An Analysis of Accommodation Needs of Adults with an Intellectual Disability in Toowoomba and Surrounding Areas

Dr Diann Eley
Professor Desley Hegney
Mrs Joanne Boyes

This project was proudly funded by the Queensland Government's Gambling Community Benefit Fund.

The research team would like to thank those who contributed their time and support to this project including those on the Project Reference Group.
Eley, Diann
An analysis of accommodation needs of adults with an intellectual disability in Toowoomba and surrounding areas.

ISBN 0 909756 87 2


362.1968

Published by the Centre for Rural and Remote Area Health, University of Southern Queensland, Toowoomba, Queensland, Australia.
TABLE OF CONTENTS

EXECUTIVE SUMMARY .....................................................................................................viii

1.0 INTRODUCTION AND LITERATURE REVIEW ...............................................................1

1.1 Background to the study .............................................................................................1

1.2 Review of the literature .............................................................................................2

1.2.1 The prevalence of intellectual disability in Australia ..........................................3

1.2.2 Commonwealth State/Territory Disability Agreement ..............................................4

1.2.3 Ageing ...................................................................................................................4

1.2.3.1 Statistics on ageing carers .............................................................................4

1.2.3.2 Statistics on people with intellectual disabilities .............................................4

1.2.3.3 Statistics on decreased carer rates and increased disability rates .....................4

1.2.3.4 Current situation of ageing and accommodation for carers of and people with intellectual disability .................................................................4

1.2.4 The caring role .......................................................................................................5

1.2.4.1 Overview .........................................................................................................5

1.2.4.2 Experiences with services for the intellectually disabled .....................................5

1.2.5 The transition to care from home to life in supported accommodation ....................5

1.2.5.1 The experience of the carer ............................................................................5

1.2.5.2 The experience of the person with intellectual disability .....................................6

1.2.6 Alternatives for care .............................................................................................6

1.2.6.1 Sibling carers ..................................................................................................6

1.2.6.2 Aged care facilities .........................................................................................7

1.2.7 Disability specific accommodation .......................................................................7

1.2.7.1 The meaning of ‘home’ ....................................................................................7

1.2.7.2 Residence size ...............................................................................................8

1.2.7.3 Level of intellectual disability ........................................................................8

1.2.7.4 Staffing ...........................................................................................................8

1.2.7.5 Friends ...........................................................................................................9

1.2.8 Models of accommodation types .........................................................................9

1.2.8.1 Overview .........................................................................................................9

1.2.8.2 Campus, cluster and dispersed housing models ..............................................9

1.2.8.3 Cost ...............................................................................................................9

1.2.9 Summary of the literature ....................................................................................10
2.0 METHOD .........................................................................................................................11

2.1 Project funding ..............................................................................................................11

2.2 Project management .....................................................................................................11

2.3 Role of the reference group ........................................................................................11

2.4 Role of TIDSA .............................................................................................................11

2.5 Participants ..................................................................................................................12

2.6 Materials ......................................................................................................................12

2.7 Procedure .....................................................................................................................13

2.7.1 Criteria for interview selection .............................................................................13

2.7.1.1 Carers ...........................................................................................................13

2.7.1.2 Persons with intellectual disability ................................................................13

2.7.2 Ethical considerations ..........................................................................................14

2.8 Data analysis ..............................................................................................................14

2.8.1 Quantitative data .................................................................................................14

2.8.2 Qualitative data ....................................................................................................14

3.0 RESULTS ........................................................................................................................15

3.1 Quantitative data from the Phase One questionnaire ................................................15

3.1.1 Response rate .....................................................................................................15

3.1.2 Demographic data ...............................................................................................16

3.1.2.1 Geographical area ........................................................................................16

3.1.2.2 Age of primary carers ...................................................................................18

3.1.2.3 Secondary carer ...........................................................................................20

3.1.2.4 Age range of people with intellectual disability .............................................21

3.1.2.5 Overall support needs ..................................................................................23

3.1.2.6 Degree of care required ................................................................................24

3.1.2.7 Day activities of people with intellectual disability ........................................25

3.1.2.8 Current accommodation ..............................................................................26

3.1.2.9 Suitability of and satisfaction with current accommodation .......................26

3.1.2.10 Carers’ perception of person with intellectual disability’s happiness with current accommodation .................................................................28

3.1.2.11 Future accommodation ...............................................................................28

3.2 Qualitative data of carers who care for a person with intellectual disability living at home ..................................................................................................................................................................................................................32

3.2.1 Ageing ..................................................................................................................33

3.2.1.1 The ageing carer ..........................................................................................33

3.2.1.2 Advancing age of person with intellectual disability ...................................34
3.3.3.4 Community access .................................................................50
3.3.3.5 Relationship with other residents...........................................51
3.3.3.6 Happiness ..............................................................................51
3.3.4 Government support and funding ............................................51
  3.3.4.1 Lack of support ......................................................................51
  3.3.4.2 Personal financial difficulties ..................................................52
3.3.5 Staffing .......................................................................................53
  3.3.5.1 Staffing issues ........................................................................53
  3.3.5.2 Relationship between staff and the people they care for ..........53
  3.3.5.3 Relationship between staff and carers .....................................54
  3.3.5.4 Other factors impacting on staff ability to provide care ..........54
3.3.6 Future accommodation ............................................................54
  3.3.6.1 Preferred accommodation .....................................................54
  3.3.6.2 Co-tenants .............................................................................55
  3.3.6.3 Dedicated aged care homes for intellectually disabled ..........56

4.0 DISCUSSION ..................................................................................57
  4.1 The ageing carer ..........................................................................57
  4.2 Ageing of people with intellectual disability .................................58
  4.3 The importance of family and home .............................................59
  4.4 The experience of living at home ..................................................60
  4.5 The experience of living away from home ....................................60
  4.6 Government support and funding .................................................61
  4.7 Staffing issues for those living away from home .........................63
  4.8 Accommodation needs of the future ............................................64
    4.8.1 Lack of choice ..........................................................................64
    4.8.2 Options ....................................................................................64
    4.8.3 Sibling support ........................................................................64
    4.8.4 Separation from community .....................................................64
    4.8.5 Ideal accommodation ...............................................................65
    4.8.6 Socialisation .............................................................................65
    4.8.7 Staff ........................................................................................65
    4.8.8 Location ..................................................................................65
    4.8.9 Accommodation costs .............................................................65
    4.8.10 Ageing-in-place ........................................................------------66
    4.8.11 Security .................................................................................66
    4.8.12 Working towards independence ..........................................66
LIST OF FIGURES

Figure 1  Geographical area covered in the study .................................................................18
Figure 2  Mean age of carers by accommodation type ($n=143$).................................19
Figure 3  Age range of carers who care for a person with intellectual disability living at home ($n=86$).....................................................................................................................................19
Figure 4  Age range of carers who care for a person with intellectual disability living away from home ($n=57$)...................................................................................................................20
Figure 5  Secondary carers within accommodation type ($n=141$).............................................21
Figure 6  Mean age of people with intellectual disability in each accommodation type ($n=156$)...............................................................................................................................................22
Figure 7  Age range of people with intellectual disability living at home ($n=86$).....................22
Figure 8  Age range of people with intellectual disability living away from home ($n=70$) .......23
Figure 9  Overall support needs of people with intellectual disability ($n=156$).....................23
Figure 10  Day activity of people with intellectual disability ($n=152$)........................................25
Figure 11  Distribution of accommodation type among all participants ($n=156$)..............26
Figure 12  Suitability of current accommodation for person with intellectual disability ($n=150$)...............................................................................................................................................27
Figure 13  Carer satisfaction with current accommodation ($n=147$)..................................27
Figure 14  Carer perceived happiness of person with intellectual disability with current accommodation ($n=150$) ........................................................................................................28
Figure 15  Predicted change in accommodation needs of persons with intellectual disability living at home ($n=71$)..............................................................................................................29
Figure 16  Predicted change in accommodation needs of persons with intellectual disability living away from home ($n=52$)..............................................................................................................29
Figure 17  Preferred accommodation for the future ($n=147$)....................................30
Figure 18  Preferred accommodation type by current accommodation status ($n=147$)........31
Figure 19  Anticipated future involvement in the lives of the person they care for ($n=140$)....31
LIST OF TABLES

Table 1.1 Reported world prevalence of intellectual disability.............................................3
Table 3.1 Endeavour people who chose not to participate ($n=34$)........................................16
Table 3.2 Age and gender of primary carers and people with intellectual disability..........16
Table 3.3 Postcodes covered in the distribution of Phase One questionnaires ...............17
Table 3.4 Breakdown of care needs by core activity..........................................................24
Table 3.5 Definitions of accommodation types used within the study..............................26
EXECUTIVE SUMMARY

Introduction
The objective of this study was to analyse the accommodation needs of people with intellectual disability over the age of 18 years in Toowoomba and contiguous shires. In 2004, a group of carers established Toowoomba Intellectual Disability Support Association (TIDSA) to address the issue of the lack of supported accommodation for people with intellectual disability over the age of 18 and the concerns of ageing carers. The Centre for Rural and Remote Area Health (CRRAH) was engaged by TIDSA to ascertain this need and undertook a research project funded by the Queensland Gambling Community Benefit Fund.

While data specifically relating to people with intellectual disability and their carers are difficult to obtain, the Australian Bureau of Statistics report that carers of people with a disability are more likely to be female and at least 65 years of age. Projections by the National Centre for Social and Economic Modelling (NATSEM) show that disability rates are increasing and carer rates are decreasing. Thus the problem of appropriate support to the increasing number of ageing carers and those who they care for will be a major challenge to policy makers and is an issue of immediate concern.

In general, what was once the norm of accommodating people with intellectual disability in large institutions is now changing to accommodating into community-based residences (Annison, 2000; Young, Ashman, Sigafoos, & Grevell, 2001). However, in Toowoomba and contiguous shires, TIDSA have noted that the availability of suitable accommodation for people with intellectual disability over the age of 18 years is declining with no new options available in an environment of increasing demand. Most effort seemed to be directed towards crisis provision.

Method
This study employed two phases of data gathering, the first being the distribution of a questionnaire through local service providers and upon individual request to the carers of people with intellectual disability over the age of 18. The questionnaire comprised of Likert-type items intended to measure various aspects of current and future accommodation issues. Most questions were followed with space for free-response comments to provide the opportunity for carers to further clarify and expand on their responses. The second phase comprised semi-structured interviews conducted with ten carers and ten people with intellectual disability who had participated in the Phase One questionnaire. Interviews were transcribed verbatim and subjected to content analysis where major themes were explored.

Results

Age and gender
Carer participants in this study totalled 150. The mean age of these carers was 61.5 years and ranged from 40 – 91 years. Females comprised 78% of the sample (mean age = 61.49; range from 40-91) and 22% were male (mean age = 61.7 range from 43-81). The mean age of people with intellectual disability in our study was 37.2 years ranging from 18 – 79 years with 40% female (mean age = 39.5; range from 19-79) and 60% male (mean age = 35.6; range from 18-59).

The average age of carers caring for a person over the age of 18 who is living at home is 61 years. The average age of the carer who cares for a person who is living away from home is 62 years. The overall age range of both these groups of carers is between 40 and 81 years. The oldest group of carers (mean age = 70 years) were those where the person with intellectual disability lives away from home in a large residential facility. Almost one quarter of people with an intellectual disability who currently live at home is cared for by one primary carer and this is almost exclusively a parent.
Current accommodation
Eighty-six persons with intellectual disability (55%) live at home and the remaining 70 live away from home in a residential facility, a group house or some other form of accommodation. Seventy-seven percent of all carers reported that they were satisfied with their current accommodation arrangement however 64% reported that they see a need for change in accommodation for the person with intellectual disability within the next 10 years. This figure rises to 70% for those who currently live at home. In addition, preferences for future accommodation were evenly distributed between a small residential, house or unit and village style accommodation.

Qualitative data
These data were separated and analysed according to the current accommodation situation of the person with intellectual disability. Thus two sets of experiences were analysed, those of the carers who care for someone at home and those of the carers who care for someone who lives away from home. Both groups expressed concern about, a) their advancing age and the ageing of the people with intellectual disability for whom they care, b) the importance of family in the life of people with intellectual disability and c) lack of government support in accommodation needs and d) future accommodation.

In addition, the separate groups offered information specific to their current and past experiences. For example, those who care for people with intellectual disability at home expressed concerns regarding the strain this places on themselves and other family members and how the lack of respite options affects the caring role which is now compounded by their age. Alternatively, those carers who care for people with intellectual disability who live away from home expressed how this has impacted on the quality of life for the person with intellectual disability. These carers were able to offer some insight into systemic issues such as residential accommodation, in particular staff and management.

Major findings and study recommendations
The findings of this study have highlighted in particular the plight of the ageing carer. The anxiety and fear they have for themselves in their ability to carry out their role as a carer and for the person they care for who resides in a community that offers them little or no support for their future needs. The following summary points are considered most salient and are offered as recommendations that elucidate the results of this needs analysis.

1. Database of carers and people with intellectual disability
Due to a lack of streamlining among Toowoomba services and uncertainty of the prevalence of intellectual disability within the Australian community, an accurate figure of people with intellectual disability residing in Toowoomba and contiguous shires is unavailable. This finding was unexpected but of great significance because it exposes a major weakness in the system which provides services to carers of people with intellectual disability. The implications of this weakness have presented as a major limitation of our study.

No universal database or record exists that all service providers can tap into that would help ensure that carers and persons with intellectual disability are identified and do not ‘fall through the gaps’. This study would make a strong recommendation to government agencies to update and reform their current records system so that everyone ‘out there’ who is entitled to assistance with the person they care for is aware of their rights and their entitlement. This is of particular importance to older carers and those who reside in rural areas who are less likely to be mobile and in touch with available services.

- There needs to be more efficient coordination of services within the community.
2. Immediate attention is needed to address the accommodation situation for older carers who care for people with intellectual disability.

The advancing age of both carers and those people with intellectual disability for whom they care is associated with problems such as declining health, mobility, self esteem and independence that escalate on a daily basis. The urgent nature of this issue cannot be understated. Action must be taken immediately to find ways of providing options and opportunities for carers and service providers to cope with individual accommodation needs before these older carers are no longer able to provide care. The ramifications of this scenario will most likely result in the burden of care for these people with intellectual disability placed on the community. At present this level of care in the community does not exist.

- Carers of people with intellectual disability over the age of 18 who live at home are almost exclusively an ageing parent. The mean age of parent carers in this study was 62 years.
- Regular respite should be more easily available for older carers who care exclusively for their person with intellectual disability.
- Disability services need to provide assistance to older carers to allow them to plan for the future. This forward planning would alleviate anxiety and disruption to care should the carer fall ill or die.
- Government and disability services are not recognising the changing needs of people with intellectual disability in connection with their advancing age.
- Government and disability services are not recognising the urgency of increasing care needs due to advancing age of the carer.
- As the person with intellectual disability ages, services should provide close monitoring for increased physical support needs (e.g., hand rails, ramps, wheelchairs, hoists, installation of shower recesses) and ensure these are provided.

3. There is a dearth of choice and options for accommodation in Toowoomba and contiguous shires for people with intellectual disability over 18 years.

This needs analysis has shown that there is a great degree of variation in the accommodation needs of intellectually disabled people. We have shown that no one style of accommodation suits all people with intellectual disability. Therefore, a range of accommodation options to better suit as many people as possible needs full exploration. This must be done in consultation with carers, people with intellectual disability and service providers to ensure that flexibility and appropriateness of accommodation is maintained. Furthermore there are persons with intellectual disability who have fallen through the ‘net’ and are housed in inappropriate accommodation. This is primarily due to inadequate assessment of their care needs and compounded by the dearth of available accommodation.

4. The person with intellectual disability who lives at home in a family environment is an ideal situation but this comes at great cost to the carer.

When a person with intellectual disability resides at home, their needs such as meals, medical, security, behaviour monitoring, and financial assistance can all be provided by the carer - who is almost exclusively an ageing parent. However, this idyllic scenario comes with a cost. This study found that carers who care for someone full time equate this to an end of a ‘normal life’. While retirement from the workforce is looming, retirement from the caring role is never ending. Therefore, life for many carers will not change in the foreseeable future.

- Many in-home carers want to continue care as long as possible but if they choose to care at home, there should be more services to support them.
- The lack of respite opportunities needs to be addressed.
- Services should be available to encourage more activities away from primary carers and the home environment. This would increase the independence and social skills of
people with intellectual disability enabling them to make the transition to living away from home more successfully at some stage in the future.

- There should be provision of support for sibling carers who take their brother or sister into their home for care. Siblings need to be recognised as primary carers with any benefits or support transferred to them to help enable them to continue their own lives (e.g., work, family).
- Access to carer support through Centrelink should be explored to facilitate transfer from one carer to the next when the parents can no longer care or die.

5. The person with intellectual disability living away from home in various community residential facilities comes with added burdens and uncertainties for the future.

What every carer wants for their person with intellectual disability is safe and secure accommodation that allows appropriate individual support. However, current accommodation services are not only outdated but filled to capacity. Physical safety as well as security of tenancy is paramount for people with intellectual disability. This is not only their right but safe and secure accommodation instils confidence in both carers and people with intellectual disability and is conducive to a feeling of permanency.

For those people with intellectual disability who have settled in disability accommodation services, the care provided was generally reported of a high quality. Furthermore, carers feel that these people are well looked after, safe and secure. However, for a person with intellectual disability accommodated outside of the specific disability services, such as residential aged care, the type and quality of care is very different. Respondents in our study reported that these facilities do not cope adequately to the ageing care needs of the person with intellectual disability. Utilising nursing homes to meet the care needs of ageing people with intellectual disability is not appropriate. Care facilities that understand and can cope with the needs of people with intellectual disability are urgently required.

Although in general the care at residential care facilities was considered good, it was widely reported that staff required training at a higher level to understand and provide for the needs of residents with intellectual disability. Attention to individual's needs are vital to ensure that persons with intellectual disability reach their full potential, are allowed to contribute to and interact in the community if able and achieve the highest possible quality of life.

6. Staffing issues at care facilities

Ongoing support at residential facilities is the most expensive part of accommodation services. Recruitment, training and remuneration of appropriate staff should be revisited by government services and restructured in order to meet the increasing needs of the older person with intellectual disability. Appropriately trained staff should be recruited and employed who will help ensure that the individual needs of people with intellectual disability are met in order for them to achieve their full potential. This is their right and imperative to maintain quality of life.

