual disability.

Despite special staff training being an important consideration for some, no clear pattern emerged as to how important training was, or the type of training which would be most helpful. There were varied comments about what was helpful, as the following comments illustrate:

> The main issue is educating staff about understanding the difference between intellectual disability and dementia.

> Half of our staff went to dementia training. This has helped us in dealing with challenging behaviour.

The other main staff issue was the impact on staff time and resources when residents needed a high level of individualised attention. Again, the issue is apparent in some of the previous comments, but is a stronger focus in the comments that follow.

> More often than not, such residents require one to one for activities which then leads to staffing issues.
>
> Our demographic is >90 percent from the homeless sector, therefore (they) always need to be accompanied by a staff member for all medical and life appointments.
>
> We don't have sufficient staff to be able to meet activity needs beyond those usually supplied. Insufficient funding.
>
> Personalised programs involving one to one activities often requiring lengthy times that staff don't always have time to do. Excessive physio programs and no staff to attend.
>
> Staffing levels to address sometimes very specialised care needs.
>
> (Such residents) need constant activities which is not always possible because staff are not always available.

Pastoral care programs

The survey asked whether facilities had a pastoral care program. We did not offer any definition of such a program. The telephone follow-up calls raised the question of how facilities understand pastoral care programs and what constitutes a formal (and perhaps an informal) pastoral care program. We are not aware of any research that has explored this area.

Frequent responses to the question of whether the facility had a pastoral care program were '… well, we do have visiting priests from various religions come to the facility' or '… the local churches come on a regular rotating basis and we call in someone from a particular religion if necessary'.

In addition, a number of respondents said they had regular church services and/or religious observances and opportunities for residents to celebrate or commemorate events in a religious setting. A respondent from a facility in a regional city said: 'We have a palliative care service and psych services. It's not a pastoral care team as such, but we do have these things. We also have the Catholic priest come and give communion and we have memorial services'.

Our understanding of pastoral care is the need to recognise the universal nature of human spirituality. A pastoral care program need not necessarily have a religious background. In aged care facilities, such programs are often administered by outside sources, usually the local religious communities.

It was decided to record any response which referred to visits by people from various religious faiths as a pastoral care program, given that the survey form did not provide a definition, and that it was not possible from the limited information available from facilities to make an informed judgement about whether the service offered constituted a formal pastoral care program. Sixty-nine percent of all of the responding facilities were therefore recorded as having a pastoral care program in their facility, although it is more accurate to say that this proportion said that, at a minimum, the facility had visiting representatives from one or more religious communities.

The difference between the proportion of metropolitan facilities which had a pastoral care facility by this definition and the proportion of non-metropolitan facilities (71 percent compared with 66 percent) is not statistically significant.

Factors contributing to positive experiences

The qualitative identification of issues and other comments sought from respondents were not designed to identify factors which contribute to positive experiences for residents, to high quality care and appropriate activities. However, taken together, they suggest ways in which facilities are providing positive experiences and appropriate care and activities for residents with lifelong intellectual disability, sometimes with quite limited resources. There are examples of facilities:

- using community resources where and if they are available;
- using the services of diversionary therapists,
- adapting activities and services for residents in general, such as aromatherapy, music, etc.
- encouraging and supporting family members to maintain contact and occasionally seeking out family members where contact has been infrequent,
- drawing on family and community knowledge of individual residents, and
- using support and assistance from disability services which have prior knowledge of the resident.

Some examples are below.

> No issues; managed well. The diversional therapist is very aware of their needs and runs activities. Everyone loves them for what they are. Doctor sees one of them every week, he is very good. Pastoral care worker takes one of them to chapel each week to light a candle for her recently deceased mother. She has aromatherapy and walks in the garden.
>
> Diversionary therapy is available and very good. They work out a specific program for the resident. The resident is very pleasant and integrates well.
>
> Community knowledge and understanding of the person is important.
>
> There are very limited facilities for young and disabled people in the area. Being a rural nursing home, we are probably more flexible (than a facility in the metropolitan area). So we put systems and structures in place to deal with younger people and older ID people. However, probably not the best place for them, although we do our best and meet their social and care needs (as much as we can)

Several respondents said that contact with and assistance from disability services that the person has been in contact with prior to coming into aged care was helpful. One person said it had made the transition period easier, for the resident and the facility.

> The one resident we have was living in an institution in the town. The main issue is that the settling-in period and the planning was different than for other residents. We tried to maintain some of her activities. It has all settled down now but it was different. The important thing was that she came from a nurturing community into a nurturing place. There was already an overlap. It wasn't that we had worked with this institution before but a person from the institution had regularly visited our facility. It made it much easier. It's the rural community - I think it would be much more difficult in a metropolitan area.

