

ORIGINAL RESEARCH

Accommodation needs for carers of and adults with intellectual disability in regional Australia: their hopes for and perceptions of the future

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A B S T R A C T

Introduction: This article provides an in-depth investigation of the accommodation circumstances of a population of aging adults with intellectual disability living at home with parents or in supported accommodation in an Australian regional centre. Given the ageing of both the carer and adult population with intellectual disability our research explored the accommodation needs and perceptions of future lifestyle issues from the perspective of both the carers and the adults with intellectual disability. This study aimed to describe these accommodation circumstances related to a regional/rural location and did not make direct comparisons with urban/metropolitan situations.

Methods: A mixed methods approach, specifically an explanatory design, participant selection model was utilised for the overall study. This article reports on the qualitative study consisting of data from both free response open-ended survey questions and



semi-structured interviews with selected adults with intellectual disability and their carers. This study explored and described participants' experiences and perceptions regarding their accommodation needs and future lifestyle issues. A purposive sampling technique was used to identify a representative sample of participants for interviews. The interview questions were guided by the results of the quantitative first study phase. Data were analysed by content analysis for major themes emerging from the interview and free response survey data.

Results: A total of 146 carers (mean age 61.5 years; range 40–91 years) and 156 adults with intellectual disability (mean age 37.2 years; range 18–79 years) participated in the study. Data saturation was reached after 10 interviews were undertaken with carers (mean age 60 years) and 10 with adults with intellectual disability (no age criteria applied). Six major themes were identified: ageing, family issues, living at home, living away from home, government support and funding, and future needs. The perceptions and views of both adults with intellectual disability and their carers around these major themes are reported and discussed.

Conclusions: This study indicates that there is a lack of suitable, available, supported accommodation for people aged 18 years and older with intellectual disability in this Australian regional centre. Consequently, aging parents caring at home have little choice but to continue in their caring role. For those caring away from home, existing services are decreasingly seen as fitting the ideal life they want for the person with intellectual disability for whom they care. The told experiences, perceptions and views of older carers of and adults with intellectual disability have highlighted their increasing vulnerability to the 'disability system'. The findings suggest that government and disability services must acknowledge the changing needs of people with intellectual disability in connection with their advancing age and the urgency of increasing care needs due to the advancing age of their carer/s. The overwhelming feeling is that the carer's voice will only be heard when the situation reaches crisis point. For many carers and their families this has already occurred.

Key words: adults with intellectual disability, ageing carers, qualitative research, regional Australia.

Introduction

This study provides an in-depth exploration of the accommodation situation for a population of aging adults with intellectual disability living at home with parents or in supported accommodation in a regional area of Australia. Given the advancing age of both the adult population with intellectual disability and their carers, the research questions explored their accommodation needs and perceptions of future lifestyle issues from both the carers' and the adults with intellectual disability' perspectives.

In general, the former norm of accommodating people with intellectual disability in large institutions is shifting to accommodation into dispersed homes within the

community^{1,2}. However, coincident with this decline in institutional housing is a decline in the availability of suitable accommodation for people with intellectual disability over the age of 18 years. Consequently, when few if any options are available, and in an environment of increasing demand, solutions to individual needs are usually directed towards crisis provision, that is after the parent carer falls ill or dies.

Added to the immediate challenge of coping with an ageing population of carers is the fact that people with intellectual disability, who in the past would not have reached full life expectancy, are increasingly expected to outlive their parents³. Furthermore, ageing adults with intellectual disability have their own unique range of health issues⁴. This concept of ageing people with intellectual disability with



associated health and care issues is a relatively new development in the field of disabilities. It presents the increasing possibility that parent carers will themselves require support as they age, and will eventually need assistance with planning for the eventual transition of care for their adult child.

There is also the matter of providing appropriate care to enable comfortable ageing for the person with intellectual disability⁴. For many carers, the desire is for this care to meet the standard of care they have provided over the past decades⁵. Research has shown that carers of people with intellectual disability receive a great deal of satisfaction from their caring role and report that they have meaningful relationships with their adult son or daughter. Many parents (in particular mothers) report that they would like their child to remain in family care as long as possible⁶. Older carers report that as they get older the physically demanding nature of the role^{5,6} and the effect it can have on family relationships causes a substantial level of stress⁷. Older carers also report feeling helpless, and that they lack a sense of purpose and of personal growth⁸. For older mothers in particular, the caring experience becomes less positive as time passes⁶.