- There was an overall perception that staffing levels need to be increased at most care facilities. Provision of ongoing support with proper supervision by adequately trained support staff is vital to safe and secure accommodation for persons with intellectual disability.
- There was an overriding concern regarding the quality of staff at most care facilities and this relates to the provision of adequate funding for recruitment, training and remuneration of staff.
- Provision of overnight care was seen as essential.
- At most facilities there was a high staff turnover. This is of concern and should be investigated.
• Communication between carers and support workers needs to be improved. An open door policy will assist with the provision of appropriate care and reduce the stress on carers.
• More attention is needed to provide options that suit the ‘individual’ as all needs are different.
• The individual needs of people with intellectual disability should be considered. Some people with intellectual disability only require assistance with meals, while others require 24 hour care. These differences should be accommodated by services.
• It would appear that services are not keeping pace with the increasing care needs of the people with intellectual disability and their carers. Progress in this area also needs to be monitored.

7. Equity of support and services with all levels of intellectual disability and other disability groups.

Our study found there is an overriding feeling of a ‘double standard’ that places persons with mild/moderate disabilities at a disadvantage for obtaining support and funding. Such a feeling of disadvantage relative to other disability groups and younger persons with intellectual disability was also evident. Governments must recognise that 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 become available in recent years.

Furthermore, people with lower levels of intellectual disability are currently being excluded from some service provision on the grounds that their disability is not ‘severe’ enough. Older persons with intellectual disability not only deserve access to more equitable service delivery but attention to special needs that they previously missed out on should be accommodated (such as literacy and social skills).

8. Government support and funding

A general lack of trust towards government commitment in assisting people with intellectual disability was overwhelmingly expressed by carers in our study. Governments are seen to be withdrawing support from a vulnerable segment of the community. This not only angers carers but also creates fear for their future. They feel that without government support there is no chance of securing a future for the person to whom they provide care.

• The government needs to recognise the urgent nature of this escalating situation because the need for more accommodation options, including overnight respite for ageing in-home carers will only increase.
• The application process for support packages should be streamlined to avoid completing forms year after year. Each applicant should obtain a reply regardless of the outcome.
• There needs to be acknowledgement of the needs of people with milder intellectual disabilities - these are the people most at risk of falling through the cracks in government funding. With proper and appropriate government attention and support, many people with milder forms of intellectual disability could live productively in the community therefore reducing the need for disability specific accommodation.

9. Future needs for carers of and persons with intellectual disability over 18 years.

This study has provided evidence that currently in Toowoomba and contiguous shires there is a worrisome lack of suitable, available, supported accommodation for people, aged 18 years and older, with intellectual disability. Therefore the carers caring at home have no choice but to continue in their caring role. Carers no longer see existing services as fitting the
ideal life that they would want for the person they care for. While the presence of these services at one time provided a glimmer of hope, recent changes to policy and quality standards have altered the situation. The changes to policy and quality standards are welcomed however their impact is to reduce the number of people with intellectual disabilities who can be serviced with the currently available financial resources. The overwhelming feeling is that the carers’ voice will only be heard when the situation reaches crisis point. For many carers and their families this has already occurred.

Summary
The following points summarise the key issues regarding what this study found to be necessary to help fulfil the future accommodation needs for persons with intellectual disability and their carers.

- Support and provision of safe and secure accommodation with easy access to community services and transport.
- Facilities with adequately trained staff with 24 hour support and provision also people who need care but for shorter periods of time.
- There is an urgent need for purpose-built disability systems of accommodation, perhaps similar to that within the aged care sector.
- More in-home support is needed for those that want to stay at home (e.g., hand rails, ramps).
- Respite care must be provided at a level that is readily accessible and affordable for carers.
- Our study described the ideal vision of accommodation to include the following:
  - Village or small residential type accommodation would appear to be the most desired accommodation options, but dispersed housing is also seen as highly desirable.
  - It is imperative that people with intellectual disability have their own room which they can personalise. En-suite rooms are universally seen as highly desirable.
  - The optimum number of residents per house or facility is seen as three or four.
  - The quality of support staff is paramount to a safe, secure and comfortable life. The process of recruitment and training of staff process needs investigation to ensure this.
  - Accommodation needs to be close to community services. If not, transport issues need to be addressed to ensure access to social activities and other necessary services (medical, dental shopping etc).
  - Accommodation costs must be affordable and in line with pension entitlements. This area needs further exploration to ensure appropriate and affordable housing for all levels of need.
  - Promoting independence where possible is a priority, meaning that an appropriate level of care should be provided to meet the individual needs of people with intellectual disability.

- Finally, disability services should communicate more closely with carers to ensure that residential staff understand the individual capabilities of the person with intellectual disability. This will maximise the opportunities for independence as much as possible.
1.0 INTRODUCTION AND LITERATURE REVIEW

1.1 Background to the study
The crux of this needs analysis revolves around the inevitability and circumstances of ageing in relation to the accommodation needs of persons with intellectual disability and equally their older carers.

Toowoomba and contiguous shires are not exempt from the issue of ageing carers and a need for ongoing support for ageing people with intellectual disability. In 2004, a group of carers established Toowoomba Intellectual Disability Support Association (TIDSA) to address this issue. The aim of TIDSA is to establish the accommodation needs of people with intellectual disability in Toowoomba and contiguous shires. The current study is a needs analysis of the current accommodation situation which has arisen from community observations that there is a lack of available and appropriate supported accommodation services in the area. It is anticipated that this knowledge will inform policy makers within government and influence future policy in this area.

For the purposes of this study, the following definitions were used.

a) Carers Services that assisted in this study were not given a strict definition of who ‘carers’ were. An assumption was made that most services follow the definition as laid down by the Australian or state government within their funding guidelines. However, a carer is generally the person who provides informal, unpaid care for the person with intellectual disability (Australian Bureau of Statistics, 2003). When the person with an intellectual disability resides at home, this person is usually clearly identifiable to service providers. Additionally, when the person with an intellectual disability resides in a form of supported accommodation, parents and family members clearly still provide significant support and were included in this study.

b) People with intellectual disability The term ‘intellectual disability’ in respect to the research undertaken for this needs analysis was deliberately not defined in order to allow service providers to target those whom they identified as having an ‘intellectual disability’. Therefore it was up to the discretion of the service providers to target those clients who they identify as intellectually disabled. The only criteria this study imposed were that the person with intellectual disability had to be over the age of 18 years.

c) Service Providers There are several service providers within Toowoomba and contiguous shires that provide services for people with intellectual disability over the age of 18 and their carers. Most of the service providers are located in Toowoomba city and extend their service to contiguous shires and beyond. Some services provide respite and other assistance with daily living skills and care needs to people living in the home (e.g., HHelp, Blue Care). Others provide supported accommodation that includes assistance with daily living skills and care needs (e.g., Horton Village). Endeavour Foundation is a major service provider for this group in Toowoomba and provides accommodation services as well as supported employment services, day services and support through individualised funding packages (D. Johnston, personal communication, February 16, 2006).

Less formal, unfunded services have also been established to provide social activities and support to people with intellectual disability and their carers. Some have been established by community organisations such as churches, others by carers themselves.
1.2 Review of the literature
This section of the report provides an overview of the research and published material available on the issues surrounding intellectual disability as is relevant to this study. It is organised into the following sections which relate to accommodation needs for older carers and older people with intellectual disability.

1.2.1 The prevalence of intellectual disability in Australia

1.2.2 Commonwealth State/Territory Disability Agreement

1.2.3 Ageing
  1.2.3.1 Statistics on ageing carers
  1.2.3.2 Statistics on people with intellectual disabilities
  1.2.3.3 Statistics on decreased carer rates and increased disability rates
  1.2.3.4 Current situation of ageing and accommodation for carers of and people with intellectual disability

1.2.4 The caring role
  1.2.4.1 Overview
  1.2.4.2 Experiences with services for the intellectually disabled

1.2.5 The transition to care from home to life in supported accommodation
  1.2.5.1 The experience of the carer
  1.2.5.2 The experience of the person with intellectual disability

1.2.6 Alternatives for care
  1.2.6.1 Sibling carers
  1.2.6.2 Aged care facilities

1.2.7 Disability specific accommodation
  1.2.7.1 The meaning of home
  1.2.7.2 Residence size
  1.2.7.3 Level of intellectual disability
  1.2.7.4 Staffing
  1.2.7.5 Friends

1.2.8 Models of accommodation types
  1.2.8.1 Overview
  1.2.8.2 Campus, cluster and dispersed housing models
  1.2.8.3 Cost

1.2.9 Summary of literature
1.2.1 The prevalence of intellectual disability in Australia

There are several inconsistencies in reporting intellectual disability within Australia. While the Australian Bureau of Statistics (ABS) classifies intellectual disability according to the International Statistical Classification of Diseases and Related Health Problems, Ninth Revision (ICD-9), state and local organisations classify according to the American Association on Mental Retardation (AAMR). As the AAMR change their classification requirements in response to research outcomes, the reported prevalence rates are also affected. Furthermore, developmental and intellectual disabilities are often captured together, making no distinction regarding types of disability or level of severity. This has resulted in confusion and perpetuates the dissemination of misleading and often incorrect information. Table 1.1 illustrates the range of prevalence rates currently cited from international and Australian sources (Australian Institute of Health and Welfare, 2003).

Table 1.1 Reported world prevalence of intellectual disability

<table>
<thead>
<tr>
<th>Estimates of prevalence (%)</th>
<th>Regions</th>
<th>Data sources and methods</th>
<th>Definitions</th>
</tr>
</thead>
<tbody>
<tr>
<td>0.3-0.4</td>
<td>World</td>
<td>Agency records</td>
<td>Adapted definitions of AAMR/ICD-9 etc.</td>
</tr>
<tr>
<td>0.4-0.5</td>
<td>Australian states</td>
<td>Agency records</td>
<td>Adapted definitions of AAMR</td>
</tr>
<tr>
<td>0.42</td>
<td>Australia</td>
<td>1989-90 ABS national health survey (excluded people in institutions) Mental retardation/specific delays in development as a long-term condition</td>
<td>Adapted ICD-9 classifications</td>
</tr>
<tr>
<td>0.65</td>
<td>Australia</td>
<td>1993 ABS disability survey, 'intellectual' as a primary disabling condition, identified before age 18</td>
<td>Adapted ICIDH concepts and ICD-9 classifications, AIHW groupings</td>
</tr>
<tr>
<td>0.73</td>
<td>Australia</td>
<td>1993 ABS disability survey, 'intellectual' as a primary disabling condition</td>
<td>Adapted ICIDH concepts and ICD-9 classifications, AIHW groupings</td>
</tr>
<tr>
<td>1-1.5</td>
<td>World</td>
<td>Epidemiological studies</td>
<td>AAMR/ICD etc.</td>
</tr>
<tr>
<td>1.7</td>
<td>Australia</td>
<td>1993 ABS disability survey, based on screening question of 'slow at learning or understanding'</td>
<td>All people reporting positively to the screening question of 'slow at learning or understanding'</td>
</tr>
<tr>
<td>1.86</td>
<td>Australia</td>
<td>1993 ABS disability survey, 'intellectual disability' including all relevant disabling conditions and disorders</td>
<td>Adapted ICIDH concepts and ICD-9 classifications, AIHW groupings</td>
</tr>
<tr>
<td>3.0</td>
<td>United States</td>
<td>US President's Task Force and President's Panel on Mental Retardation</td>
<td>This `theoretical prevalence' rate is an extrapolation from statistical models based on IQ scores</td>
</tr>
</tbody>
</table>

(Source: Australian Institute of Health and Welfare, 2003)
1.2.2 Commonwealth State/Territory Disability Agreement

In Australia, disability funding is administered through the Commonwealth State Territory Disability Agreement (CSTDA, 2006). This is an agreement between Australian, state and territory governments that ensures that disability services are provided under a national structure. The current CSTDA covers the years 2002–03 to 2006–07 and maintains that state and territory governments provide 80% of the funding for disability. This funding goes towards services such as accommodation, community access, support and respite. The Australian Government provides the remaining 20% and administers employment services and advocacy, information and print services (Australian National Audit Office, 2005-2006).

1.2.3 Ageing

1.2.3.1 Statistics on ageing carers

In 2003 there were 2.5 million people (13%) identified as informal carers in Australia. There are many definitions of carers but for the purpose of this study, carers are defined as ‘those people who provide informal unpaid care for someone with a disability’ (Australian Bureau of Statistics 2003). One fifth of those carers have identified as caring for someone with a disability. Fifty four percent are women over 65 years of age with 71% identifying as the primary carer. Thus carers of people with a disability were more likely to be female and at least 65 years of age (Australian Bureau of Statistics, 2003).

1.2.3.2 Statistics on people with intellectual disabilities

The rate of reported disability in Australia remained stable between 1998 and 2003. In 2003, 20% of the population in Australia (3.9 million) reported a disability that restricts their daily activities, has lasted at least six months or will last at least 6 months. The types of or extent of disability varies from restriction in at least one of the core activities of self care i.e., mobility or communication (76%), physical disabilities (84%) and mental or behavioural diagnosis.(16%). The majority (82%) of people with a disability up to the age of 59 years are reported to live in a private dwelling with only 0.1% living in supported accommodation and 0.4% in some other form of non-private dwellings (Australian Bureau of Statistics, 2003).

1.2.3.3 Statistics on decreased carer rates and increased disability rates

According to a report from the National Centre for Social and Economic Modelling (NATSEM) (2004) the projected increase in the number of carers between 2001 and 2031 under the age 65 will be 19%, while the increase in carers aged over 65 during this same period will grow by 110%. In comparison, the number of people with severe or profound disability is expected to increase to 1.39 million (an increase of 160%) during the same time period. These statistics are of great concern because the people who are the carers of this population are also getting older. These ageing carers are increasingly more likely to develop disabilities of their own and therefore contribute to the rise in disability rates. Consequently, with rising disability and falling carer rates, ensuring appropriate support will be a major challenge to policy makers and an issue of immediate concern.

1.2.3.4 Current situation of ageing and accommodation for carers of and people with intellectual disability

Added to this immediate challenge of coping with an ageing population of carers is the fact that increasingly people with intellectual disability, who in the past would not have reached full life expectancy, are now expected to outlive their parents (Carey, Cole & Boldy, 2002). Therefore the concept of people with intellectual disability ageing and the health and care issues surrounding this is a relatively new development in the field of disabilities. This brings to the fore two related issues. The first is the possibility that parental support will not endure for the life of the person with intellectual disability. Parents themselves will require support as they age and will need assistance with planning for their child to transition from parent care to another form of care. The second issue is that of providing appropriate care to enable
comfortable ageing for the person with intellectual disability (Bigby, 2004). For many carers, the desire is for this care to meet the standard of care they themselves have provided over the past decades (Llewellyn, Gething, Kendig & Cant, 2003).

In general, there has been a move away from accommodating people with intellectual disability in large institutions and into community-based residences (Annison, 2000; Young, Ashman, Sigafouos, & Grevell, 2001). Data from the Australian Institute of Health and Welfare (AIHW) (2005) report that fewer young people are entering formalised residential care and those who currently reside there are in advanced years. Deinstitutionalisation has resulted in an abundance of research into various aspects of the lives of people with intellectual disability such as adaptive behaviour, overall quality of life and whether they now lead lives more in line with the rest of the community (Young, Ashman, Sigafouos, & Grevell, 2000). It would appear that generally, this change has been a positive one (Kim, Larson & Lakin, 2001; Stancliffe, Emerson & Lakin, 2001) with a trend for more community facilities that provide a higher quality of life (Felce & Emerson, 2001).

1.2.4 The caring role
1.2.4.1 Overview
Research has shown that carers of intellectually disabled 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 under family care as long as possible (Rimmerman & Muraver, 2001). Older carers tend to report that as they get older the physically demanding nature of the role (Llewellyn et al., 2003; Rimmerman & Muraver, 2001) and the effect it can have on family relationships causes the greatest level of stress (Llewellyn et al., 2003). Older carers also report feeling helpless (Llewellyn et al., 2003), lack a sense of purpose and of personal growth (Walden, Pistrang, & Joyce, 2000). For older mothers, in particular, this caring experience becomes less positive as time passes (Rimmerman & Muraver, 2001).

1.2.4.2 Experiences with services for the intellectually disabled
Carers report that they often find themselves vulnerable to the disability system. Not only do they feel that services do not respond appropriately to the needs of their child but ‘their knowledge’ as parents and carers is not respected. Therefore, they find themselves excluded from within the circle of ‘experts’ who administer many of the services they require. Services continue to respond to people with intellectual disability as a group rather than addressing individual differences. In addition some services see the person with intellectual disability simply as the ‘client’, without acknowledging the lifetime inter-dependency that has developed between the person with intellectual disability and the carer. Changes in government policy which many service providers are bound by, often forces them to adapt services to meet frequently adjusted guidelines. This creates uncertainty and fear for carers that they will no longer be eligible for services under the new guidelines. Service providers have also recognised that older carers have spent many years lobbying for services which are now no longer available to them because the emphasis of support is shifting to younger carers (Llewellyn et al., 2003).

1.2.5 The transition to care from home to life in supported accommodation
The transition from care in the family home to supported accommodation is a life-changing experience for carers and people with intellectual disability. The carer experience is not always the same as that of the person with intellectual disability, as outlined below. However, both need the support of professionals to help them through the process.

1.2.5.1 The experience of the carer
The decision to find alternative accommodation for a person with intellectual disability who has always lived at home is often a difficult one and has been described by carers as the
“hardest and most painful decision of their lives” (Mirfin-Veitch, Bray, & Ross, 2003, p. 105). Many older carers endure a stressful search for an immediate and appropriate accommodation after experiencing an unexpected crisis such as failing health or an accident (Llewellyn et al., 2003). Given the ideal situation of appropriate services and accommodation options, the decision to find alternative accommodation is often a process of events, not one discrete act (Mirfin-Veitch et al., 2003).

The first part of the process as described by Mirfin-Veitch et al. (2003) are the events leading up to the decision to move the person with intellectual disability to another accommodation. This is often initiated by a decrease in the carer’s ability to cope with the caring role. Carers reported retrospectively that they felt themselves becoming more isolated and perceived that their other children and family members were unable to lead a normal life. Some carers resisted attempts by services to assist when they were struggling to cope, although many report they knew they were ‘delaying the inevitable’ (Mirfin-Veitch et al., 2003, p. 104). Often during this stressful stage the carer sought community based disability services but too often found they did not meet their needs. Therefore, local respite accommodation services were used more frequently as the carer needs increased. This respite allowed the family to have a break from their caring role, while a specialised disability service cared for the person with intellectual disability (Department of Health and Ageing, 2004).