In this case, the carer from the Community Residential Unit visited the facility every day in the initial stages and was a source of information and guidance for staff.

Another respondent noted that the resident's self care in the aged care facility was enhanced if they are had been connected to the disability sector in some way before entering aged care.

Summary

A large majority of residents with intellectual disability were reported as participating in onsite activities daily or weekly. Respondents' qualitative comments indicate that in some facilities with a small number of residents, this is passive rather than active participation in activities designed for the general body of ageing residents. Residents in facilities with a large number of residents are more likely to participate in offsite group activities organised by the facility. In facilities with a small number, activities include attendance at a day centre, generally for younger residents, and a range of other activities such as visits to family members and walks and occasional outings assisted by staff and/or volunteers.

Residents in facilities with a large number of residents are significantly more likely to have positive relationships with other residents and special friendships within the facility, compared to sole residents or those who are one of a small number. However, some of the latter do have positive relationships and some have close associations with staff members. Facilities try to find and organise appropriate activities for their residents with various degrees of success. Sometimes the resources are not available to do the best job possible for such residents.

Care and activity issues identified by the respondents include general care issues, the need for appropriate and individualised activities, difficulties of providing for younger residents in an environment where their needs are often different from those of other residents, a high level of 'one to one' interaction required for many residents with intellectual disability, difficulties in managing inappropriate behaviours especially when staff time and resources are limited or stretched, gaining access to support services, the need for staff training and sometimes having not enough staff resources available.

5. Discussion of the findings

Estimating the total number of residents

The study has limitations in estimating the total number of residents with intellectual disability currently residing in aged care facilities in Victoria, largely because we cannot know whether the proportion of facilities which responded to the survey and had residents with intellectual disabilities is replicated in the total population of facilities in Victoria.

However, we can make some estimates from the findings. Forty percent of responding facilities had at least one resident with intellectual disability. Extrapolating from this to the total number of facilities (826), we would assume that 330 facilities would have at least one ID resident. Our 114 facilities had a total of 207 residents. Extrapolating again, this would mean that 330 facilities might have 599 residents. We know, however, that this is an over-estimation as the 207 figures include 40 residents who are in only two facilities. Excluding the two facilities with a large number of residents and extrapolating only from the 112 facilities which have 167 residents, the estimate for 330 facilities is 492. However, realistically, we have to add in the 40 residents we know are there, making a total estimate of 532. We know that at least three facilities in the system cater for this special needs group, so this is likely to increase the estimate to perhaps 550.

A more conservative assumption is that the proportion of the total number of facilities which have at least one resident with intellectual disability is less than the 40 percent we found. If it is only 35 percent, the estimate using the same extrapolations as above and including the 40 we know are there and another 20, the estimate becomes 491. A still more conservative assumption of only 30 percent of facilities having at least one resident with an intellectual disability leads to an estimate of 429 residents statewide.

Issues raised by the present study

While the present study provides some understanding of the characteristics of residents in aged care with an intellectual disability and highlights some issues concerned with their care and lifestyle, the findings also raise other questions. For example, why are residents with intellectual disability so much younger than other residents? Why do so few of the residents in the research sample have dementia? Why is there a comparatively large proportion of residents who are admitted from the family home? Given what we know of the distribution of intellectual disability in the general population, why are there not more males with intellectual disability in the residential aged care population?

Diversity amongst people with intellectual disability

The present study asked about resident RCS levels and specific diagnoses to gain some understanding of the care needs of this resident group. The care and activity issues identified by staff assist us to understand that this resident group has a wide diversity of care and life needs. However, there remains a need for an further understanding of individual differences in levels of disability and the implications of these for quality care for individual residents. Although the severity of intellectual impairment can differ quite significantly most people with intellectual

disability have difficulties with communication. This highlights the importance of others who know them well to advocate for them and interpret their needs. It also suggests the importance of capturing well people's life stories and ensuring staff know people's histories and social networks.

When residents are admitted from a CRU, staff from the residential unit can play a very important role in providing information and in helping residents settle in. Family members also play a crucial role in providing support, information and assistance when residents are admitted from the family home. Situations vary, however, and the death or ill health of the previous primary carer or carers may mean they are no longer available. Current funding arrangements for residential aged care do not take account of the variability of special needs of this group of residents.

How are facilities adapting?

There is no one answer to how facilities are adapting to the needs of their residents with an intellectual disability.

Residents in the two facilities with a large number of residents participate in offsite activities to a greater extent; they are more likely to have positive relationships with other residents and are more likely to have a special friendship or close association with another resident. While not the only factor having an impact on the quality of people's experiences in aged care, being one of a group of people with similar health and care issues and a history of living together over a long period of time is likely to be quite different from being one person in a facility whose interests and activity needs may be very different from the majority of residents.