In 2003 there were 2.5 million people (13%) identified as informal carers in Australia, most of whom are female and at least 65 years of age⁹.

The aim of this project was to explore perceptions and opinions on the current accommodation situation and future needs in two groups of carers and the persons with intellectual disability for whom they care, that is those who *live and are cared for in the family home* and those who *live and are cared for away from the family home*. The study is descriptive of these accommodation circumstances related to a regional centre and surrounding rural towns, direct comparisons were not made with urban/metropolitan areas.

This study defined carers as 'those people who provide informal unpaid care for someone with a disability'. The focus of this study was to better understand the current

accommodation situation and future needs of adults with intellectual disability from a sample representative of regional Australia. This was achieved through a qualitative investigation using face-to-face interviews with adults with intellectual disability and their carers, and written comments provided by those carers in response to open-ended survey questions.

Method

Procedure

The overall research design utilised a mixed methods approach, specifically an explanatory design, participant selection model. The two phases of data gathering began with Phase One which consisted of quantitative methods in the form of a questionnaire to assess the demographics, current and future accommodation issues and needs of the sample population. These data are summarised (Table 1) and reported in detail elsewhere¹⁰. The questionnaire also utilised open-ended, free response questions that elicited a large volume of qualitative data from the carers.

This article reports primarily on Phase Two, a qualitative study consisting of semi-structured interviews with selected carers and adults with intellectual disability who had participated in Phase One. Additionally, the qualitative free response data from the Phase One questionnaire were analysed with the data from Phase Two. The interview questions were guided by the preliminary results from Phase One data.

Participant recruitment

Participants were recruited over a 3 month period in 2005. A purposive sampling technique¹¹ identified a representative cross-section of Phase One participants for the interviews.



Table 1: Demographics of carers and persons with intellectual disability they care for

Demographic characteristic	Living place of person cared for	
	At home	Away from home
Primary carer (n = 146)†¶		
Number (total)	80	57
Female n (%)	63 (79)	51 (89)
Age§ (years) n (%)		
Mean	61	62
40-50	13 (16)	8 (14)
51-60	32 (40)	18 (32)
61-70	20 (25)	20 (35)
71-80	12 (15)	9 (16)
≥ 81 - oldest carers	3 (4)	2 (3)
Intellectual disabled (n = 156)		
Number n (%)	86 (56)	70 (44)
Gender n (%)		
Male	52 (55)	41 (44)
Female	34 (54)	29 (46)
Age§ (years) n (%)		
Mean	37.8	39.8
18-30	39 (45.5)	14 (20)
31-40	14 (16.5)	24 (34.5)
41-50	25 (29)	21 (21)
51-60	7 (8)	9 (13)
≥ 60	1 (1)	2 (3.5)
Support‡ required		
Overall level	Medium	Medium
Very high	3 (4)	4 (5)
High	22 (27)	19 (25)
Medium	35 (44)	35 (46)
Low	18 (25)	18 (24)
Type		
Communication	Medium - High	Medium - High
Mobility	Low - Medium	Low - Medium
Self-care	Medium - High	Medium - High
Day activities	75 (49)	77 (51)

†6 Carers supported more than one person with an intellectual disability; ¶number denotes 'n' for each item, number in parenthesis denotes percentage in each column; §4 carers did not report their age; ‡3 core activities denoting degree of care are identified as per the Australian Bureau of Statistics (2003) [9].

Carer interviews: It was initially envisaged that 10 in-depth interviews would provide a rich description of the participants' perceptions, and it was decided that this number would be increased if data saturation was not obtained. In an effort to obtain a representative sample, interviews were conducted with carers, half of whom cared for people with intellectual disability in their home and half cared for those who lived away from home. Both groups had a mean age of 60 years. Interviews with carers ranged from 20 to 70 min. Example interview questions to carers are:

- 'Can you describe the type of accommodation that you would like for your child?'
- 'How will you know when you are no longer able to care?'