The ultimate decision for the person with intellectual disability to move out of the family home is usually made by mothers. This is influenced by the mother’s mental health and a need for her to maintain balance for her family and other children. Support from general practitioners and psychologists is very important at this time as they facilitate the transition and validate carer’s feelings of stress and guilt (Mirfin-Veitch et al., 2003).

Once the person with intellectual disability has moved to supported accommodation, this does not mean they are no longer a part of the family. Most carers continue to have regular visits in accordance with policy of the residential facility. These visits also enable staff to communicate and confer with parents and helps them feel that they are involved in the decision making around the care of the person with intellectual disability (Schwartz, 2005).

1.2.5.2 The experience of the person with intellectual disability

The move from the family home is not always perceived as stressful for the person with intellectual disability, particularly if they feel they will be adequately supported through the process. In fact some find this a positive experience as life-long dreams are fulfilled. Research has found that two to four weeks following the move, extra support and greater access to social networks may be needed. For anyone who is making a major life move, this is the period when the excitement of the move has waned and reality has set in (Bramston & Cummins, 1998).

1.2.6 Alternatives for care

1.2.6.1 Sibling carers

While carers do not necessarily have an extensive plan established for the care of their child with an intellectual disability, many have less formal, often implicit plans, usually involving siblings (Bigby, 1996). Siblings of people with disabilities have a unique relationship with their brother or sister. They often partake in some aspect of their care from an early age (Stoneman, 2001) and feel ‘obligated’ to continue assisting in the care of their disabled brother or sister (Jewell & Stein, 2002). As the parents age, there are often expectations that siblings will continue to provide care. However, many siblings have their own lives, careers and families and are unable to be as supportive and dedicated to the caring role as their parents (Lefley & Hatfield, 1999). In addition, many siblings put into the position of providing care are themselves dealing with the death or disability of their parents. Therefore a change
in caring roles may not be a smooth transition and may be affected by two issues: 1) how the person with intellectual disability now perceives their sibling carer and 2) how service providers respond to and support either one or more siblings now taking over the caring role (Dew, Llewellyn, & Balandin, 2004).

1.2.6.2 Aged care facilities
There has been much debate about accommodating people with intellectual disability in aged care facilities and how well this type of accommodation meets the needs of this group. While people with intellectual disability undergo the same ageing process as the general population, they often experience poorer health throughout their lives and therefore require higher care needs as they age (Bigby, 2004). Aged care facilities are regarded as inappropriate for people with intellectual disability and they can be forgotten in a system that is not suitable or equipped to care for them (Thompson, Ryrie, & Wright, 2004). They are often placed in aged care facilities for reasons unrelated to their ageing but as a result of the death of their parents. Furthermore it is unclear at which age or stage in their ageing it is acceptable for people with intellectual disability to move across into the aged care system (Bigby, 2002).

Thompson and Wright, in a study of people with intellectual disability in residential services for older people, found that people with intellectual disability were living “the life of the much older and frailer people in these services” (Thompson & Wright, 2001, p. 20). For these people with intellectual disability residing in an aged care facility, one third were unable to access the community on a weekly basis and regular activities were restricted as was contact with family and friends. In addition, they were not receiving any support from specific disability services. This could further result in loss of contact with friends and social networks (Thompson et al., 2004). In particular staffing levels and training were inadequate to deal with people with intellectual disability in an aged care facility.

Conversely, Heller, Millar, and Factor (1998), found that those people with intellectual disability who moved out of an aged residential facility into community-based settings displayed higher levels of adaptive behaviour, community integration and health. One contributing factor was the physical environment. These dwellings allowed the residents to personalise their rooms, buildings had more windows with nicer views and décor was varied throughout the residences. This illustrates that the needs of people with intellectual disability are different from the normal ageing population. In order for aged care services to meet these care needs, the roles of disability and aged care sectors may need to be examined and a suitable approach to providing appropriate options explored (Bigby, 2004).

1.2.7 Disability specific accommodation
It would appear that at least three factors are required to provide more severely disabled and people with specific disabilities better opportunities and quality of life. They are: a) ensuring that activities are available, b) having adequate numbers of staff to support residents in these activities and c) ensuring that this support is appropriate for their level of need (Felce, 1998).

Felce (1998) suggests that supported accommodation needs to move away from an environment where staff take care of everything and towards an environment that encourages resident participation and independence. For this to be successful, organisations need to ensure that they have a commitment to this, and that staff are trained and monitored appropriately to coordinate this level of care and supervision.

1.2.7.1 The meaning of ‘home’
For many years, institutions that housed people with intellectual disability were referred to as a ‘home’ without any regard as to what the meaning of home really meant (Annison, 2000). O’Brien (1994) proposed that ‘home’ for people with intellectual disability involved three
elements. The first included the establishment of a ‘sense of place’ (O’Brien, 1994, p. 2). This is established by such things as being able to personalise their environment, establishment of routines, physical and emotional safety and freedom to invite people to visit and maintain friendships. The second is control over where they live and who they live with. The final element is that of security of place that is achieved through either ownership or the establishment of residential stability with sufficient support.

1.2.7.2 Residence size
People with intellectual disability who reside in smaller groups with less support have been found to have greater access to community facilities, more involvement in household tasks and more choice and control in their lives. They also report higher levels of social satisfaction, possibly because of the sense of control they have over their social life (Stanciliffe & Keane, 2000). Parents perceive their child to be happier when residing in smaller residences and they believe that it ensures a better quality of life (Schwartz, 2005). However, research has found that the size of the residence is only one factor that contributes to the happiness of the person with intellectual disability. Smaller size has not been identified as a causal factor, but one of many confounding factors of happiness in general (Felce & Emerson, 2001).

1.2.7.3 Level of intellectual disability
One aspect of quality of life for people with intellectual disability is their ability to communicate and their level of living and social skills. Those with more severe disabilities have been found to participate less in daily living activities, socialising and exercising. In addition, those with lower levels of intellectual disability receive less attention from staff. Thus the people who require more help actually receive less (Perry & Felce, 2003). This may be due to the inability of people with higher intellectual disability to provide staff with satisfying social interactions. Consequently staff gradually lose that skill of communication (Felce, 1998). According to Mansell, Ashman, Macdonald and Beadle-Brown (2002), housing people with different levels of intellectual disability will ensure that staff communication skills are maintained. When people with similar levels of intellectual disability are housed together, staff adapt their practices to conform to the skill level of the clients. For example, if all clients are non-verbal, it may reduce the number of staff required, but those staff may in time stop communication altogether which would be to the ultimate detriment of the clients.

1.2.7.4 Staffing
More staff does not necessarily translate into higher levels of life-style satisfaction or activity levels for the people they care for. In research exploring community accommodation with various staffing levels, those residences with less staff were found to have contributed to higher life-style satisfaction of their residents. It would appear that residents feel more in control when lower staffing levels allow them the opportunity to make decisions and have more responsibilities. When staffing levels are lower, staff more actively engage in assisting residents to acquire more independent skills (Schwartz, 2003).

Similarly, resident participation in daily activities does not increase with more staff and has been shown to be dependent on the amount of assistance and attention provided by the staff (Felce, Lowe & Jones, 2002). Likewise higher staffing levels do not result in increased staff contact with clients (Emerson et al., 2000). Staff assisting residents to help themselves increased quality of life of those residents but staff with prior experience in working with people with intellectual disabilities have been found to provide this better than those with no experience (Felce et al., 2002). Thus it would appear that it is important that staff are trained in how to ‘actively support people with intellectual disability. Jones et al., (1999) propose that with the right training, this can be achieved without increasing staff numbers.
1.2.7.5 Friends
People with intellectual disability were found to be more likely to have friends with intellectual
disability rather than friends without intellectual disability and were more likely to participate
in activities with their friends in public places, not at home. In addition, where a person lives
is more important in developing friends than the social skill level developed or the personal
qualities of the individual (Emerson & McVilly, 2004). This suggests that accommodation
types that allow social contact may be beneficial to improving social skills and maintaining
friendships.

1.2.8 Models of accommodation types

1.2.8.1 Overview
There is a large amount of research comparing various types of accommodation services for
people with intellectual disability. While de-institutionalisation is generally regarded as a
positive step in enabling a higher quality of life for people with intellectual disability,
classification of accommodation settings has yet to be standardised. In addition, it is still
unknown which type of accommodation provides the best quality of life. Broadly however,
accommodation types are based on models from the United Kingdom (UK) and are broken
into three main categories. The first are campus type facilities which house large numbers in
atypical buildings separated from the surrounding community. The second are intermediate
community settings such as in a village style again separated from the community. The third
are community or dispersed housing, which are regular houses located within the community
(Felce & Emerson, 2001).

1.2.8.2 Campus, cluster and dispersed housing models
Emerson et al., (2000) compared a 24 hour supported campus style setting (independent
cottages but sharing facilities such as a shop) and 24 hour supported dispersed community
housing. It was found that dispersed housing provided overall higher quality care. This care
included better quality staff who were involved in more activity and personalised planning
and offered more flexible and positive support. In addition, this accommodation was found to
be more ‘home-like’. People with intellectual disabilities in dispersed housing were able to
have a greater say in their lives and engaged more with the wider community, attending a
greater variety of activities more often as compared to those in the campus style setting
(Emerson et al., 2000).

Additionally, research into cluster housing and dispersed housing has shown that people with
intellectual disability in cluster housing are more likely to live in a larger setting with more
people. Cluster housing also offers respite facilities, receives less support from staff many of
whom are casually employed. In addition residents have been found to have less control
over their environment, are less active and participate in fewer social activities. Therefore,
while there is a perception that living in cluster housing allows people with intellectual
disability to connect better with the community there appears to be no evidence to support
this (Emerson, 2004).

1.2.8.3 Cost
The financial cost of different accommodation for people with intellectual disability is an area
that has not received much attention within the literature. In addition, due to the confusion
over standardised definitions of accommodation styles, it is difficult to provide accurate
comparisons. For example, a study by Emerson et al., (2000) from the UK found that
dispersed housing was more expensive to run than cluster housing and staffing costs
associated with dispersed housing were found to be as much as 28% more per week higher
than cluster housing. A study by Stancliffe and Keane (2000) in Australia, examined the
differences in cost and quality of life for people with intellectual disability living in either semi-
independent living or group housing. Semi-independent accommodation was defined as one
to four people living in dispersed housing with part-time support but not including overnight assistance. Group housing was defined as three to seven people with full-time support during waking hours and variations in levels of night support. Per-person, group housing was found to be more expensive to run with no better quality of life for the residents than that achieved in semi-independent living. Thus, residents in these group houses may not need the level of support currently provided and may achieve similar quality of life outcomes living semi-independently, at a lower cost.

1.2.9 Summary of the literature
The disability sector within Australia appears to be in a state of confusion. Not only is there a lack of agreement about the definition of intellectual disability, and confusion over prevalence rates within Australia, but services do not appear to be responsive to the needs of people with intellectual disability and their carers. The CSTDA maintains that day to day services for people with a disability are provided for by state and territory governments. However, carers in Australia are ageing as are people with intellectual disability and services are now needed to provide appropriate accommodation and support within a more community-based system.

Appropriate support and quality of life for the person with intellectual disability is a desire of carers. Research indicates that current services do not always respond appropriately to people with intellectual disability and their carers. Carers struggle to find some way of coping with the physical and mental consequences of their own ageing and the ageing of the person with intellectual disability with limited support from service providers. One option for carers is to rely on their other children for this support. However, siblings of the person with intellectual disability have their own lives and find it hard to take over the care when their parents have died. Another option is to access the aged care system but it is ill-equipped to care for people with intellectual disability.

Optimum quality of life for people with intellectual disabilities in disability-specific supported accommodation depends in part on the ability of the individual to interact with other people and the environment. Therefore a choice of various residential environments is the ideal scenario to cater for all needs. Research has found that people with intellectual disability need to feel a sense of control in the running of their home. This includes such things as: being able to personalise the room, having input into the day to day decision making and appropriate community involvement.

Continued family involvement also contributes to the quality of life for people with intellectual disability. An important point that emerges from the literature is that the size of the supported residence does not automatically guarantee that people with intellectual disability will receive more attention and support from staff or a better quality of life. While smaller residences help allow greater community access and more choice for the intellectually disabled, the ability of the staff to actively engage with residents, encourage and support their independence is by far more vital in achieving quality of life.

There is currently no world-wide standardisation of disability housing classifications. Thus research is inconclusive as to which particular style of accommodation is preferable for people with intellectual disability. However, dispersed housing through the community has been found to provide a higher level of care compared to cluster housing. The cost of dispersed housing has been found to be more expensive in the UK while in Australia, group houses have been found to be more expensive than semi-independent housing.

Therefore it is clear from past research that there is no one solution that will address all accommodation needs of people with intellectual disability and their carers. However, accommodation that includes flexibility, appropriately trained staff and a degree of independence for residents will all contribute to the quality of life of people with intellectual disability.
2.0 METHOD

2.1 Project funding
The Toowoomba Intellectual Disability Support Association (TIDSA) approached the Centre for Rural and Remote Area Health (CRRAH) in 2004 to assist them in investigating their research question which focussed on assessing the accommodation needs of people with intellectual disability over 18 years of age in Toowoomba and contiguous shires. TIDSA and CRRAH subsequently applied for and secured funding through the Gambling Community Benefit Fund (GCBF) to undertake this project which commenced in June 2005.

2.2 Project management
The Chief Investigators on the project comprised:

- Dr Diann Eley - Senior Research Fellow, University of Queensland (UQ) and Centre for Rural and Remote Area Health (CRRAH)
- Professor Desley Hegney – Director; CRRAH, University of Southern Queensland (USQ) and UQ
- Mrs Joanne Boyes - Research Assistant, CRRAH

A Reference Group (RG) of key stakeholders from within the community guided the project and comprised in alphabetical order by surname:

- Chris Allison (Community Development Officer, Carers Qld)
- Jane Arnold (TIDSA representative)
- Leigh Bailey (Community Development Officer, Carers Qld)
- Trish Feehely (Senior Resource Officer, Disability Services Qld)
- Bill Grace (Manager, Hhelp Services, Toowoomba)
- Diana Johnston (Area Manager, Endeavour Foundation)
- Tony Lanigan (TIDSA representative)
- Diana Mckay (TIDSA research representative)
- Michael Mutze (Area Manager SW Qld, Department of Housing)
- Angela Thrower (Darling Downs Community Housing Resource Worker, Wambo Shire Council)
- Mary Wagner (Board of Management, Lourdes Home For The Aged)

2.3 Role of the reference group
The RG was formed by TIDSA members to guide the study, ensure integrity and offer insight and expertise to the outcomes. This was provided through:

- regular meetings
- assistance with finalisation of the questionnaire design
- provision of feedback and discussion regarding results of the study
- input to the final report and discussion of study outcomes.

2.4 Role of TIDSA
TIDSA offered support and guidance through:

- provision of a service distribution list
- the development of the study
- design of the questionnaire
- distribution of the questionnaire to service providers
- promotion of the questionnaire
- discussion of the study results.
This involved regular meetings between TIDSA representatives and members of CRRAH during which updates were given and feedback received.

2.5 Participants
Participants were recruited over a three month period through the dissemination of the study questionnaire. Due to confidentiality issues, this was achieved predominately via local service providers and community organisations that were identified as offering services to people with intellectual disabilities and their families. Study questionnaires were also provided to individuals who made a request through either TIDSA or CRRAH.

Participants were also recruited by TIDSA through various activities such as:

- media awareness campaigns through local television and radio stations - these were conducted prior to the commencement of the study and during the recruitment period
- distribution of study questionnaires at local community events where potential participants were reasonably expected to be in attendance
- word of mouth through TIDSA networks.

2.6 Materials
Prior to the involvement of CRRAH, a trial questionnaire was developed and tested by TIDSA members to assess accommodation needs amongst potential participants at a public meeting. This trial questionnaire was used as a guide to the development of a more extensive questionnaire used in Phase One of the research.

The Phase One questionnaire was intended for the unpaid carer of a person with intellectual disability who was over the age of 18. The questionnaire comprised of four sections with a mixture of quantitative (tick boxes, yes-no and Likert scale) and qualitative (free response, open ended) questions.

The first section of the questionnaire captured demographic information including:

- name and contact information, gender and year of birth of person with intellectual disability and whether the carer thought the person with intellectual disability would be interested in participating in a follow-up interview
- name and contact information, gender and year of birth of carer and whether the carer would be interested in participating in a follow-up interview.

The second section captured information regarding the current living arrangement of the person with intellectual disability. This included Likert-type items intended to measure overall satisfaction with the current accommodation situation. Following most of these questions, carers were given the opportunity to expand on their responses by providing free response comments.

The third section sought information on the carer’s perceptions of the future. Again carers were asked to rate their views using Likert-type items and given the opportunity to expand their responses, through qualitative comments.

The fourth section invited carers to comment on any concerns or issues of interest (both positive and negative) they may have regarding future accommodation needs.
2.7 Procedure
The study comprised of two phases.

Phase One involved the completion of the questionnaire by carers of people with intellectual disability. Service providers in Toowoomba and contiguous shires who provide services to a person with intellectual disability and their families were identified and approached by TIDSA members to assist in the distribution of the study questionnaire to their clients. Questionnaires were distributed through these service providers with the criteria for distribution being:

- carers who reside in Toowoomba and contiguous shires (as identified by postcodes)
- carers who care for a person with intellectual disability over the age of 18 years.

It was requested that service providers also distribute the questionnaire to carers of people who had a primary diagnosis other than intellectual disability but whose diagnosed disability included an intellectual component.

A follow-up mail out was initiated through Endeavour Services to ensure that as many carers of people with intellectual disability as possible were give the opportunity to participate and thus increase our response rate. This second mail-out was targeted at those who had not responded to the first questionnaire. Carers were invited again to participate in the study or to indicate a reason as to why they had chosen not to participate by ticking the appropriate tick box on their information letter.