At the same time, it is apparent that facilities with one or a small number of residents are perceived as being able to provide a satisfactory environment for people with intellectual disability, especially if they are able to identify and provide activities which interest the resident, where there is regular support from and contact with family members, where staff have time, the facility has adequate physical resources (buildings, equipment, space etc) and for younger people, where there is support from at least some disability services.

At present, there are some indications that, in the absence of training, quality care is sometimes 'hit and miss' and may be dependent on whether someone in the facility has some knowledge, understanding or experience of intellectual disability, either in an aged care environment, the community or their own family.

While there are clearly some general consistencies in the care and activities issues identified by respondents across facilities, it is also apparent that respondents have quite varied perspectives on some of those issues and their comments sometimes suggest different underlying assumptions. Further research is needed to understand more fully both the perspectives and the assumptions, including how staff and management perceive similarities and differences between care and activity issues for people with lifelong intellectual disability and other residents in aged care, residents with dementia and residents with an acquired brain injury.

The fact that the majority of residents with intellectual disability are the sole person or one of a very small number with similar special needs in the facility tends to make relationships with others especially important for a sense of personal well-being. The findings suggests that, when there are few or no close family relationships available, relationships with staff members can be very important. However, expectations of residential aged care funding is much more specific and focussed on provision of care than funding for disability services. Aged care is expected to 'do' certain things rather than to provide satisfying relationships between staff and residents, time pressures on staff, changing shift patterns and lack of training make for variable success in achieving positive relationships.

Funding for the aged care sector is tied to specific assessed levels of care and therefore regarded as fairly inflexible. The different levels of disability, the variety of individual resident care needs, as

well as the recurring theme in the study findings of the need for 'one-to-one' interaction between staff and residents with intellectual disability, has implications for funding. It may be that intellectual disability could be regarded in a similar way to dementia and be funded as a specific category in residential aged care.

Further research: Australian Research Council Grant

An ARC Linkage grant has been awarded to Associate Professor Ruth Webber, Associate Professor Christine Bigby and Professor Barbara Bowers to continue their research on intellectual disability and ageing. This project is titled: Accommodating the Needs of People with Lifelong Intellectual Disability in Residential Aged Care[5].

The research project will examine different pathways into residential aged-care for ageing people with an intellectual disability and identify important decision-making points and factors influencing those decisions. It will examine the consequences for relevant players of placing people with intellectual disability in a residential aged-care setting. It will track over a three-year period intellectually disabled people with health issues as they move from the disability sector to the residential aged care sector. It will gather information from a number of sources: managers, carers, target people, family members and wider connections. The findings will inform policy development in the Aged Care, Disability and Health sectors about the support and service needs of this group.

The aims of this project are to:

- Understand existing partnerships and working relationships between disability services and residential aged care and Aged Care Assessment Teams.
- Investigate the different pathways into residential aged care for older people with intellectual disability living in different forms of accommodation.
- Investigate the quality of care experiences of older people with intellectual disability in residential aged care, and analyse their relationships between family and other informal support network members and examine the roles that informal support plays in decision making and monitoring their quality of care.

The key research questions are:

1. What are the pathways taken by older people with an intellectual disability to residential aged care, including identification of important decision points and factors influencing those decisions?
2. What are the consequences for them and for other key players of placing older persons with an intellectual disability in residential aged care facilities?

[5] For further information about this project, contact Associate Professor Ruth Webber: ruth.webber@acu.edu.au.

Implications of the Research for the ARC linkage project

This study has shown that many people with a life-long intellectual disability are living in residential aged care facilities in Victoria. While the data indicates that there were different pathways and circumstances into aged care facilities, the triggers that led to this move are not known.

The *'Mapping the Terrain'* study provides a great deal of valuable information about people with an intellectual disability who are residing in an aged care facility. It also forms a backdrop that will allow the new research project to not only explore in more detail the routes that intellectually disabled people take into aged care, but also to identify important decision points and factors that influence the decision to relocate. It will also explore the consequences for them and their families as well as other key players of placing them in residential aged care facilities.

An important factor that emerged from the present study is that a large proportion of residents were assessed as having low dependency needs. The results of this study led us to ask to a number of questions which we anticipate the new study will address.

- What could have been done or could be done in the future to allow people to stay in place longer, particularly if they have low dependency needs?
- When is the most appropriate time for a person with an intellectual disability to move into residential aged care?
- What are the indicators and what can be done to make the move as less stressful for all concerned. How can the various parties be best prepared?
- What needs to be put in place well before any move occurs or in fact prior to it even being on the near horizon?

The new study will help to identify the challenges faced by people with intellectual disabilities and their families (their caregivers and the service system) as they age and begin to experience medical problems related to ageing. Hopefully this will lead to the development of more effective systems and services for people who are ageing with an intellectual disability.

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