Examples of open-ended survey questions are:

- 'Do you foresee a change in your child's accommodation needs in the future'? (multiple response options) followed by:



- 'Would you like to tell us more about your reasons for this choice'?

Adults with intellectual disability interviews: Similarly interviews were undertaken with adults with intellectual disability after permission from their primary carer and agreement by each individual. The specific nature of the intellectual disability was not a criterion of interest and all participants were able to live at home or in supported accommodation in the community. As with the carers, 10 interviews were initially planned with the option of increasing this if data saturation was not obtained. Half were conducted with those who lived at home and half with those who lived away from home. No age criteria were applied. All interviews were conducted in their homes or place of residence by a trained project officer, audio-taped and transcribed verbatim. These interviews were simplified and of shorter duration compared with carer interviews. Example interview questions for the adults with intellectual disability are:

- 'Do some of your friends live away from their mums and dads?'
- 'What kind of things do you do around the house?'

Analysis

Qualitative data from the semi-structured interviews and the survey free response comments were transcribed verbatim and analysed using the five-stage framework described by Pope¹². This process entails: (i) familiarization – immersion with the raw data; (ii) identification of a thematic framework; (iii) indexing – coding of this framework; (iv) charting and organization of the codes into themes and; (v) mapping and analysis of themes. All data were coded and checked independently by two researchers and thematically categorised. Inter-coder reliability was checked by two coding sessions to ensure consensus of themes and integrity of coding. Interpretation of our analysis follows an explanatory design with emphasis on the qualitative data collected in this second phase of the study, combined with the qualitative data from the Phase One survey.

Ethics approval

Ethics approval (H04REA416) was obtained from the Human Research and Ethics Committee of the University of Southern Queensland.

Results

Demographics

The full results of Phase One and details describing the sample population are reported in detail elsewhere^{10,13}. A summary of these is provided (Table 1).

Primary carers

A total of 146 carers ($n = 146$) consented to participate in the study (mean age 61.5 years; range 40–91). Females comprised 78% of the total sample. There was no statistical difference in the average age between our sample of carers who cared for an adult with intellectual disability at home (mean 61 years; range 40–91) and those who cared away from home (mean 62 years; range 40–81).

Adults with intellectual disability

The prevalence rate of adults with intellectual disability in this regional area of Australia was determined to be 0.17%, which is congruent with previously reported incidence¹⁴. The 156 adults with intellectual disability in our sample had a mean age of 37.2 years (range 18–79). The mean age of adults who lived at home (mean 35 years) and those who lived away from home (mean 39.8 years) was not statistically different.

Current accommodation

Our sample was stratified by current accommodation type, that is carers who cared for adults with intellectual disability



either: (i) living at home or; (ii) living away from home. Six types of accommodation were used for this study and are detailed elsewhere^{10,13}. The majority (56%) of the people with intellectual disability lived at home, with the second highest proportion (15%) residing in a medium-sized residential facility (10-12 residents).

Overall support needs

There was no difference between the overall care needs (among all core activities) of the adults with intellectual disability who lived at home and those who lived away from home. The degree of care required was rated by each carer (Table 1).

Day activities

The majority of the sample (61%) accessed a service provider for some form of supported accommodation or day service. A slightly greater proportion (51%) of those living away from home compared with 49% of those living at home regularly accessed this support.

Future accommodation

Carers were asked to predict when, if at all, they might require a change in their current accommodation needs. This was posed as a question with choices: not applicable; within one year's time; within 2 to 5 years; in 5 to 10 years; and over 10 years. Overall, 70% of all carers foresaw a need for some other form of accommodation within the next 10 years. This was further broken down by age of carer where the majority (76%) over 61 years, and 57% under 60 years, predicted a need for change within 10 years. In contrast, only 21% of younger carers (under 60 years) predicted that no change will ever be needed to meet the accommodation needs of the person with intellectual disability.