Phase Two of the study comprised only qualitative methods. Semi-structured interviews were conducted with ten carers and ten people with intellectual disability. A preliminary descriptive data analysis was conducted to provide an overview of participants (carers) from Phase One. This information allowed a purposive sampling technique to identify a representative cross section of participants for the interviews. The interview questions were guided by the preliminary results from both the quantitative and qualitative analysis of Phase One. Descriptive and thematic analysis was performed on the returned questionnaires to identify areas for further elaboration.

2.7.1 Criteria for interview selection

2.7.1.1 Carers
Ten interviews were conducted. Of the carers interviewed, five cared for people with intellectual disability in their home (n=5) and five care for people with intellectual disability who lived away from home (n=5). Furthermore, five of these carers were over 60 years of age and five were under 60 years of age. This ensured that the group interviewed was representative of carers of people with intellectually disability in Toowoomba and contiguous shires. Interviews with carers ranged from 20 minutes to 70 minutes.

2.7.1.2 Persons with intellectual disability
Similarly interviews were undertaken with persons with intellectual disability. Five lived at home and five lived away from home. No age criteria were applied to persons with intellectual disability regarding inclusion for an interview. The research team sought advice on how to perform this aspect of the methodology from Dr Louise Young, an expert in the area of intellectual disability at the University of Queensland.

A pool of eligible interviewees was collated from those who responded to the box on the questionnaire indicating ‘interest in participating in an interview’. Contact was made with the carer to identify a possible interview time for either themselves or the person with intellectual
disability. One appointment with a person with intellectual disability was made directly with them at the request of the carer. All other appointments were made via the carer.

Those who consented to an interview were interviewed in their homes, with the interview being taped and later transcribed verbatim for further analysis. Prior to the commencement of the interview, all participants were provided with an information sheet explaining their participation and upon agreement were asked to sign a consent form. The information sheet contained all telephone and email contacts of the research team including the direct telephone number of the project officer conducting the interviews. Interviews with people with intellectual disability were generally shorter in duration compared to those with the carers.

2.7.2 Ethical considerations
Ethics approval (H04REA416) was obtained from the Human Research and Ethics Committee of the University of Southern Queensland. Participants were informed that participation was voluntary and that they could withdraw at any time without penalty. Confidentiality was assured and any information used within the report would be de-identified.

A Plain Language Statement and Consent form were developed which explained the purpose of the study; informed potential participants of their rights, included contact details of the research team, and provided contact details for counselling assistance should it be required.

The Project Officer was the only person to have access to identifying information which was stored in a locked filing cabinet at CRRAH. Data were stored on the H drive at USQ which is password protected and requires changing every 90 days.

In accordance with NHMRC Guidelines for Human Research, all material related to this study will be stored for five years and then destroyed as confidential waste.

2.8 Data analysis
2.8.1 Quantitative data
Quantitative data were analysed using SPSS statistical software package, with graphs created with the use of Microsoft Excel. These results comprise only descriptive statistics, frequencies and valid percentages to provide a description of the carers in the sample and their opinions of current and future accommodation needs for the person with intellectual disability.

2.8.2 Qualitative data
Qualitative data from the Phase One questionnaires and the Phase Two interviews were transcribed verbatim and subjected to the cycles of content analysis (identification of emerging themes, further hierarchical identification of dominant themes, coding of these themes and quotes within the text, re-analysis through text search, re-interpretation of the themes and re-confirming initial analysis). Reliability of this process was tested by a sample of interviews being independently analysed by two of the researchers and themes and sub-themes consequently agreed upon.

The first thematic analysis involved analysing the content of the questionnaires to inform the areas for exploration during the interviews. These interview questions were developed and agreed upon by two members of the research team. Verbatim transcriptions of the interviews were completed by a transcription service used regularly by CRRAH. To ensure confidentiality, the transcription service was able to identify each interview only by a number.
3.0 RESULTS

The study results are presented in three sections.

- **3.1** presents only quantitative data as reported in the questionnaire from Phase One.
- **3.2** presents all qualitative results (free response comments on questionnaires and semi-structured interviews) as reported by carers of people with intellectual disability and people with intellectual disability who live at home.
- **3.3** presents all qualitative results (free response comments on questionnaires and semi-structured interviews) as reported by the carers of people with intellectual disability and people with intellectual disability who live away from home.

3.1 Quantitative data from the Phase One questionnaire

3.1.1 Response rate

The number of carers of people with an intellectual disability over the age of 18 years was unknown for Toowoomba and contiguous shires. Consequently it was unknown how many questionnaires would be needed. The initial distribution of questionnaires totalled 621. These were distributed in the following ways:

- distribution to local service providers
- mail-outs as requested by individuals
- mail-outs distributed via service providers as they came into contact with eligible clients.

Two months after the initial distribution, 106 usable questionnaires had been returned. A further eight were also returned, but they were either from outside out target area or completed by a support worker, thus rendering them unusable.

It was decided that a second mail-out should occur through the largest service provider, Endeavour Services. The reason being that they are the largest provider of services for our target group and therefore the provided best opportunity to reach any carers that might have been missed during the first mail out. A further 211 questionnaires were distributed. The second questionnaire included the opportunity to give reasons for non-compliance (see reasons in Table 3.1). In addition to those reported in Table 3.1, a further six recipients of the questionnaire contacted CRRAH by telephone to report that they were not going to participate in the survey. It is not known how these six people received the questionnaire.

Including responses from the second mail-out, a total of 205 responses were received. Of the 205 responses, 40 were from people who chose not to participate. A further 15 were unusable because they were either from outside the target area, the person with intellectual disability was under 18 years of age or the survey was completed by a support worker – not a primary carer. Therefore, a total 150 carers participated in this study. Six of these carers identified as caring for more than one person with intellectual disability and therefore a total of 156 people with intellectual disability were referred to. PLEASE NOTE that not all carers responded to all questions asked in the questionnaire. Therefore some totals in the graphs and tables may not balance to the totals listed above due to missing data.
Table 3.1 Endeavour people who chose not to participate (n=34)

<table>
<thead>
<tr>
<th>Reason</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>This was sent to me in error</td>
<td>2</td>
</tr>
<tr>
<td>Accommodation is not an issue for me</td>
<td>19</td>
</tr>
<tr>
<td>I just don’t want to</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>11</td>
</tr>
</tbody>
</table>

Our overall response rate was 36%. Endeavour Services response rate was 50% while the response rate from other services was 20%.

While it is known how many questionnaires were despatched from CRRAH, it is not known how many questionnaires were distributed by the service providers to carers. We are also certain from casual reports and personal communication that many carers received more than one copy. As questionnaires were numbered, the research team was able to identify responses from each service provider. Where no returns were recorded from a service provider, the assumption was made that they had not been despatched to carers so these questionnaires were excluded from the response rate calculations.

3.1.2 Demographic data

Table 3.2 Age and gender of primary carers and people with intellectual disability

<table>
<thead>
<tr>
<th></th>
<th>Carers (n=146)*</th>
<th>Persons with intellectual disability (n=156)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean Age</td>
<td>61.53 years</td>
<td>37.22 years</td>
</tr>
<tr>
<td>Range</td>
<td>40-91 years</td>
<td>18-79 years</td>
</tr>
<tr>
<td>Males</td>
<td>32 (22%)</td>
<td>93 (60%)</td>
</tr>
<tr>
<td>Females</td>
<td>114 (78%)</td>
<td>63 (40%)</td>
</tr>
</tbody>
</table>

*The total number of carers in study = 150; four carers did not report their age.

3.1.2.1 Geographical area

Table 3.3 lists the postcodes covered in the distribution of the Phase One questionnaire. The majority of carers (66%) resided in Toowoomba, with 22% of carers not residing within any of the contiguous shires. Likewise nearly 86% of people with intellectual disability also resided in Toowoomba. Figure 1 shows a graphical depiction of the geographical area covered in this needs analysis.
Table 3.3 Postcodes covered in the distribution of Phase One questionnaires

<table>
<thead>
<tr>
<th>Postcode and shires</th>
<th>Carer</th>
<th>Valid %</th>
<th>Persons with intellectual disability</th>
<th>Valid %</th>
</tr>
</thead>
<tbody>
<tr>
<td>4350 Toowoomba Crows Nest</td>
<td>95</td>
<td>66</td>
<td>130</td>
<td>85.8</td>
</tr>
<tr>
<td>Jondaryan</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Qld</td>
<td>30</td>
<td>20.1</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>4352 Cambooya Crows Nest</td>
<td>9</td>
<td>6.2</td>
<td>9</td>
<td>5.8</td>
</tr>
<tr>
<td>Jondaryan Rosalie</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4401 Jondaryan Rosalie</td>
<td>3</td>
<td>2.1</td>
<td>3</td>
<td>1.9</td>
</tr>
<tr>
<td>4354 Crows Nest Rosalie</td>
<td>2</td>
<td>1.4</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td>4356 Jondaryan Pittsworth</td>
<td>2</td>
<td>1.4</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td>NSW</td>
<td>2</td>
<td>1.4</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td>4400 Rosalie</td>
<td>1</td>
<td>0.7</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td>4364 Pittsworth</td>
<td>1</td>
<td>0.7</td>
<td>1</td>
<td>0.6</td>
</tr>
<tr>
<td>Totals</td>
<td>145</td>
<td>100</td>
<td>149</td>
<td>100</td>
</tr>
</tbody>
</table>
3.1.2.2 Age of primary carers

Figure 2 shows the mean age of carers by the accommodation type. The oldest group of carers were those where the person with intellectual disability *lived away from home* in a large residential facility. Those who identified their accommodation as ‘other’ were predominately living in a private rental accommodation or boarding with other family members. Figure 3 shows that 60% of carers where the person with intellectual disability *lived at home* were aged between 51 and 70 years. Similarly, 67% of the carers of people who *lived away from home* were aged between 51 and 70 as seen in Figure 4. Therefore we see no major difference in the age range of carers who care for a person with intellectual disability *living at home* or *living away from home*. 
Figure 2  Mean age of carers by accommodation type (n=143)

![Bar chart showing the mean age of carers by accommodation type.]

Figure 3  Age range of carers who care for a person with intellectual disability living at home (n=86)

![Bar chart showing the age range of carers living at home.]

---

19
3.1.2.3 Secondary carer

A secondary carer was identified on the Phase One questionnaire as any person who also had a portion of the responsibility for the care of the person with intellectual disability. In most instances this secondary carer was another parent and sometimes a sibling. Sixty three percent of carers of people with intellectual disability living at home identified the other parent as a secondary carer with 22.5% identifying no other carer at all. In contrast, for those carers whose person with intellectual disability lived away from home, 30% identified another parent as a secondary carer and 47% identified secondary carers as other. For the majority of these carers, other refers to service providers and/or support workers. See Figure 5.
3.1.2.4 Age range of people with intellectual disability

The mean age of people with intellectual disability in our study is illustrated in Figure 6. The oldest group live in large residential facilities. Those who identify as other are predominately residing in a private rental accommodation or boarding with other family members.
Figure 6 Mean age of people with intellectual disability in each accommodation type (n=156)

Figure 7 illustrates the age range of people with intellectual disability who live at home. Nearly half of these (45%) were between 18 and 30 years of age with 30% aged between 41 and 50 years.

Figure 7 Age range of people with intellectual disability living at home (n=86)
Figure 8 shows the age range of people with intellectual disability who *live away from home*. Over half (64%) are aged between 31 and 50 years with an average age of 39.8.

**Figure 8  Age range of people with intellectual disability living away from home (n=70)**

3.1.2.5 Overall support needs

Overall support needs of people with intellectual disability indicate that the needs of those *living at home* are similar to those *living away from home*. Forty-four percent of those *living at home* required a medium level of support, compared to 46% of those *living away*. This is illustrated in Figure 9.

**Figure 9  Overall support needs of people with intellectual disability (n=156)**
3.1.2.6 Degree of care required

Three core activities were identified as per the Australian Bureau of Statistics (ABS) (2003). These are:

- communication
- mobility
- self care

For the purposes of this study, these core activities are rated on a scale from very high support, high support, medium and low support. A question asked carers to rate the degree of care their person with intellectual disability required on a daily basis. A breakdown of these care needs appears in Table 3.4.

In general, across all core activities it would appear that care needs do not differ between people with intellectual disability who live at home and those who live away from home. However, statistical analysis of this is beyond the scope of this study.

<table>
<thead>
<tr>
<th>Core activity area</th>
<th>Number living at home</th>
<th>Valid percent</th>
<th>Number living away from home</th>
<th>Valid percent</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Communication</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very high support</td>
<td>8</td>
<td>10.3</td>
<td>13</td>
<td>18.1</td>
</tr>
<tr>
<td>High support</td>
<td>18</td>
<td>23.4</td>
<td>17</td>
<td>23.6</td>
</tr>
<tr>
<td>Medium support</td>
<td>31</td>
<td>40.3</td>
<td>20</td>
<td>27.7</td>
</tr>
<tr>
<td>Low support</td>
<td>20</td>
<td>26</td>
<td>22</td>
<td>30.6</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>77</td>
<td>100</td>
<td>72</td>
<td>100</td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very high support</td>
<td>5</td>
<td>6.5</td>
<td>3</td>
<td>4.2</td>
</tr>
<tr>
<td>High support</td>
<td>8</td>
<td>10.4</td>
<td>10</td>
<td>13.9</td>
</tr>
<tr>
<td>Medium support</td>
<td>22</td>
<td>28.6</td>
<td>18</td>
<td>25</td>
</tr>
<tr>
<td>Low support</td>
<td>42</td>
<td>54.5</td>
<td>41</td>
<td>56.9</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>77</td>
<td>100</td>
<td>72</td>
<td>100</td>
</tr>
<tr>
<td><strong>Self-care</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very high support</td>
<td>12</td>
<td>15.4</td>
<td>6</td>
<td>8.1</td>
</tr>
<tr>
<td>High support</td>
<td>15</td>
<td>19.2</td>
<td>23</td>
<td>31.1</td>
</tr>
<tr>
<td>Medium support</td>
<td>38</td>
<td>48.7</td>
<td>25</td>
<td>33.8</td>
</tr>
<tr>
<td>Low support</td>
<td>13</td>
<td>16.7</td>
<td>20</td>
<td>27</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>78</td>
<td>100</td>
<td>74</td>
<td>100</td>
</tr>
</tbody>
</table>
3.1.2.7 Day activities of people with intellectual disability

People with intellectual disability who live at home or live away from home access various day services or activities in the community. These may range from paid employment, Endeavour services (working in shop or farm, school) or involvement in a combination of these activities. This is illustrated in Figure 10 which shows the number of persons with intellectual disability and their various day activities.

The majority of all persons with intellectual disability (61%) access an Endeavour service, usually some form of supported accommodation or day service. A greater proportion, (76%) of persons with intellectual disability were living away from home compared to 45% of those still living at home.

Seventeen percent of persons with intellectual disability both living at home or away were either at an educational facility, working or unemployed, while 11% identified as having accessed services provided by other service providers. This is often no more than several hours per week and includes either organised activities (eg. craft, sporting activities) or one-on-one assistance with a support worker. The balance, 10% of people with intellectual disability received a combination of services. For example, an individual may attend Technical and Further Education College (TAFE) one day a week and work one day a week.

A closer inspection of Figure 10 indicates that apart from Endeavour services, a greater number of persons with intellectual disability who live at home, compared to those who live away from home are involved in other day activities such as employment, other services providers, combination of these and are unemployed.

Figure 10 Day activity of people with intellectual disability (n=152)
3.1.2.8 Current accommodation

Six types of accommodation were used for this study and were defined in the questionnaire as follows:

Table 3.5 Definitions of accommodation types used within the study

<table>
<thead>
<tr>
<th>Dwelling</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>With you at home</td>
<td>with little or no support from outside services</td>
</tr>
<tr>
<td>With you at home</td>
<td>with a great deal of formal support from outside services</td>
</tr>
<tr>
<td>Large residential</td>
<td>accommodating more than 20 people</td>
</tr>
<tr>
<td>Medium residential</td>
<td>accommodating 11 to 20 people</td>
</tr>
<tr>
<td>Small residential</td>
<td>accommodating up to 10 people</td>
</tr>
<tr>
<td>Group house</td>
<td>single house shared by 4 to 6 people with varying levels of support</td>
</tr>
</tbody>
</table>

Figure 11 illustrates the distribution of accommodation type among all participants. The majority (56%) of the people with intellectual disability resided at home, with the second highest proportion (15%) residing in a medium residential facility.

3.1.2.9 Suitability of and satisfaction with current accommodation

The suitability of current accommodation was ascertained by a question that asked carers to rate how suitable the accommodation was for the person with intellectual disability. This was rated on a five point scale from very suitable to very unsuitable. As seen in Figure 12, 82% of all carers feel that the current accommodation is suitable.

Likewise, Figure 13 shows that 79% of carers of persons with intellectual disability who live at home were satisfied with the current accommodation situation, while 75% of carers of person with intellectual disability who live away from home also expressed satisfaction. Overall 77% of all carers reported that they were satisfied with their current accommodation arrangement.
Figure 12  Suitability of current accommodation for person with intellectual disability (n=150)

Figure 13  Carer satisfaction with current accommodation (n=147)
3.1.2.10 Carers’ perception of person with intellectual disability’s happiness with current accommodation

Carers’ were asked to rate the degree of happiness they felt the person with intellectual disability had with their current accommodation. As illustrated in Figure 14, 87% of people with intellectual disability who live at home, and 83% of people with intellectual disability who live away from home were reported to be either happy or very happy with their current accommodation arrangement.

Figure 14 Carer perceived happiness of person with intellectual disability with current accommodation (n=150)

3.1.2.11 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 two to five years time, in five to ten years time and over 10 years.

Figure 15 illustrates this for carers of person with intellectual disability living at home. Overall 70% of these carers foresee 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%) of the carers aged 61 years and over and 57% of carers aged 60 years and under predict a need for change. In contrast only 21% of carers 60 years and under predict no change will ever be needed to meet the accommodation needs of the person with intellectual disability.
Figure 15  Predicted change in accommodation needs of persons with intellectual disability living at home (n=71)

Figure 16 illustrates this for carers of persons with intellectual disability who live away from home. For these carers, 31% foresee no need for change in accommodation for the person with intellectual disability. The majority (60%) of these carers aged 60 years and under predict a need for change within the next five years while only 30% of carers aged 61 years and over reported a need for change in the same period of time. Overall 54% of these carers foresee a need for some other form of accommodation within the next 10 years.

Figure 16  Predicted change in accommodation needs of persons with intellectual disability living away from home (n=52)
Thus, in total, 64% of carers report that they see a need for change in accommodation for the person with intellectual disability within the next 10 years. Fourteen percent of all carers see this need will arise in over 10 years time, while the remaining 23% do not see a need for change at all.

Carers were then asked what type of accommodation would best suit their needs for the future. Figure 17 clearly illustrates that carers are evenly divided in their preference choosing small residential, house or unit and village style accommodation for their future needs.

Figure 17 Preferred accommodation for the future (n=147)

A further breakdown of this question by current living arrangement, that is people with intellectual disability living at home or living away from home, is shown at Figure 18. For carers caring at home, the first preference was village style (35%) followed by house/unit (28%) and then small residential (22%). For carers who care for a person with intellectual disability living away from home, 37% preferred small residential, followed by house/unit (30%) with 23% preferring the village option.
Finally carers were asked, “How involved would you like to be with the support of the person you care for in his/her accommodation?” Figure 19 shows that 35% of carers anticipated total involvement, while 42% anticipated moderate involvement.

Figure 19  Anticipated future involvement in the lives of the person they care for (n=140)
The major themes and sub themes that emerged from the analysis of the qualitative data from Phase One (questionnaire) and Phase Two (semi-structured interviews) are divided into those participants who live at home (Section 2) and those who live away from home (Section 3). An elaboration on each of these major themes will now be presented and supported with relevant quotes from both the carer of and the person with intellectual disability and the person with intellectual disability.

3.2 Qualitative data of carers who care for a person with intellectual disability living at home

The following results are based on responses from 86 carers who care for a person with intellectual disability living at home.

Major themes:

3.2.1 Ageing
   3.2.1.1 Ageing carer
      3.2.1.1.1 A desire to care as long as possible
      3.2.1.1.2 Concern for the future
   3.2.1.2 Advancing age of person with intellectual disability

3.2.2 Family and home
   3.2.2.1 Family
   3.2.2.2 Suitability of living at home
   3.2.2.3 Lack of experience

3.2.3 The experience of living at home
   3.2.3.1 Positives of living at home
   3.2.3.2 Negatives of living at home
      3.2.3.2.1 Friction
      3.2.3.2.2 Dependence on carers
      3.2.3.2.3 The carers life
      3.2.3.2.4 Socialisation

3.2.4 Government support and funding
   3.2.4.1 Lack of support
   3.2.4.2 Issues with respite

3.2.5 Future accommodation
   3.2.5.1 Lack of choice
   3.2.5.2 Options
   3.2.5.3 Sibling support
   3.2.5.4 Separation from community
   3.2.5.5 Ideal accommodation
      3.2.5.5.1 Home-like
   3.2.5.6 Socialisation
   3.2.5.7 Staff
   3.2.5.8 Location
   3.2.5.9 Cost
   3.2.5.10 Ageing in place - nursing homes as an option
   3.2.5.11 Security
      3.2.5.11.1 Mixing males and females
   3.2.5.12 Working towards independence
   3.2.5.13 Carer involvement

32
3.2.1 Ageing

3.2.1.1 The ageing carer
The average age of the carer who is caring for a person with intellectual disability living at home was 61 years (see Figures 2 and 3). This ‘advanced age of the carer’ was reported by 69 (78%) of the respondents as being an area of increasing concern. Thirty (43%) of these carers either divulged their age or commented on the fact that their advancing age was becoming problematic, that is, that they would not live forever. Some carers reported that they have already experienced ill health which impacts on the care of their person with intellectual disability. One carer simply stated:

My time is coming.

Added to this anxiety was the concern that no one in authority appeared to be aware of this dilemma:

Governments are not realising we are going to die.

The anxiety surrounding the inevitability that as they age, they will no longer be able to continue providing the necessary care was expressed by 29% of carers (n = 20). One commented that:

We are not sure that we can continue to support his needs fully as we get older.

3.2.1.1.1 A desire to care as long as possible
In spite of the uncertainty of their future ability to care for their person with intellectual disability, 14 carers (20%) expressed a desire to continue caring as long as possible (see Figures 12 and 13). One carer said:

I'm very happy to look after her as long as I'm capable.

For some, other arrangements would only be necessary if they could no longer care:

If H went into care it would only be if I could not take care of her.

3.2.1.1.2 Concern for the future
This concern and uncertainty about the future was felt by 56% (n=39) of carers as demonstrated by the following quotes:

We can't foresee what the future holds for any of us.

For many of these carers, there is no one else to take over the caring role for the person with intellectual disability. This is best summed up with one question:

What happens when I can no longer care for her?

Further comments from carers who shared the caring role included:

When we die there is no one else to look after him.

Who will care for him when we are gone?

We are concerned like most parents of children with a disability about what will happen when we are gone.
This is particularly important for sole carers as one described:

_I am the only living relative who could take care of J._

Having somewhere that the person with intellectual disability could go to when the carer could no longer provide care was the crux of this uncertainty:

_It would be good to know that there will be somewhere she could go when the need arrives._

For some carers (13%) it would be preferable if this care could be organised before they were unable to care any longer or in the event of their death as described by the following:

_I would really like to see her set up for the future that should something happen to me she could continue on._

_When I pass on S has nowhere to go as it is at the moment._

_We are also feeling an urgency as older age looms._

_My husband and I just feel so helpless and sometimes this feeling is overwhelming._

3.2.1.2 Advancing age of person with intellectual disability

Although the average age of persons with intellectual disability in this study was 35 years (see Figures 6 and 7) the natural physical deterioration that accompanies the ageing process was commented on by only seven (8%) carers. Current care needs of the persons with intellectual disability in our study can be seen in Table 3.4. Several carers have noticed a physical deterioration and with this an increasing need one carer described this:

_K’s mobility is decreasing with age and he has a lot of trouble getting into the bath to have a shower._

In some instances, this deterioration has been confirmed by a medical specialist, with the outcome being:

_She will need full time care within 10 years._

3.2.2 Family and home

3.2.2.1 Family

A large proportion (40%) of carers wrote about the importance of being around family for the person with intellectual disability. Many reported that being around family provided safety and security, as well as social interaction with immediate and extended family members. For some carers this was seen as the best option:

_It is by far best for him that he remains living at home with his family._

_H loves being at home living with his parents._

The opportunity of the person with intellectual disability to contribute to their living arrangement was seen as an important aspect of living with family. One person with intellectual disability spoke proudly about her contribution to the family:
**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.**

3.2.2.2 **Suitability of living at home**
Several carers (21%, \( n = 18 \)) commented that having the person with intellectual disability living at home is suitable for both carer and person with intellectual disability:

*The situation is suitable to both parties at the moment.*

*We are all happy to continue with present situation.*

However, there is also recognition that as ageing occurs this will no longer be suitable. Two parents explained that the current arrangement was:

*Suitable for the present but not good for later years.*

*Suitable at the moment as his carers are only in their 50’s.*

3.2.2.3 **Lack of experience**
Concern was expressed by 11 carers (13%) about the person with intellectual disability residing with people other than family. For some, living at home is the only experience they have ever had and this was also a source of anxiety should the present situation deteriorate.

*K has always lived with us at home.*

Others describe limited experience, for example:

*No experience in other accommodation for 15 years, (state, government department) accommodation very hospital like.*

3.2.3 **The experience of living at home**

3.2.3.1 **Positives of living at home**
Thirty-four carers (40%) commented on some aspect of the experience of living at home with a person with intellectual disability. Of these carers 56% (\( n = 19 \)) described this as a positive. The person with intellectual disability is seen to be happy and well cared for. The care needs that are met include meals, medical, security, behaviour monitoring, and financial assistance. **One person with intellectual disability** commented on the need for monetary assistance:

*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.*

Living at home allowed most persons with intellectual disability to live comfortably having access to their own room and being able to experience a level of independence. (See Figure 10 for more details regarding activities). One mother described her son’s life:

*Why would he want to leave home when he has everything done for him? He has his very own slave.*
3.2.3.2 Negatives of living at home

3.2.3.2.1 Friction
Not all carers, however, described the situation in a positive way. Negative effects were described by 24 carers. Having the person with intellectual disability living at home can cause friction between family members. Five carers described problems between themselves and the person with intellectual disability as a result of communication issues and problems with siblings. Examples of this friction are:

- *F* feels we try to control his behaviour and can become quite irrational and upset at reasonable demands.
- *J* can be very jealous of her sister and brother, and uses any opportunity to upset them and create unrest.

3.2.3.2.2 Dependence on carers
Ten carers felt the dependence on them may be detrimental in the long term and this caused some distress for them. The biggest concern was that dependence would not be possible for ever. This was described by one carer:

*He is getting more attached to being just with us. Not good if we drop dead someday.*

Three of these carers have been told by the person with intellectual disability that they would not leave home and one carer found that attempts to move him into supported accommodation were unsuccessful:

*The suggestion caused deep distress- depression.*

3.2.3.3.3 The carers life
Caring for a person with intellectual disability also had a negative effect on the carers’ life. Thirteen carers (33%) described not having a normal life including not being able to have some time alone with their spouse. Two carers described:

- Sometimes my husband and I need ‘together’ time – talking without someone else being there.
- It withholds my husband and myself at home more as we have to think about L and what he will do.

One person with intellectual disability was also aware of the huge toll placed on her carers:

*They’re my parents and naturally I don’t want to hold them down. That’s why I go to – I went to rest at (names of nursing homes) respite places.*

With some carers facing upcoming retirement, this continual caring role will mean that they will not be able to enjoy the activities that many of their peers have. One carer explained:

*We would like more freedom to travel in the years ahead.*

For other carers, retirement will never occur.

*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 caring role. My ‘place of employment’ is at home and sometimes it becomes quite depressing.*
3.2.3.2.4 Socialisation
For both the carer and the person with intellectual disability, living at home can result in isolation and lack of friends. Social activities revolved mainly around family activities. The carers also feel this isolation which evolves from their caring role. One carer explained:

_We live outside Toowoomba and don’t really have a lot of interaction with others due to limited support hours._

_We are socially isolated from respective peers._

Carers felt a great deal of responsibility in their ongoing caring role and felt that if some accommodation was available, it would be a reprieve for them. One carer explained:

_There’s a constant responsibility with J so you probably – you wouldn’t have that and you’d feel freer._

3.2.4 Government support and funding

3.2.4.1 Lack of support
Several issues were raised by 17% (n=15) of carers with regard to government attitude toward and funding for older person with intellectual disabilities. Some of the issues included waiting lists, closures of local institutions, lack of funding packages and overlooking those persons with milder disabilities. One carer said:

_I put through years ago, put in to have grants just to do up – we have a back room behind the garage - and do up a little flat for M so he could be independent. I got tired of filling out the same forms and doing the same thing all the time and receiving the same feedback. He’s not high enough level. It wouldn’t have been too expensive, but (State Government Department) never saw that it was needed, you know._

Funding was cited by all as the main obstacle to the provision of accommodation services for people with intellectual disability. One carer explained this as:

_We are concerned with the current lack of supported accommodation and governments move away from supporting people with impairments._

3.2.4.2 Issues with respite
Lack of respite accommodation services for people with intellectual disability in the local area was an issue identified by 20 (23%) carers. Respite was identified as allowing the person with intellectual disability to experience life away from home as explained by one carer:

_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._

It was also seen as enabling the carer to have a break from their caring role. One third of these carers said there were no respite options and that they either went without or accessed support from other community members. Two experiences were:

_In the past there was no vacancies when I needed help after an operation. I am of the belief there is still no options for us._

_When my husband and I went overseas I had to rely on friend’s kindness to look after him._
Only three carers stated that they had regular respite and that it was successful.

* M has overnight respite a few times during the year. He is happy to go as I am happy for him to go.
For those who have some knowledge or experience, the financial cost was considered too great. One carer asked:

* The cost of respite. If you don’t have funding how can the average person afford this?

Another carer reported having accessed residential respite in a nursing home due to the medical needs of the person with intellectual disability. However, due to her age, this respite avenue is no longer available and she is now caught between two systems:

* I had no end of blank walls trying to get her reassessed because they say the Government’s changed the rules now and people in this younger age group are taking up beds that old people should be using. I went to Disability Services, Queensland. They said M didn’t come under their umbrella and to go back to Aged Care Assessment Team, so I’ve been you know sort of in between the two.

### 3.2.5 Future accommodation

#### 3.2.5.1 Lack of Choice

Lack of available, suitable supported accommodation in Toowoomba was reported by 21 carers (24%). This left no other choice than for the person with intellectual disability to live at home. One carer described the dilemma:

* Because there’s no other accommodation out there really for myself to feel that I could put him in there and know that he was being taken care of and that’s my biggest thing is that he’s treated as a human being, that he’s treated as a person, that he’s given responsibility to a certain degree, but these people have a disability and they need to – people need to recognise that, hey look, they’re not like the normal person.

One father described his observations of current supported accommodation in Toowoomba:

* At present there doesn’t appear to be any purpose built systems for the intellectually handicapped apart from some outmoded (service provider) residential.

At one stage, there appeared to be some hope for carers, but that no longer exists according to one carer:

* In the past (service provider) undertook to look after them when parents or carers are gone. This is no longer the case.

Another carer explained the limitations of accessing accommodation services:

* Unless you hit a crisis situation you have no hope in hell of getting any suitable accommodation.

#### 3.2.5.2 Options

Accommodation options were explored by some carers. These included listing with the housing commission, building or buying a granny flat or unit or hoping that the person with intellectual disability would be taken in by another family. Six carers have decided that the
person with intellectual disability will be able to stay indefinitely in the family home. One carer described:

    We have discussed this problem at some length and have decided to go for home care, not residential care.

The depth of this problem has also been explored by those persons with intellectual disability. One in particular thought about future options for when her parents were no longer able to care for her:

    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.

3.2.5.3 Sibling support

Sibling support for the person with intellectual disability, when the primary carer has died, is an option that is expected by seven carers. For four of these carers, this was a decision made by the family as a group. One carer described her circumstances:

    He has a brother who is willing to take over the job but he would require support so that he can continue to work.

Six carers commented that they did not want their other children to take over the care as they had their own lives and families. One carer explained:

    I don't want my children to have the responsibility, even though I've said to them and you know in my will I've put that I want them to financially make sure that M's able – you know is looked after, but I don't want them to have to have the responsibility. It's not fair to them. It's not fair to their families or if they're with – in their relationship with another person to have to think and I've heard of situations like that, but the thing is where do you go here in Toowoomba?

While this is a viable option for some, one carer expressed that this was not ideal:

    T's siblings have made positive suggestions but we would prefer there be other accommodation options.

For some carers, the person with intellectual disability is a lot younger than their brother or sister, so the ageing issue also applied to the siblings. One carer said:

    See this is another thing with the brothers being so much older they're going to be in nursing homes before she is unless something happens, and this is it. You don't know with these kids whether they are going to deteriorate rapidly.

3.2.5.4 Separation from community

Carers expressed concern about people with intellectual disability living in a separate facility amongst their own as opposed to living integrated within the community. Some were of the opinion that living amongst others with intellectual disability was important:

    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.

However, this is not the opinion of all carers and one expressed disagreement with this:
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 think big conglomerate places are for the benefit of service providers really.

3.2.5.5 Ideal Accommodation

Living with a small group of people while being supported by care workers appeared to be the most appropriate and desirable arrangement for people with intellectual disability (see Figures 17 and 18). This can be achieved in a small residential or in a self-contained environment either in the community or within a village atmosphere. One carer described:

Well, I would like to have somewhere I think you know like these retirement villages where they have somebody on call 24 hours that if you know the electricity or something plays up that these people can go to the managers of this facility and say, look, this has happened and maybe like a little one bedroom or two bedroom if they wanted to have a friend that they would be able to sense responsibility, to be treated, I suppose, as normal but still have the tight supervision – not tight, but supervision.

Small was generally defined by carers as two or three others, while one carer thought up to seven would be acceptable. **One person with intellectual disability** thought that ten people was probably the maximum that he could cope with

*Ten would be too many to cook for 10 and…*

**Another person with intellectual disability** expressed:

*Two or three, if they are my sort of people.*

Individual differences should be included in the decision making as some people with intellectual disability prefer company and some do not.

*If J was by himself it would probably be difficult because he probably needs company.*

Many carers were clear about what they did not want for the person they cared for. Some believed that the person with intellectual disability would not cope with large numbers. One carer expressed the fear that her son would not be treated appropriately in a large facility:

*Do not want M in an institution and not being cared for. My son M is a human being and would like him to be treated as so.*

3.2.5.5.1 ‘Home-like’

Living in a ‘home-like’ environment providing their personal space was considered very important. In other words, each resident must have their own room as described by these two carers:

*C would like to live in a home environment as he has always been used to- like his own space for quiet music, magazines, TV.*

*Sort of a place to herself with her own private space that she could do with what she liked.*

This view is also shared by **people with intellectual disability** who commented favourably on their experiences with accommodation services:
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.

At (service provider) it’s got the room and it’s got the shower and toilet in the same room. That’s excellent. I don’t want to be showing myself to everyone.

It is apparent that people with intellectual disability also recognise this need for their own space:

Yep. Like a TV in my room so I can watch whatever I like instead of me fighting with other people.

Another carer described a facility that appeared to meet the personal needs of people with intellectual disability as well as provide a ‘home-like’ environment together with the opportunity for socialisation:

They had the one big old house, yes, and then they built units, little units and they’d all come into the one massive kitchen for their meals and that.

3.2.5.6 Socialisation
Future accommodation was seen by 14 carers (16%) as being positive in allowing the person with intellectual disability a greater social network. Greater socialisation was perceived as reducing the isolation felt by some living at home. One carer described her son:

R likes people and people tend to like R so I think he would enjoy a situation with access to and interaction with others.

3.2.5.7 Staff
Some concern about staffing at residential facilities was expressed by eight carers. Of greatest importance was the right choice of staff. Previous experience with support staff has not always been positive and carers feel that staff require certain characteristics such as:

Patient, tolerant and understanding and the ratio of staff to client must be appropriate.

In addition, many of the people with intellectual disability require a high level of care, with five carers stating that they need 24 hour support and that staff must be on the premises 24 hours a day. One carer spoke about a local accommodation service:

No carers at night. They come and do the meals and then go home. So they’re left by themselves at night. I wouldn’t want G like that.