Interview results

The major themes and sub-themes that emerged from the analysis of the qualitative data were unexpectedly similar in

carers and persons with intellectual disability who care and/or live at home and those who care and/or live away from home. This highlights the overall severity of the accommodation situation for older adults with intellectual disability and the parents who care for them. It further suggests that carers of adults with intellectual disability face similar challenges regardless of their accommodation situation. With this in mind, the qualitative data were analysed and is discussed as a whole with no direct comparison between 'living at home' or 'living away from home'. However, as is shown in Table 2, certain major themes were exclusive to the accommodation circumstance. Table 2 summarises the qualitative results as major themes, first order sub-themes and representative quotes from participants with intellectual disability and their carers. Table 2 represents the themes taken from all the qualitative data, that is Phase One free response survey comments and Phase Two semi-structured interviews. The representative quotes are taken only from the interview transcripts. It is pertinent to note the large volume of written commentary elicited by the open-ended survey questions. Written comments were provided on 96% of the returned surveys with several participants writing 2-3 handwritten pages relating to the questions/issues contained in the survey.

Results and Discussion

Major theme – ageing

The ageing carer: Advancing age was reported by 81% of carers as being their major area of increasing concern, and for many it was already a problem. Carers' failing health, in particular, was reported as impacting on the person with intellectual disability. Although several carers expressed the desire to 'care as long as possible', there exists anxiety that time is running out and few options are available for alternative care.



Table 2: Themes emerging from interviews with carers and adults with intellectual disability and carers' free response survey comments

Number [†] (%)	Sub-theme	Representative quotes from carers [§]	Representative quotes from persons with intellectual disability [‡]
Ageing (n = 137)[¶]			
111(81)	Ageing carer	My time is coming. We are not sure that we can continue to support his needs fully as we get older.	My sister said, when you die, Mum, we will take him on.
66 (48)	Concern for the future	When we die there is no one else to look after him. It would be good to know that there will be somewhere she could go when the need arrives.	
20 (29)	Carer health	I'm very happy to look after her as long as I'm capable.	
86 (63)	Age of person with intellectual disability	Our main concern is for when he is too old to stay there. As he gets older he will need to be in accommodation that will cater for his future needs, especially health. As my son gets older he will need more support, not less.	
Family issues (137)			
63 (46)	Importance of contributing to the family Suitability of home	It is by far best for him that he remains living at home with his family. He loves being at home living with his parents. Suitable for the present but not good for later years.	Doing the dishes, washing up and then somebody has to wipe up for me. Yep and sometimes on Wednesday nights, that's today, I help my Dad cook – like cook spaghetti.
27(20)	Family & living away from home Family important	We take him out on regular outings such as family weddings. I have my son home for holidays on a regular basis - as often as I feel I am able to.	Yeah, I do my shopping Thursday – Friday afternoon with my Mum.
45 (33)	Distance - forcing options & variety of care	I had no choice 13 years ago - nothing in Brisbane too many waiting lists since and no options for him during day. I just feel I should keep an eye on what's going on in J's life	Yes, sometimes they (parents) call in. Sometimes to see how things are going.
Living at home (80)			
45 (56)	Positives - security & independence	Why would he want to leave home when he has everything done for him? He has his very own slave.	Well, I know how to handle money, it's just like I don't know how much to give them, like how much paper money sort of thing.
96 (70)	Negatives Personality friction Increasing dependence	He feels we try to control his behaviour and can become quite irrational and upset at reasonable demands. She can be very jealous of her sister and brother, and uses any opportunity to upset them and create unrest. He is getting more attached to being just with us. Not good if we drop dead someday.	
34 (43)	The carer's quality of life	I will never retire in my role as carer. Highly likely (my) husband will not be working in 10 years - it would be nice to have some time together away from the caring role, sometimes it becomes quite depressing.	