The level of care required on a daily basis for a person with intellectual disability was described by 40% of carers (n=34). Twenty carers reported a constant need for supervision, with a further eight commenting on the need for assistance with medical problems. Meal preparation assistance was reported as a requirement by seven people with intellectual disability with a further six requiring help with managing money and hygiene.

3.2.5.8 Location
The physical location of accommodation facilities for people with intellectual disability was seen as an important, albeit frustrating issue as highlighted by the following quotes:

What’s wrong with Glenvale? There’s plenty of land out there. What’s wrong with Highfields? What’s wrong with Crows Nest?
Although if accommodation services were too far out of Toowoomba, other issues such as transport would need to be addressed. This was recognised by those with intellectual disability as illustrated by the following:

How am I going to get around? Oh, like transport? Oh, yeah. I can't walk all of the way out from Glenvale. I would be tired. Oh, yeah like transport.

Preferably in town because I'm not allowed to drive.

3.2.5.9 Cost
Concern about the cost of accommodation for the person with intellectual disability was divided. Options included paying according to a means test (% of income) or paying a flat rate per fortnight. One carer’s opinion on means testing was:

It would have to be means tested on how much that they’re getting paid. I don’t think those kids should be having to pay exorbitant rents.

Some carers thought that if a percentage was to be paid, the maximum set for accessing residential respite in an aged care facility of 85% (Department of Health and Ageing, 2003) was too high. It was pointed out that people with intellectual disability had different needs to those in aged care facilities.

You can’t put 85% on intellectually handicapped kids. We’re talking about these kids trying to be independent. They have a life time ahead of them.

3.2.5.10 Ageing in place - nursing homes as an option
Nursing home care was seen by most carers as inappropriate option as explained by the following carer:

You know for these intellectually handicapped kids to go into a situation like that and everything is like a production line – it’s not that way, it isn't that way, but the girls are so busy that these kids need time. They need time for things to be explained to them. They can't be rushed.

Well, of course, she’s so active now in everything and so young. Well, she certainly couldn’t go into a nursing home.

3.2.5.11 Security
The physical security of the person with intellectual disability is paramount and a given right to everyone in society. Many carers were concerned about issues such as disrespect or exploitation of their person with intellectual disability:

We will not, however, consider allowing L to take up a placing which does not meet his needs or future happiness. We don’t want him exploited, disrespected or limited in the choices he is able to make.

5.11.1 Mixing males and females
Another concern is sexual security. Many people with intellectual disability do not understand social norms regarding appropriate sexual behaviour. One carer explained:

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.
Some carers felt that mixing genders was an important factor and in need of special consideration. Two carers explained their views:

*He would probably be better sharing with someone else, not female, male because the boundaries there with female can get a bit tricky.*

*Well, if there was supervision it would be ok with mixing genders. You’d probably need radar for the girls’ doors. As long as it was well supervised.*

This concern was also voiced by *people with an intellectual disability* as described by one young lady:

*You just never know what could happen. Some guy might just come along that you just don’t feel comfortable with.*

### 3.2.5.12 Working towards independence

Ten carers expressed an awareness that preparation for the future was necessary and that they had been working towards increasing the independence level of the person with intellectual disability for just this purpose. For six carers this preparation has meant that the person they care for will be prepared for a change to supported accommodation in their late 20s or early 30’s. One carer described her son’s progress as:

*If N continues to make steady progress in all areas of development, then our hopes and plans for him are that he will eventually be able to successfully live in a small personalised supported accommodation situation.*

Fourteen carers (16%) commented on the need to start preparations for change in accommodation in order to avoid the trauma experienced if something unexpected was to occur.

*We would like to see K settled into supported accommodation before we reach an age of high risk for health issues.*

This preparation will increase quality of life, provide dignity and self-esteem and will mean that:

*He is able to have a happy/fulfilled life apart from us.*

Nine carers were certain that the person with intellectual disability will, given the appropriate support, be able to live independently when the time comes.

*M is still able to learn and with training with independent living skills he should be able to manage with supervision.*

Conversely, 12 carers (14%) were of the opinion that the person they cared for could never be independent.

*F does not, I believe have the capacity to develop the skills to live independently.*

### 3.2.5.13 Carer involvement

Twenty-seven percent of carers ($n = 23$) explained that if they were provided with appropriate accommodation, they would continue to play a part in the lives of their person with intellectual disability, as long as their own health permitted (see Figure 19 for further detail).
However, degrees of involvement differ, with some believing that involvement would decrease as the person with intellectual disability became more adapted to their living environment. One carer explained this:

*We would expect to be more involved in the initial stages then as he becomes settled we would need to give less support.*

Other carers anticipated playing a larger role, for example:

*Would be very concerned if we didn’t know everything that was happening in her life.*

While some carers see themselves as playing a less supportive role, keeping a watch on what is happening in the life of the person with intellectual disability and seeing them on a regular basis:

*I’ve got off rather lightly, but it doesn’t matter, the fact is that it’s been a bloody long haul and I would still be involved. You know, I would like him to come over and have tea with us as a family, you know. If he wants to come home on a weekend, I would never, never say, no.*

Still others would be able to become more involved as required:

*We will always be there for him if he was ill.*

Finally, three carers expressed a desire to be involved in the development and structuring of appropriate supported accommodation. One carer explained:

*Certainly I would like to be involved with determining the type of care and activities and people that S will spend his time with.*
3.3 Qualitative data of carers who care for a person with intellectual disability living away from home

The following results are based on responses from 70 carers who care for a person with intellectual disability living away from home.

Major Themes:

3.3.1 Ageing
   3.3.1.1 The ageing carer
      3.3.1.1.1 Concern for the future
      3.3.1.2 Advancing age of person with intellectual disability

3.3.2 Family and home
   3.3.2.1 Family
   3.3.2.2 Distance
   3.3.2.3 Carer involvement

3.3.3 The experience of living away from home
   3.3.3.1 Transition to care
   3.3.3.2 Care provided
   3.3.3.3 Positive impact on person with intellectual disability
   3.3.3.4 Community access
   3.3.3.5 Relationship with other residents

3.3.4 Government support and funding
   3.3.4.1 Lack of support
   3.3.4.2 Personal financial difficulties

3.3.5 Staffing
   3.3.5.1 Staffing issues
   3.3.5.2 Relationship between staff and the people they care for
   3.3.5.3 Relationship between staff and carers
   3.3.5.4 Other factors impacting on staff ability to provide care

3.3.6 Future accommodation
   3.3.6.1 Preferred accommodation
   3.3.6.2 Co-tenants
   3.3.6.3 Dedicated aged care homes for intellectually disabled
   3.3.6.4 Ageing

3.3.1 Ageing

The average age of the carer of a person with intellectual disability living away from home was 62.4 years (see Figures 2 and 4 for more detail). The ageing and inevitable death of carers was commented on by 31% of respondents (n=22). Of these, ten (45%) commented generally that they were of an advanced age and their ability to play a part in the life of the person with intellectual disability they care for was going to or already had changed. One carer expressed his concern:
As ageing parents who presently are able to maintain close contact with our daughter and (service provider) staff, the next few years may prevent this level of support and care.

3.3.1.1 Concern for the future

The uncertainty about the future was evident for 39% of carers (n=27). While nine commented on the inevitability that current accommodation would one day be inappropriate, they saw no alternatives for the future. Two carers commented:

*Our main concern is for when she is too old to stay there.*

*As he gets older he’ll need to be in accommodation that will cater for his future needs, especially health.*

In contrast to this uncertainty, some carers expressed that nursing home care would be the next step for persons with intellectual disability as demonstrated by the following:

*In time she is going to require nursing home type care for her and in a facility that understands a person who talks a lot to herself and other people.*

Another carer expressed concern that care standards would decrease if he was not there to monitor the situation:

*At my age I am worried that S will be neglected, should I relocate or die*

The increasing care needs and the ability of current services to cope with increasing care needs was questioned by these carers. 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.

The average age of residents of (service provider) is rising simultaneously so hopefully activities and care will adapt to meet their changing needs. However, not all carers are concerned for the future and the following quote indicates a belief that care will always be available:

*As an aged parent my health is failing and I feel relieved to know he is under care.*

**One person with intellectual disability** was quite optimistic about the future, knowing that there would always be someone to care for him:

*My sister said, when you die, Mum, we will take him on.*

3.3.1.2 Advancing age of person with intellectual disability

Although the average age of 39.8 years, (see Figures 6 and 8 for more detail), the physical deterioration of the person with intellectual disability was an important issue for 63% of carers (n=38). In particular, 15 carers (40%) commented that ageing will result in a deterioration in health and physical abilities. One carer explained:

*His physical abilities will need to be nurtured as with age, cerebral palsy will gradually decrease his flexibility.*

With physical deterioration, care needs will increase. One carer commented on this aspect of ageing:

*As my son gets older he will need more support, not less.*
For those people with intellectual disability who do not live in supported accommodation this is particularly worrying for their parents. One carer stated:

*Health issues cause some concerns about his living alone.*

The main concern about deteriorating health was the loss of mobility and was addressed by six carers. Two carers described their concerns:

*I would think age and general deterioration in mobility would be main concern - though he is quite mobile at present.*

*Becoming less independent - mobility poor.*

### 3.3.2 Family and home

#### 3.3.2.1 Family

The importance of family and home was apparent even to these carers who do not live with their person with intellectual disability. Forty percent of carers (*n* = 28) commented on at least one aspect of this. Sixteen carers described regular visits and outings with the person with intellectual disability. For example:

*We take him out on regular outings such as family weddings. He is a pleasure to take out.*

**One person with intellectual disability** described a weekly outing:

*Yeah, I do my shopping Thursday – Friday afternoon with my Mum.*

Other carers stated that the person with intellectual disability comes home every weekend. Still other carers opted to have the person with intellectual disability home for extended periods of time regularly throughout the year as reflected by one mother:

*I have my son home for holidays on a regular basis - as often as I feel I am able to.*

#### 3.3.2.2 Distance

While having regular contact appears to be an ideal situation for those close to Toowoomba, this is not possible for 20% of carers (*n* = 14) who described living too far away. Many of these carers lived in Brisbane and other parts of Queensland and New South Wales. This is illustrated in Table 3.4. Many of these carers were forced into making the only decision available to them at the time:

*I had no choice 13 years ago - nothing in Brisbane too many waiting lists since and no options for him during day.*

These carers also expressed a desire to be more involved in person with intellectual disability’s life such as:

*It is 3.5 hour drive from where his parents live. If accommodation was available we would have greater visits and offer him more outside activities.*

This was such an issue for one couple that they relocated in order to find accommodation for their child. This father explained:
My wife and I had to stay in Toowoomba until we found (service provider) and soon after moved here, partly to be near him for supervision.

Sibling carers in particular sometimes end up living a long distance from their brother or sister. Sibling carers usually take on the caring role when their parents are no longer able to care. Three of these carers expressed concern about their sibling being too far away. This was articulated as:

*It would be most preferable for her to be closer to us so that she could have more family involvement.*

*My sister lives in Toowoomba 800 km from her nearest sibling, so has little support.*

*We worry about him being on his own and if he needed help in a hurry it would take time for either of us to get there.*

One carer made a plea for help from the government to address the problem of distance by providing:

*Funding to allow workshops to remain open within the local region, still allowing clients to remain within reasonable proximity to family and relatives.*

3.3.2.3 Carer involvement

Carer involvement in the life of the person with intellectual disability was variable for 33% of carers. Six of these carers made general comments which indicated they had regular contact with the person with intellectual disability. This allowed them to monitor their health and any problems or concerns they might encounter while living in a residential facility. A carer commented:

*I just feel I should keep an eye on what's going on in J's life*

This concern for ‘checking up’ was acknowledged by a person with intellectual disability who also identified regular contact with her parents:

*Yes, sometimes they call in. Sometimes to see how things are going.*

Five carers reported an intimate involvement in the life of the person with intellectual disability. Some visited daily:

*I like to go to her residential any time of the day. I am always involved in Dr’s visits. I like to be totally informed about her care.*

In contrast, other carers described not wanting to know daily events, but liked to have knowledge of and involvement in more significant aspects of their lives. These quotes are examples of this:

*Do not need to know about day to day decisions but medical decisions I need to know about.*

*Today I just took him back to the doctor myself, to our doctor, but I used to take him to the doctor and everything but then I handed over I think, well to take a little bit of pressure off me, the staff can do all that*…
However some carers described frustration and concern that distance prohibited their involvement:

I live in Brisbane and can support by phone or with regular visits but I cannot provide enough support to ensure K is safe and well cared for in her accommodation.

3.3.3 The experience of living away from home

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

3.3.3.1 Transition to care

For some carers the transition from living at home to living away from home was as a result of a crisis within the family as told by one carer.

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 - you know I’m the first to admit I accidentally dropped J by transferring him. The people from (service provider) said, “Well, look, you are going to have to do something sooner or later or otherwise what good am I?” If I’m in a wheelchair I am no good to J.

One sibling carer described the advantages of pre-planning for a crisis:

He’d lived at home with my parents caring for him, and then when 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.

3.3.3.2 Care provided

The level of care provided within residential facilities was important to the majority of carers (62%). Of these, 83% (n=20) were positive comments. It would appear that for the majority of carers, their perceptions were that the person with intellectual disability was well cared for, safe and secure. This was summed up by one carer:

I have only positive things to say about his present accommodation with (service provider).

In contrast to this, four carers felt that care provided was inadequate, either due to low staffing levels or lack of response to the deterioration in health and increasing needs of the person with intellectual disability:

J 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.

Carers of people not living in a form of residential accommodation, expressed the concern that increasing care needs are not being met in the level of support provided. Two mothers described the life of their children who are not living at home but are housed in inappropriate facilities for their level of need:

His behaviour, his cleanliness and personal hygiene has deteriorated. He has frequently gone missing, sometimes for 1 to 2 days. Last month he did not arrive home when expected and it was thought he had gone walkabout again but thankfully he was found waiting at a bus stop.

No support on daily basis. Becoming less independent- requires more help with most daily living activities - can’t use saucepans/microwave/etc. Needs lots of help.
Homecare ½ hour in the morning. He has fits and relies on police to pick him up if he fits. Can’t feed himself properly; can’t communicate when in need. No hands free phone. No Vital call. Can’t use ordinary phone.

3.3.3.3 Positive impact on person with intellectual disability
Life in a residential facility can have a positive affect on the person with intellectual disability. This includes providing a normal environment in which residents participated in daily living skills such as meal preparation and washing their own clothes. Moreover, one carer commented on how this lifestyle had given the residents:

A sense of worth and independence

One person with intellectual disability proudly listed off his chores he was responsible for in the residential accommodation:

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.

3.3.3.4 Community access
The social aspect of living in a residential facility was of great importance for 19 carers. Of these, 42% (n=8) were positive comments. One positive aspect was that interaction with the wider community was encouraged. Some of the community interaction involved residents:

Given opportunities to attend TAFE, go to church and other community activities

One carer described the importance of community interaction:

They need to be out in the community and integrated, but they need that support to do that, yeah... Well, look it depends on the level of intellectual disability.

In contrast to this, some facilities were seen as not providing adequate social stimulation, particularly on the weekend. Smaller group activities or more one-on-one assistance was seen as desirable.

The residents are generally seen as a ‘group’ and this presents challenges when one requires support or attention to do activities.

Some carers commented that they tried to address this issue during visits but this was not always successful.

K needs more social stimulation which we attempt to help achieve but cannot do entirely. More group outings would be good.

While those people living in a residential situation have the potential to have social interaction, carers of people with intellectual disability that do not live in a such a facility describe this aspect of life as lacking. One mother expressed her concern:

H is very critically lonely; he desperately needs some form of employment.

This was supported by one person with intellectual disability who expressed happiness at being independent but given the choice would prefer:

Sometimes to share I think.
For some people with intellectual disability transport issues limit community access as described by one carer:

Very top of my wish list is to have a bus to go out that is on site, especially on weekends that the guys, the staff can take the guys out either just up to K-Mart to get their money out of the bank every second weekend, or just to get out and go for a drive.

3.3.3.5 Relationship with other residents
Socialising with other residents was described by many carers as a positive experience. These carers were happy that the person with intellectual disability was living not only with other who have intellectual disability, but they were all friends and in some cases have been together for many years. This was described by one carer:

They all get on well together and have grown up together, she loves all of her mates she lives with.

Persons with intellectual disability indicated that they are supportive of each other (fellow residents), helping with daily living chores and looking out for each other as evidenced by the following:

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.

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.

3.3.3.6 Happiness
The happiness of the person with intellectual disability was very important to carers and 83% of people with intellectual disability were perceived by their carers as being happy (see Figure 14). Most carers were certain that their person with intellectual disability was happy in their current accommodation. For one carer the experience had been life-changing, not only for the person with intellectual disability but also for herself as the carer:

This accommodation and support saved his life and probably mine.

The remaining 32% of carers expressed uncertainty about this level of happiness as the person with intellectual disability was unable to express this fully. This is often realised when there is some distress shown at the end of a visit:

He doesn’t like to see us depart - but we are unable to take care of him

Likewise one person with intellectual disability reported being happy with the present accommodation arrangement but was uncertain of the future:

Oh, through ’til the end of the year. It’s hard to know.

3.3.4 Government support and funding
3.3.4.1 Lack of support
Government attitudes and funding in regards to people with disabilities angered 26 carers (37%). Nine carers questioned the Government’s commitment to supporting those with
disabilities and expressed fears for the future as a result of this lack of commitment. One carer stated:

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 inevitably fall.

Carers reported that they would like to see genuine attempts by all Governments to take a more serious attitude towards the plight of people with disabilities and their carers as is clear form the following comment:

> I would like to think that the Government, both state and federal were truly serious about caring for the disabled, so much so that they made a serious long term financial commitment to their future

Closer to home, 13 carers expressed concern over the viability of specific local services who are attempting to provide assistance to people with intellectual disability in a climate of government cutbacks.

> 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.

Finally, carers expressed frustration that the search for suitable accommodation and support has been hampered and prolonged by the necessity of fulfilling government requirements. As one carer commented:

> Government agencies didn't want to know. There was an inordinate amount of paperwork and questionnaires for Government assistance.

3.3.4.2 Personal financial difficulties
A declining standard of living for people with intellectual disability was identified by 11 carers. Issues arose around the increase in fees and living expenses. This included transport and medical costs which were becoming harder to meet. One carer shared the following:

> K has very little left out of her pension after her monthly costs are taken out. This leaves no money for recreation or special outings.