Table 2: cont'd

Number [†] (%)	Sub-theme	Representative quotes from carers [§]	Representative quotes from persons with intellectual disability [‡]
Living away from home (57)			
42 (73)	Transition to care Action as a result of a crisis situation	It was a real crisis point where I hoped that I would have been able to look after him but it just come to the stage, where it was either me, my health or. If I'm in a wheelchair I am no good to J. He'd lived at home with my parents caring for him, and then my mother got very ill and knew she was dying, even though she'd had his name down we couldn't get him in for three years.	That was really good actually because I actually got my own bed and my own en suite. That's like my shower and toilet and my basin
12 (21)	Care - positive Care - negative	I have only positive things to say about his present accommodation with (service provider). He is often dirty and his toe nails are unkempt. He needs reasonably constant care and in the last few years although constantly trying, I cannot get more help.	
27 (47)	Positive aspects Negative aspects Relationships with other residents	The residents are generally seen as a 'group' and this presents challenges when one requires more support or attention to do activities. He is very critically lonely; he desperately needs some form of employment. They all get on well together and have grown up together she loves all of her mates she lives with.	We used to practice for fire drill. If there was a real fire we had to go let the girls out before we did. We used to do mopping, vacuuming, washing up, keep our rooms tidy. We put the four fellows washing in with mine – three others. Two would peg it out in the morning and two would bring it in at night. Sometimes to share, I think.
41 (73)	Perceived level of happiness - positive	This accommodation and support saved his life and probably mine.	One day it was raining and I'm going to ten pin bowling. The others bowl with me. K said, where are you going and I said, I'm going to town. He said, I will wait with you 'til you get on that bus and I said, thanks man.
16 (28)	Perceived level of happiness - negative	He doesn't like to see us depart - but we are unable to take care of him.	
Government support and funding (137)			
64 (47)	Lack of support Government cutbacks Lack of commitment Closure of institutions	Governments are not realizing we are going to die. Governments of both persuasions cannot guarantee any future security of care. This is enormously stressful for ageing parents and extended family - where the burden will fall. It worries me that (service provider) may not have the resources to look after my cousin in his old age. His parents died believing (service provider) would care for him for life.	How am I going to get around? Oh, like transport? Oh, yeah. I can't walk all of the way out from [suburb]. I would be tired. Oh, yeah like transport.
33 (45)	Respite services Lack of openings No options	Would like to have him in respite on a regular basis for practice on basic living skills and get used to being with other people. In the past there were no vacancies when I needed help after an operation and there are still no options for us.	I've got a friend - not a boyfriend, but he's a very close friend - and he's got his own home so he would probably take me in. He owns his home. He works hard



Table 2: cont'd

Number [†] (%)	Sub-theme	Representative quotes from carers [§]	Representative quotes from persons with intellectual disability [‡]
22 (16)	Personal financial difficulties Cost of living increasing	The cost of support that L receives from the support worker has increased recently and we would assume that this trend will continue impacting on his disposable income. He is vulnerable to fluctuation in rent due to his fixed income.	
Future needs (137)			
70 (51)	Lack of choice No options Parents do not want to pass on responsibility to siblings	In the past (service provider) undertook to look after them when parents or carers are gone. This is no longer the case. Unless you hit a crisis situation you have no hope in hell of getting any suitable accommodation. He has a brother who is willing to take over the job but he would require support so that he can continue to work.	Preferably (to live) in town because I'm not allowed to drive.
22 (16)	Separation from community - differing views	See when they're with their own kind and that probably sounds cruel...they relate, they relate, and you know I really don't see why they wouldn't relate together in a village situation. I have always, always felt very strongly that B is a member of the community and that's where he needs to live. That's where he gets his modelling, that's where he gets his real learning experiences. He loves – like he gets to know all sorts of people.	I want to make sure that I like the people I live with and I get on with them.
113 (83)	Ideal/ preferred accommodation: mixing males and females small residential Security/support	Sort of a place to herself with her own private space that she could do with what she liked. He will talk to anybody whether it be male or female, young girls get put off by that, whereas M doesn't understand the boundaries there and I don't want anything to happen. Sharing accommodation with up to 3 other similarly disabled people would be ideal and most closely resembles family life. My sister needs continual support and this can be given in a small group setting. Not in a large residential, not enough care.	Ten would be too many to cook for 10. Two or three, if they are my sort of people. You just never know what could happen. Some guy might just come along that you just don't feel comfortable with.