One carer expressed concern that her son who rented privately was finding it hard to keep up with rising costs:

> 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 the fluctuation in rent due to his fixed income. It would be good if L could obtain a rental unit at a fixed percentage of his income.

Another carer described the lack of funding and hardship involved with caring for a wheelchair bound daughter who was not receiving enough support to cover her care needs:

> She’s got 37 hours a week, but it’s not enough. If A had more funding which is a priority and I guess – they say Oh well, we can’t get you any more funding but I said, Well, you know she’s high support, she’s dependent on all that you know for everything. Like her meals, her showering, her in and out of her wheel chair, all of her personal care and everything. You know…
3.3.5 Staffing

Staffing issues were identified as a concern for carers of people living away from home with 46% (n=32) commenting on various aspects related to staff quality and quantity. Carers’ opinions of staffing were mixed, with 46% of the comments being of a positive nature.

3.3.5.1 Staffing issues

Seven carers (10%) felt that residential facilities were inadequately staffed. Whilst acknowledging that many of the staff are genuine in their efforts to provide adequate care, this was often hampered by the few numbers of staff employed. One carer observed:

I am sure they do their best, but I think there are just not enough staff to give the residents the personal attention they need.

Equally important and for some carers, the optimum level of support was 24 hours a day seven days a week, not only for the safety of the person with intellectual disability, but also to ease concerns of the carers.

I would like to see a stay over person on duty at all times, as everyone would feel much safer.

One person with intellectual disability left the residential when overnight carers were removed, but only after he was certain that it was what he wanted:

I tested it out first before I asked Mum and Dad can I come back home.

High staff turnover rates also caused concern for carers. This can cause disruption to the resident’s routines as one carer described:

Over the last few years there have been a lot of staff and timetable changes.

It is recognised that permanent staff allows for more familiarity with the resident’s routine and for greater access to the wider community in the form of external excursions to the movies, dinner and picnics. The use of non-permanent staff was also disruptive for the clients and had the potential to be dangerous. One carer expressed concern over lack of client familiarity and the potential for errors to occur:

I wonder if mistakes are made in administering daily medications with changes in staff who are unfamiliar with the clients.

Likewise employing quality staff who are genuinely interested in providing care is of vital importance. One carer described her experience:

I have found that a lot of the support workers that come to work with disabled people do not have the best interests of that person as a number 1 priority - a lot is about making it look good on paper to get funding.

3.3.5.2 Relationship between staff and the people they care for

The relationship between staff and the people they care for was identified by 13 carers (19%) as being of prime importance and necessary for an environment of trust and confidence. The majority of these carers (93%) provided positive comments regarding this relationship. Staff were described as caring and creating a home environment where the residents are treated like family members. In addition, one carer commented on how her daughter was valued and encouraged to develop as a person:
Through the caring people in charge H learns trust, patience and cooperation and friendship.

It appears that the size of the accommodation facility can make a difference in how successful this relationship becomes. In smaller accommodation services, people with intellectual disability are encouraged to participate in decision making. One carer described:

*The staff are really good and you know they include them in – ask them what meals, what they would like for dinner, and their washing is done.*

However the converse is also true and while certain staff may encourage independence, sometimes expectations exceed the ability of the person with intellectual disability as one carer explained:

*They put too much pressure on him to do things he can’t handle.*

3.3.5.3 Relationship between staff and carers

Carers were evenly divided in their opinion on their relationship with staff at their respective residential facilities. The main concern for half of the respondents was that the staff were unapproachable which severely restricted communication between staff and the carer. This situation is amplified in cases where the carer lived a long distance away. For example, one carer commented:

*I would like (name of supervisor) to be more approachable*

However, the other half of carers reported a good relationship with staff at the residential facility. They felt they were not only kept up to date during visits, but were also happy to communicate via the phone.

3.3.5.4 Other factors impacting on staff ability to provide care

Staff ability to provide adequate care is perceived by some carers as being influenced by the lack of support that they receive from the service organisation and by the amount of paperwork and ‘political correctness’ that staff are required to follow. Organisational change also impacts on the care provided as one carer explained:

*Changes in administration with different ideas for caring and also petty ‘politically correct’ rules are very annoying*

3.3.6 Future accommodation

3.3.6.1 Preferred accommodation

The majority of carers would prefer a smaller accommodation type than the residential where the person with intellectual disability currently lived (see Figures 17 and 18). The advantages of a smaller residential facility were reported to be safety, the formation of friendships and more one-on-one support which is seen to encourage independence. Smaller accommodation would also allow for a more normal or family like living environment as explained by one carer:

*Sharing accommodation with up to 3 other similarly disabled people would seem to be ideal and most closely resembles family life.*
Carers also described the necessity for people with intellectual disability having their own personal space. Descriptions of rooms included:

She’s got her own room, with her own bed, her own television, her drawers, cupboards In J’s bedroom he’s got his own TV, he’s got his own stereo, he’s got his own DVD, own video.

Accommodating different personalities and preferred life-styles was necessary in deciding how people with intellectual disability should be accommodated. Two differing opinions included:

The ideal for P, ok, would be living in a flat where someone was coming in every day and would supervise that he would do his washing, cook a meal. He doesn’t have the motivation to survive.

A multi-purpose home and there was other co-tenants and it was on acreage, that type of thing, out of town on a bit of home acreage, where they can have a few animals and have a leisurely life.

For many carers, issues other than the physical building were more important. One carer expressed:

I think they need someone who is going to – who cares about them and is going to greet them and – there has to be rules in the house when you’ve got a number of people living together but it has to be applied fairly kindly.

Carers of people with intellectual disability who do not live in a residential situation also expressed their accommodation concerns:

I want a safe environment. Support with money and personal needs. Companionship and social interaction.

My sister needs continual support and this can be given in a small group setting. I wouldn’t like to see her in a small or large residential- not enough individual care.

Something appropriate to accommodate the high level of support required by our daughter, yet provide her with the freedom which she demands.

One carer however, warned that any sweeping changes to the provision of accommodation should be explored thoroughly before implementation:

Well meaning people have pushed the ‘independent living idea’ previously without listening to family/residence supervisor and often don’t have the best interest of the person with the disability. It is also very traumatic for everyone when they fail when trying to achieve something that is out of their reach.

3.3.6.2 Co-tenants

Concern was raised by some carers regarding the choice of co-tenants. One carer described the need for screening to ensure safety:

We had another guy came in who had a good package deal, but the co-dependency didn’t work out. He was rather violent and did $700 worth of damage.

Another carer was concerned about mixing males and females:
They don’t seem to be able to cope with the female intellectually disabled. Like it seems to set up the hormones somehow and in all cases we get violent - jealous type of violent.

**One person with intellectual disability** was adamant that he wanted to take part in the selection of co-tenants:

> I want to make sure that I like the people I live with and I get on with them.

3.3.6.3: Dedicated aged care homes for intellectually disabled

Finally a carer expressed the desire for accommodation to support people with intellectual disability as they age:

> Well, yeah, I think that age in care is going to have to be set up for the intellectually disabled. I don’t think they’re going to fit into normal nursing homes. Our intellectually disabled are going to age earlier. They’re going to be looking for a nursing home somewhere between 50 and 60, not 80 like most – 80/90. They’re not going to be able to cope with – our kids don’t have the language, concentration, so I can see – if poor L was in aged care, they’re going to isolate him because L’s speech is so bad.
4.0 DISCUSSION

This report presents the results of a study on behalf of the Toowoomba Intellectual Disability Support Association (TIDSA) and funded through the Gambling and Community Benefit Fund. This study is the first of this kind to be conducted in Toowoomba. It has enabled people who care for someone over the age of 18 years with an intellectual disability and the people themselves with intellectual disability over the age of 18 to express their accommodation needs for the future.

The project has identified two groups of carers. These are; a) carers whose person with intellectual disability lives at home with them and b) carers whose person with intellectual disability live away from home. The study has enabled a unique examination of the difference between expectation of accommodation services and real experiences with those services. In addition, those carers who have experience in dealing with accommodation services have provided invaluable information for organisations currently providing or considering the provision of such services.

A discussion of the findings is presented below with summary points listed after each section. Following this, limitations of the present study and future considerations for further work will be listed.

4.1 The ageing carer

The findings of this study clearly indicate that the age of carers of people with intellectual disability in Toowoomba and contiguous shires is an issue of great concern and increasing importance. The average age of carers caring for a person over the age of 18 who is living at home, is 61 years. The average age of the carer who cares for a person with intellectual disability who is living away from home is 62. The overall age range of both these groups of carers is between 51 and 70 years. This data is a direct reflection of the older age group of carers who care for a person with intellectual disability over the age of 18. While carers caring at home identify a spouse as a secondary carer, it can be assumed that the spouse would be of a similar age. Nearly one quarter of these carers identify no other carer.

Carers are not only aware of the consequences of their ageing and inevitable death but also fear that their health will deteriorate to the point that they will no longer be able to provide quality care while they are alive. The overwhelming fear is that there is no person or service that will be able to provide support for their person with intellectual disability when they are unable to continue care or die. Some carers are already experiencing ill health which affects their ability to care and believe that this will only become worse as they get older. These concerns are already producing a great deal of anxiety and fear for both groups of carers. This anxiety stems from the lack of clear vision of the future for their person with intellectual disability. The lack of choice and options for future accommodation has been brought about by poor government planning and little support and interest in this area of disability need. While those carers who care for someone at home express a need to continue caring as long as possible, ensuring contingencies for the future is currently impossible due to a lack of available options.

Carers who care for someone with intellectual disability who is living away from home also fear for the future. There is growing awareness that existing services will no longer continue to provide adequate quality of care once the carer has died and is unable to monitor the service provision. There is also doubt that current services can accommodate the person with intellectual disability indefinitely due to their increasing care needs that is; advancing age. With this doubt comes confusion about where the person with intellectual disability will receive the necessary care in an environment that understands their particular disability and care needs. Carers would like to see some options available for consideration before they
are too old to continue caring or they die with nothing in place for their person with intellectual disability.

However amidst all this concern, not all carers are apprehensive about the future of the person they care for. A small proportion feels that current services are coping well at the moment and they see no reason for that to change. Alternatively, transfer from disability services and into nursing home care is seen as a logical progression. Likewise not all people with intellectual disability are concerned about the future, with some expecting ongoing family support or residential provision continuing indefinitely.

**Important summary points:**

- Carers are ageing and need some assistance immediately.
- There is little choice of suitable, available accommodation in Toowoomba and contiguous shires for people with intellectual disability.
- There are concerns that the current services may not be monitored adequately in their provision of care. In addition, it is not clear to carers who is monitoring the service providers and how that is being done.
- It would appear that services are not keeping pace with the increasing care needs of the people with intellectual disability and their carers. Progress in this area also needs to be monitored.
- Utilising nursing homes to meet the care needs of ageing people with intellectual disability is not appropriate. Care facilities that understand and can cope with the needs of people with intellectual disability are urgently required.

4.2 Ageing of people with intellectual disability

Ageing of the person with intellectual disability and its associated consequences is of great concern for carers. People with intellectual disability living at home are on average, younger than those living away from home. People with intellectual disability can often experience poorer health than the general population and many are likely to begin the ageing process at an earlier stage in their life (Bigby, 2004). This is being observed by carers now and adds to the urgency of their situation. The carers in our study have noted physical deterioration in their person with a disability, such as increasing difficulty completing basic skills (e.g., getting in and out of the bath).

Loss of mobility of the person with intellectual disability in particular appears to be a major concern for carers, as this will inevitably reduce their independence. Physical deterioration is not only being observed by carers, but is also being seen and confirmed by their General Practitioners. Thus as the person with intellectual disability ages and deteriorates physically, increased care needs will place more strain on carers and services.

It was reported that services are not prompt in reacting to necessary changes to the physical environment in the home (e.g., installation of hand rails, installation of a shower recess). Compounding the problem is the situation of an older carer less able to meet the increasing care needs of the ageing person they care for. This translates to inadequate support for both the person being cared for and their carer. Little wonder why levels of anxiety are high among all concerned.

**Important summary points:**

- The advancing age and associated needs of the person with intellectual disability is recognised and is a matter of great concern for carers.
- As the person with intellectual disability ages, services should conduct close monitoring for increased physical support needs (e.g., hand rails, ramps, wheelchairs, hoists, installation of shower recesses) and ensure these are provided if necessary.
In home support services need to be increased to assist those people in who live at home. This should include respite and personal care.

4.3 The importance of family and home
This study has found that the family is a vital part of the life of people with intellectual disability. Family is seen as providing the safety, security and love that paid carers do not provide. For those who are living at home, family provides a social network and enables the person with intellectual disability to participate in daily living activities such as helping with cleaning and cooking. This participation in the family activities is identified by people with an intellectual disability as being very important and gives them a feeling of belonging. For some carers, home is the preferred place of residence indefinitely, for others it is suitable only until they can no longer care or other options are presented. Many people with intellectual disability have never experienced life away from home, and carers are apprehensive and uncertain about how the person with intellectual disability would cope. Furthermore, for those who have had a taste of life away from home, the experience was not always successful for various reasons including the fact that services were not able meet their care needs, resulting in a return to home.

Those carers who care for someone who does not live at home, feel strongly that connecting regularly with the person with intellectual disability is very important. Likewise this feeling is shared by people with intellectual disability who live away from home. However the degree of contact is different for each family. Many in Toowoomba and contiguous shires have regular contact and see their person with intellectual disability daily or see them weekly for a regular visit (e.g., shopping) or as needed (e.g., medical appointment). Still others come home for the weekend or less regularly but for an extended period of time.

For carers who live a long distance away from the person they care for, regular support other than by telephone is not possible. There are two main reasons for this situation. The first is dearth of options available to accommodate their person with intellectual disability closer to the family home. Carers from Brisbane and other parts of Queensland report that they were told by service providers where to place their person with intellectual disability. Therefore some families are separated from the person with intellectual disability due to lack of choice and available options.

The second reason is that the primary carer in Toowoomba (usually the parents) have died, leaving siblings to take over the caring role. Distance again compounds this problem. Siblings who had moved away and started their own families suddenly find themselves responsible for taking over the role of carer, often over great distances. This is a major cause for concern for these carers who often have to drive many hours to visit or attend to matters on behalf of their intellectual disabled sibling. Furthermore they are unable to offer immediate support should an emergency occur and are restricted in their ability to provide the desired family interaction. Our study found that these carers would prefer to have the person with intellectual disability live closer to them so that family involvement can play a bigger part in the life of the person with intellectual disability. However, the dearth of accommodation options available to these carers leaves this situation unchanged.

Important summary points:

- In-home support should be encouraged as in-home carers want to continue care as long as possible. If that is the carer’s choice, there should be more services to support them in the home.
- People with intellectual disability need to be near their family. This ideal situation offers support and assurance to both the carer and the person with intellectual disability.
There is a need for more accommodation in the local area where the family is based. It is also imperative that there is flexibility within the system for people with intellectual disability to move from one place of accommodation to another in situations where the family moves. There should be more flexibility of services and availability of accommodation options to encourage carers to interact as much as possible with each other, thus offering support for each other.

4.4 The experience of living at home
When a person with intellectual disability resides at home, this means that personal needs such as meals, medical appointments, security, behaviour monitoring, and financial assistance can all be provided by the carer who is almost exclusively an ageing parent. Our study found that people with intellectual disability acknowledge that they need this assistance and that it is provided by their parent(s). Living at home means that the person with intellectual disability has all the comforts normally attributed to home such as their own room and independence. However this idyllic scenario comes with a cost.

For example, family squabbles can occur which frustrates both parties creating jealousy and friction with other siblings. Carers feel the person with intellectual disability living at home becomes too dependent on them for their care. This not only restricts the carer’s freedom but most certainly means that their person they care for faces a greater upheaval and adjustment to life without them when they die. Additionally, this dependence decreases confidence in the person with intellectual disability to the extent that they become afraid to ever leave home. This study found that carers who care for someone full time equate this to an end of a ‘normal life’. While retirement from the workforce is looming for these carers, retirement from the caring role is never ending. Therefore, life for many carers will not change in the foreseeable future. Concern for the price parents pay in the caring role is also seen by people with intellectual disability who understand that their parents are ageing and tiring and will not be able to care for them forever. Carers believe that if services were available to help take over or share the caring role, the burden of responsibility would be lifted and they would no longer have to fear the future.

Important summary points:

- Carers of people with intellectual disability over the age of 18 who live at home are almost exclusively an ageing parent.
- Regular respite should be more available for those who care exclusively for their person with intellectual disability.
- More services should be available to encourage more activities away from primary carers and the home environment. This would increase the independence and social skills of the person with intellectual disability so they may make the transition of living away from home more successfully at some stage in the future.

4.5 The experience of living away from home
Our study found that the transition to living away from home can often be the result of a crisis in the family. The carer either becomes ill and unable to care or dies suddenly. This is traumatic for all involved with or connected to the person with intellectual disability, particularly when there are no strategies in place to continue care. Planning ahead for such an eventuality results in a much smoother transition for all involved and ensures trauma to both the carer and the person with intellectual disability is minimal. While this statement may appear obvious – in reality this type of forward thinking by carers is delayed and even obstructed because there are so few options available to plan for future care.
For those persons with intellectual disability who have settled in disability accommodation services, the care provided was reported of a high quality. Furthermore carers feel that they are well looked after, safe and secure. However for a person with intellectual disability accommodated outside of the specific disability services, such as residential aged care facilities, the type and quality of care is very different. Respondents in our study reported that these facilities do not cope adequately to the ageing care needs of a person with intellectual disability. This is often due to communication problems or other behavioural issues of people with intellectual disability. Moreover, as behaviour deteriorates other community services such as the police or ambulance, often become involved in providing some degree of security, medical support and a transport service.

Important summary points:

- Disability services should provide assistance to carers with planning for the future in order to alleviate anxiety and disruption to care should circumstances suddenly change and they are unable to continue care.
- Government and disability services are not recognising the changing needs of people with intellectual disability in connection with their advancing age.
- Government and disability services are not recognising the urgency of increasing care needs due to advancing age of the carer.
- There are persons with intellectual disability who have fallen through the ‘net’ and are housed in inappropriate accommodation. This is primarily due to inadequate assessment of their care needs and compounded by the dearth of available accommodation.