Concern for the future: The crux of their concern for the future was the 'feeling of uncertainty' that the person they cared for would have somewhere suitable to live when they could no longer provide care. Obviously it would be preferable if this care could be organised before a crisis arose, such as their illness or death. For those who cared away from home, the increasing care needs and the ability of current services to cope with these needs was questioned. In general it was hoped that they would be able to continue care at their present facility, therefore eliminating the need for disruption to the life of the person with intellectual disability, but this too was uncertain.

Advancing age of person with intellectual disability: With an average age of 37.2 years, the physical deterioration of the person with intellectual disability was an important issue for the majority (63%) of carers.

Major theme - family issues

Family and home: A family environment for the person with intellectual disability was important to most carers to provide safety and security, as well for social interaction with immediate and extended family members. Another important aspect was that it provided the person with



intellectual disability an opportunity to contribute to the family and family lifestyle. The importance of family and home was apparent even to carers who did not live with the person they cared for. A variety of care was extended by these carers, ranging from weekends to extended periods of time at home as well as regularly throughout the year.

Suitability of living at home: There was wide recognition that as time progresses living at home will no longer be suitable for these ageing families. Concern was expressed by carers about the person with intellectual disability residing with people other than family. For some, living at home was the only experience they have ever had and this was a source of anxiety should the present situation deteriorate.

Distance: While having regular contact appears to be an ideal situation, this was not always possible for carers who lived too far away. Distance associated with rural/regional living has often forced decisions regarding accommodation arrangements, including the family moving to be closer to the person for whom they care.

Carer involvement: Carer involvement for those who cared away from home was variable but regular contact was described by most carers. This involvement was primarily focused on monitoring their health and any problems or concerns they might encounter while living in a residential facility.

Major theme - living at home

Positives of living at home: Over half the carers who cared at home commented on a variety of issues related to that experience. Most carers remarked on the positive aspects of this arrangement that met the needs of the person with intellectual disability, such as meals, medical care, security, behaviour monitoring, and financial assistance.

Negatives of living at home: Communication issues and friction with siblings were the prominent negative aspects of caring at home.

Dependence on carers: Many carers commented that living at home was contributing to an increasing over-dependence on them, and felt this may be detrimental in the long term.

Carers' quality of life: An acknowledged result of their constant caring role was a coincidental loss in quality of life for the carer. With many carers facing upcoming retirement, this continual caring role will mean idyllic retirement may never occur. Many recognized that only ill health or death would cease their caring role.

Major theme - living away from home

Over half (73%) of carers commented on at least one aspect of the experience of caring for a person with intellectual disability who lives away from home.

Transition to care: Often the transition from living at home to living away from home was the result of a crisis within the family. As mentioned, this is most often due to failing health or the death of the primary carer (parent). Although it was recognised that any transition to residential care should be planned, the lack of available alternative accommodation makes this impossible.

Level of care provided: The level of care provided within residential facilities was important to the majority of carers. Positive comments reflected a safe and secure facility with good management and competent staff. Negative reports highlighted inadequate care due to low staffing levels, inadequate staff training or lack of attention to the deteriorating health and increasing needs of the person with intellectual disability.

Positive impact on person with intellectual disability: Life in a residential facility can have a positive effect on the person with intellectual disability. This was seen as including the provision of a normal environment in which residents participated in daily living skills, such as meal preparation and washing their own clothes.



Community access: The social aspect of living in a residential facility attracted both positive and negative comments from carers and persons with intellectual disability. Positive aspects reflected the opportunities to interact with the wider community, such as attending local events and activities. Smaller group activities or more one-on-one assistance was seen as desirable.

Relationships with other residents: Socializing with other residents was generally described as a positive experience and reflected the level of happiness perceived by their carer.

Level of happiness: The level of happiness with current accommodation was mixed. For some, the experience had been life-changing and was of benefit to both parties. However, other carers expressed uncertainty about the level of happiness of the person with intellectual disability as this was unable to be expressed fully.

Major theme - government support and funding

Lack of support: Several issues were raised by carers with regard to government attitudes about and funding for older persons with intellectual disabilities. Some of the issues included long waiting lists, closures of local institutions, lack of funding packages, overlooking those persons with milder disabilities, and general fears for the future as a result of lack of commitment.

Issues with respite: Lack of respite accommodation services in the local area was an issue high on carers' agenda. Respite was identified as allowing the person with intellectual disability to experience life away from home. It was also seen as enabling the carer to have a break from their caring role. One-third of carers said there were no respite options and that they either went without or accessed support from other community members when possible.

Personal financial difficulties: Several issues relating to the increase in living expenses and the fixed income of adults with intellectual disability were expressed. In particular this

was apparent in a noticeable decline in their standard of living.

Major theme - future accommodation

Lack of Choice: A lack of available, suitable supported accommodation in the region of the study was reported by half the participants.

Options: Accommodation options were explored by many carers. These included listing with public housing, building or buying a granny flat/unit, or hoping that the person with intellectual disability would be taken in by another family member. Sibling support when the primary carer had died or could no longer care was an option for few families.

Separation from community: There were differences of opinion about the advantages of living in the community or among others without intellectual disability. Some felt that community interaction was beneficial intellectual stimulation and social modelling, while others maintained that persons with intellectual disability are better on their own – but together as a group.

Ideal accommodation: Living with a small group of people in a small residential facility while being supported by care workers appeared to be the most appropriate and desirable arrangement to the majority of participants. This is congruent with the literature which reports that a home-like environment is desired where there is security and interaction with other family members or house-mates¹. The advantages of smaller residential facilities were reported as safety, the formation of friendships and more one-on-one support, which is seen to encourage independence and provide a more normal or family-like living environment. This can be achieved in a small residential or self-contained environment either in the community or with a village atmosphere.

Home-like: Living in a 'home-like' environment in their own personal space was considered very important to both carers and people with intellectual disability.



Security: The physical security of the person with intellectual disability was seen as paramount, and many carers were concerned about issues like disrespect or exploitation. Further concern was raised by some carers regarding the choice of co-tenants and the need for screening them to ensure safety.

Working towards independence: There was considerable anxiety among carers regarding the need to start preparations for a change in accommodation arrangements sooner rather than later, in order to avoid inevitable trauma if something unexpected was to occur. However, the dearth of options indicated to carers that there was little opportunity to help the person they cared for work towards increased independence.

Ageing in place: Nursing home care was seen by most carers as an inappropriate option and many expressed the desire for specific accommodation to support people with intellectual disability as they age.

Limitations

The limitations of this study include a small sample size that is from one region in one Australian state. The issue of sample size was further complicated by the difficulties in identifying the target population, as discussed. Also of interest would be a comparison of urban/metropolitan with regional/rural accommodation circumstances, particularly in the light of the difficulties encountered in the service coordination of resources in this regional/rural area.

Conclusions

The full report of this study^{10,13} indicates that our findings relate to issues that are congruent with previous work¹⁴. This article, through the experiences, perceptions and views of adults with intellectual disability and their older carers, has highlighted the increasing vulnerability of this population to the 'disability system' in regional Australia. The changing needs of people with intellectual disability in relation to their

advancing age, and the urgency of increasing care due to the advancing age of their carer, require greater attention. As was demonstrated by our data collection procedures in Phase One^{10,13}, there is an urgent need for a more efficient coordination of services within regional communities.

The outward ideal environment for an adult with intellectual disability living at home with parent carers comes at a great cost to the carers. While the carers of those living away from home in various communities' residential facilities experience added burdens and uncertainties about the future. Current accommodation services are not only outdated, but also filled to capacity with few, if any, options for the future. Furthermore, utilising nursing homes to meet the care needs of ageing people with intellectual disability is not appropriate. Aged care facilities that understand and can cope with the specific needs of people with intellectual disability are urgently required.

Our study noted a feeling of a 'double standards' that places persons with mild/moderate disabilities at a disadvantage in obtaining support and funding. This older generation of people with intellectual disability are further disadvantaged by their age, because most have missed out on special education programs and support packages that have only become available in recent years.

Ageing parents caring at home and away from home have little choice but to continue in their caring role, with few options to increase the level of care at a time of increasing age and care needs. The overwhelming feeling is that the carer's voice will only be heard when the situation reaches crisis point. For many carers and their families this has already occurred.

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