Our study found that when accommodated and supported appropriately by disability specific services, people with intellectual disability have the opportunity to live in what might be considered a normal home-like environment. They are mostly happy, but can display some distress at being separated from family. Many of the people with intellectual disability see themselves as living with their friends and this level of comfort and familiarity is reflected in the way they talk about their lives and the way they support each other. At appropriate care facilities they are encouraged to increase their independence and develop daily living skills such as meal preparation and washing their own clothes. This is reported by their carers as instilling a feeling of pride, importance and self-esteem. A positive feature of some accommodation services in Toowoomba is their integration with the wider community, providing the opportunity for residents to attend Technical and Further Education Colleges (TAFE), church and social activities with their peers.

Conversely, some people with intellectual disability are not as able or willing to join in on large group activities and require more individualised support. It appears that the larger residential facilities are not meeting this need adequately and offer little or no attention to individual levels of need. Carers try to provide this extra support and attention during visits but are unable to replicate the advantages of contact and the socialisation with peers.

Important summary points:

- Service providers should support and encourage as much integration with the community as possible.
- More person-centred support is required in large residential facilities to avoid the resident getting ‘lost’ in the system with little peer contact or social opportunities.

4.6 Government support and funding

A general lack of trust towards government commitment to assisting people with intellectual disabilities was overwhelmingly expressed by carers in this study. Governments at all levels are seen to be withdrawing support from a vulnerable segment of the community. This not only angers carers but also creates fear for their future. They feel that without government
support there is no chance of securing a future for the person they care for. Withdrawal of government support is seen in the form of funding cutbacks, increased waiting lists, closure of local institutions and lack of individual government funding packages. Carers report that they are continually filling out applications for support yet often get no reply. Carers feel that a double standard policy exists where only a child with a “severe disability” qualifies for the support packages that are available. Therefore the needs of carers and those people with milder but no less important levels of disability are overlooked. This situation supports the feeling that the government does not recognise the urgency of this dilemma of accommodation needs for ageing carers of ageing persons with intellectual disability.

Our study participants report that accommodation options put forward by families to state government services have been disregarded because of the mild level of intellectual disability. Despite the proactive approach and the conviction of the families that ‘they know what is best for their child’, state government services will not enter into a dialogue with those families unless their care needs are perceived as being high enough.

The well published local service cut-backs have frightened many carers. Our study found that in the past many carers assumed that the eventual care of the person with intellectual disability would be automatically taken over by local services. There is increasing realisation that this is not so. Indeed carers who currently have a person with intellectual disability residing in supported accommodation are no longer confident that the government will provide enough funding to ensure services will continue to provide care once they have died.

One area affected by lack of government funding is that of respite. Respite has two main roles for carers. The first is to provide a break from the caring role. Our study has clearly shown that the already urgent need for this is further exacerbated by advancing age. Secondly, respite allows people with intellectual disability who have never lived away from home to experience what life would be like with his or her peers in a safe and supported environment. This is invaluable for gaining confidence and learning the social skills necessary to eventually cope outside the home environment. Very few carers have access to regular overnight respite due either to its unavailability or the high cost for those with no government support package. However our study showed that in a few instances where respite was arranged, both carer and person with intellectual disability found it a benefit and relief.

Furthermore, carers increasingly find themselves caught between State and Australian Government services. Respite beds in aged care residential facilities which were once accessed by carers of people with intellectual disability are now no longer available. This is due to the demand of the general ageing population and the restriction of access to these beds by the government. With no disability service to specifically address this issue, these carers are no longer able to access overnight respite.

Participants in our study cited that government funding is not keeping up with increasing care needs and rising costs leaving more and more people with intellectual disability with less disposable income. This situation impacts directly on their ability to connect with their community. For example, expenses for social outings and transport are less likely to be met. People with intellectual disability are also struggling with medical expenses which are likely to rise as they age. Those living in supported accommodation are not always supplied with appropriate levels of support and rely on friends or share support packages to top up their care needs.

Important summary points:
• The government needs to recognise the urgent nature of this escalating situation because the need for more accommodation options, including overnight respite for ageing carers will only increase.
• The lack of respite opportunities needs to be addressed.
• The application process for support packages should be streamlined to avoid completing forms year after year. Every applicant should obtain a reply regardless of the outcome.
• There needs to be acknowledgement of the needs of milder intellectual disabilities - these are the people most at risk of falling through the cracks in government funding.
• More attention is needed to provide options that suit the ‘individual’ as all care needs are different.
• With proper and appropriate government attention and support, many people with milder forms of intellectual disability could live productively in the community therefore reducing the need for disability specific accommodation.
• The government needs to coordinate disability services within the community.
• There needs to be more consistent and regular monitoring of fees for services.
• An increase in basic pensions needs to be reviewed and kept up to date with cost of living.
• Support packages need to be appropriate for the level of care required.
• A better way of managing rent increase should be investigated for those who want to live in the community.

4.7 Staffing issues for those living away from home

Our study respondents reported that overall most of the staff within residential facilities are caring and attempt to create a home-like environment for their residents (persons with intellectual disability). Staff often engage residents in decision making and assisting with daily chores. However this level of attention is dependent on both the number of staff available and the amount of training they receive. Twenty-four hour care is seen as the ideal level that provides complete safety for the residents and provides the desired overnight support. And residents themselves report feeling more secure when they know there is someone on the premises at all times.

However, our study noted also that the quality of some staff is not always in accordance with the needs of the residents. The dedication to providing individual attention and quality care appears to be overruled by the burden of endless paper work. There was no clear consensus for the reason why staff at residential care facilities is often under par.

Equally important was the concern that staff turnover is high in some residences. This can result in disruption to the lives of the residents and at times decreases their access to the wider community. The risk of harm to residents was seen to be higher when staff were not familiar with their individual needs and routines.

Often the relationship between staff and carers was reported as less than ideal. This was primarily thought to be due to communication issues, with many carers feeling that staff are unapproachable and unwilling to provide detailed information on the person with intellectual disability. This is a cause for disappointment and worry for carers who live long distances away and see their person with intellectual disability infrequently.

Important summary points:

• Generally the care at residential care facilities is considered good, however, there needs to be increased staff training at a higher level to understand and provide for the needs of residents with intellectual disability.
• There is an overall perception that staff levels need to be increased at most care facilities.
• Provision of overnight care is seen as essential.
• The individual needs of people with intellectual disability should be an important consideration. Some people with intellectual disability only require assistance with meals, while others require 24 hour care. These differences should be accommodated by services.
• The reason for high staff turnover is of concern and should be investigated.
• Open up communication between carers and support workers. An open door policy will assist with the provision of appropriate care and reduce the stress on carers.

4.8 Accommodation needs of the future

4.8.1 Lack of choice
This study has provided evidence that currently in Toowoomba and contiguous shires there is a worrisome lack of suitable and available supported accommodation for people with intellectual disability. Therefore those carers caring at home have no choice but to continue in their caring role. Furthermore current accommodation services are not only outdated, but filled to capacity. Carers no longer see these services as fitting the ideal life that they would like for their person with intellectual disability. While the presence of these services at one time provided a glimmer of hope for carers, recent government cut-backs have extinguished this hope. The overwhelming feeling is that the carers’ voice will only be heard when the situation reaches crisis point. For many carers and their families this has already occurred.

4.8.2 Options
Many carers have explored other options to this accommodation crisis. Acquiring a granny flat or accessing accommodation through the Department of Housing, are examples. However remaining in the family home is also an option that some feel very strongly about. For those who feel that ‘home’ is the only place to be, the plan is usually that the family home is left to the person with intellectual disability who will reside there indefinitely with in-home support from disability services. While for some carers this may appear ideal, not all carers are in a financial position to be able to bequeath the family home to the person with intellectual disability and then have adequate services assured to support them. This option appears a risky one when it is already apparent that services are decreasing - not increasing. People with intellectual disability have also recognised that there is not one solution to the accommodation issue and are also exploring alternative solutions such as sharing accommodation with friends.

4.8.3 Sibling support
When the carer is no longer able to care, some families plan for the siblings to take over the caring role. Not all carers are happy with this arrangement and would prefer services to take over this role, allowing the siblings to continue with their own lives. In some situations the sibling taking over the role of the carer is not practical. In many instances the siblings can be a great deal older than the person with intellectual disability and therefore dealing with their own ageing issues or they may live long distances away.

4.8.4 Separation from community
There is some disagreement between carers about accommodation services being established exclusively for people with intellectual disability. Some carers feel very strongly that people with disabilities like to be amongst other people with disabilities. Other carers feel equally strong that people with intellectual disability should live amongst the community and not be isolated from non-disabled people.
4.8.5 Ideal accommodation
The village style or small residential are seen as most desirable accommodation types because they are perceived as providing privacy, along with the support and social needs of people with intellectual disability. According to carers, a home-like environment is imperative to overall happiness and security. This home-like environment generally includes residents having at the very least their own room with an en-suite also highly desirable. People with intellectual disability in our study pointed out the need for their own space so they can have time alone or with others as they please.

4.8.6 Socialisation
Apart from providing day to day care, residential facilities are seen as providing a social network that some in-home carers struggle to provide. On the other hand, most carers are also concerned that the number of people with intellectual disability living in the one place should be kept small with two or three people being the ideal. The general consensus among carers and people with intellectual disability is that seven to ten would be the absolute maximum residing in one dwelling. While socialisation is seen as a good outcome, some people with intellectual disability do not want or need extensive interaction with others and this should also be catered for when planning accommodation facilities.

4.8.7 Staff
Carers in our study report their prior experience with many of the staff at residential facilities has made them wary and discerning about the qualities required for support staff. Qualities that carers feel that staff should possess included patience, tolerance and understanding. In addition to these personal attributes staff also need to be adequately trained to cope with a wide range of intellectual disabilities and therefore provide various levels of support. Obviously adequate numbers of staff are expected to be present throughout the day including 24 hour support. However promoting independence where possible is a priority, meaning that an appropriate level of care should be provided to meet the individual needs of the resident.

4.8.8 Location
The physical location of accommodation facilities is an important consideration to carers as easy access to the community means that people with intellectual disability can participate in community activities such as bowling, shopping and going to the movies. While many of the people with intellectual disability are either able to use public transport or use Taxi services, accommodation away from these services will require other transportation strategies to be explored.

4.8.9 Accommodation costs
Appropriate accommodation cost is an area that needs further exploration. While some carers were happy for people with intellectual disability to pay the going rate of 85% of their pension in accommodation costs, others felt this was too high. Paying this amount allows very little disposable income to cover social, transport and medical costs. A flat rate for accommodation which covers running costs is another option, as many people with intellectual disability are in receipt of a Disability Support Pension and this would ensure that costs will be distributed fairly.
4.8.10 Ageing-in-place
Ageing in place is seen as a desirable option and ensures that people with intellectual
disability are cared for by people who understand their needs. It also eliminates the problem
of younger people being forced to live with people at aged care facilities who are not their
peers. Conversely, elderly people are not subjected to behaviour from younger people that
could be seen to be inappropriate.

4.8.11 Security
The safety and well-being of people with intellectual disability is of paramount importance
and all carers are concerned that people with intellectual disability are treated with respect at
all times and not in danger of exploitation. Physical and sexual security is seen as areas that
can not be compromised, both by carers and people with intellectual disability.

4.8.12 Working towards independence
Carers live in the hope that somewhere, someday there will be help for them in
accommodating the person with intellectual disability and work constantly towards ensuring
that a certain level of independence has been achieved. Some carers are aiming for an
adequate level of independence by the late 20’s or early 30’s. This preparation for eventual
independence is vital in order to reduce any trauma in the event of an unexpected happening
such as the death of the primary carer. Most carers believe that acquiring a certain level of
independence will also provide dignity and self-esteem and will help ensure that the people
with intellectual disability have a better chance of living a happy and full life.

4.8.13 Carer involvement
Most carers do not see their caring role ceasing if alternative accommodation was provided
for the person with intellectual disability. Carers anticipate they will continue providing varying
degrees of support, depending on their own health status. Some anticipate support
decreasing as the person with intellectual disability becomes more independent and
confident in the new accommodation. The amount of anticipated involvement with their
person with intellectual disability varies from carer to carer with some just happy to know
when there is a problem and others expecting regular contact and involvement in day-to-day
decisions.

Important summary points on accommodation needs for the future:

- There is an urgent need for purpose built disability systems of accommodation,
  perhaps similar to that within the aged care sector.
- More respite and in-home support is needed for those that want to stay at home (e.g.,
  hand rails, ramps).
- There should be provision of support for sibling carers who take their brother or sister
  into their home for care. Siblings need to be recognised as primary carers with any
  benefits or support transferred to them to help enable them to continue their own lives
  (e.g., work, family).
- Access to carer support through Centrelink should be explored to facilitate transfer
  from one carer to the next when the parents die.
- There is no clear evidence as to whether it is best for people with intellectual disability
  to live in dispersed housing in the community or in a campus style accommodation
  among others with similar disabilities.
- Village or small residential type accommodation would appear to be the most desired
  accommodation options, but dispersed housing is also seen as highly desirable.
• It is imperative that people with intellectual disability have their own room which they can personalise. En-suite rooms are universally seen as highly desirable.
• The optimum number of residents per house or facility is universally seen as three or four.
• The quality of support staff is paramount to a safe, secure and comfortable life. The process of recruitment and training of staff process needs investigation to ensure this.
• Accommodation should be close to community services. If not, transport issues need to be addressed to ensure access to social activities and other necessary services (medical, dental shopping etc).
• Accommodation costs must be affordable and in line with pension entitlements. This area needs further exploration to ensure appropriate and affordable housing for all levels of need.
• There is an urgent need to cater for ageing requirements of people with intellectual disability. Nursing homes are not equipped for the needs of people with intellectual disability and are not appropriate in the long term.
• 24 hour care is seen as ideal to help ensure that people with intellectual disability are safe and fully supported throughout the day.
• Accommodating males and females within the same facility must be done carefully to ensure safety for all people with intellectual disability.
• Disability services should communicate more closely with carers to ensure that residential staff understand the individual capabilities of the person with intellectual disability. This will maximise the opportunities for independence as much as possible.

4.9 Study limitations and future considerations
The current study is exploratory in nature and while providing an overview of accommodation needs in Toowoomba and contiguous shires, results must be interpreted with caution. Following are some limitations of the current study and considerations for future study.

4.9.1 Response rate
Every attempt was made to ensure that all carers who met our eligibility criteria in Toowoomba and contiguous shires were given access to and an opportunity to respond to the survey. However the limited response from carers in contiguous shires could be due to several reasons.

• A major reason could be a reflection of people living outside of Toowoomba city and not being serviced by a service provider - therefore not being sent a questionnaire.
• This could be because the person with intellectual disability does not have needs high enough to meet the guidelines of funding bodies and therefore is not eligible for service support.
• It is also probable that many carers living outside of Toowoomba are hidden carers that are not known to service providers. In other words some carers have never enquired about obtaining support let alone accessed it.
• There is also anecdotal evidence to suggest that people in contiguous shires that are from a strictly rural background see accommodation for their child with an intellectual disability as an issue for family to deal with not something to be addressed by others outside the family.
• Finally, Gatton which was included in our survey area is located between Toowoomba and Ipswich. Again anecdotal evidence suggests that many carers in Gatton perceive Ipswich as their service town. Therefore a survey regarding accommodation needs and services in Toowoomba was not relevant for these carers.
4.9.2 Questionnaire distribution
Due to a lack of streamlining among Toowoomba services and uncertainty of the prevalence of intellectual disability within the Australian community, an accurate figure of people with intellectual disability residing in Toowoomba and contiguous shires is unavailable. Therefore it is not known if all carers who fit the criteria of the study were given access to the questionnaire. Moreover, some carers were not approached to participate as a result of discussions with service providers regarding their current frailty and stress levels. It was decided that the potential for harm far outweighed the needs of the study and these carers were not approached. This means that we are not certain how many carers were given the option to participate.

A great deal of time and financial expense was afforded to distribute the study questionnaire to smaller service providers within Toowoomba shire. These smaller service providers were pursued in hopes of increasing our sample size and response rate. Additionally, much effort was expended in an attempt to access all possible participants in contiguous shires and consequently it was necessary to contact other service providers outside Toowoomba shire. This study found that the gain from this outlay of time and effort was very small and not reflected in the return rate. It is suggested that any further studies of persons with intellectual disability over 18 years of age distribute materials through the main service provider only.

This finding was unexpected but of great significance because it exposes a major weakness in the system which provides services to carers of people with intellectual disability. No universal database or record exists that all service providers can tap into that would help ensure that all carers and persons with intellectual disability are identified and do not fall through the gaps. This study would make a strong recommendation to government agencies to update and reform their current records system so that everyone ‘out there’ who is entitled to assistance with the person they care for is aware of their rights and their entitlement. This is of particular importance to older carers and those who reside in rural areas who are more likely to be less mobile and in touch with available services.

4.9.3 Restriction in the age of person with intellectual disability studied to over 18 years
The main focus of this study was on needs of the ageing carer in relation to accommodation for the person with intellectual disability they care for. Therefore it was decided that only carers of persons with intellectual disability who were over 18 years of age would be included. This further focused the study on a description of current and foreseeable future needs only. A further study involving carers of children under 18 years with an intellectual disability will allow a more comprehensive exploration of accommodation needs and help speculate on a long term view of this important issue. Younger carers may hold different perspectives on this issue and might offer alternative solutions for the future. In addition, it is possible that carers of and people with physical disabilities also face the same accommodation issues. All perspectives deserve to be explored in order to fully investigate the current situation and suggest options for the future. Any information gained could prove fruitful in providing solutions to the accommodation needs for those with intellectual disabilities of all ages.

4.9.4 Self report
Allowance must be made for the self-report nature of this study. Furthermore the interviews conducted with intellectual disabled people represented a wide range in communication abilities (both comprehension and verbalisation). Finally those aspects of the questionnaire where the carer was asked to express an opinion on behalf of the person with intellectual disability may not represent the view of that person with intellectual disability.
Acknowledgements
The authors wish to thank Dr Louise Young for her expert advice on conducting the semi-structured interviews with our intellectually disabled participants. Thanks also to Ms Sarah Crundwell and Mrs Erin Bowly for their assistance with the final editing process.
5.0 REFERENCES


Felce, D., & Emerson, E. (2001). Living with support in a home in the community:Predictors of behavioral development and household and community activity. **Mental Retardation and developmental disabilities research reviews, 7**, 75-83.


6.0 APPENDICES

6.1 Covering letter
6.2 Letter to service provider
6.3 Questionnaire
6.4 Plain language statement and consent form (for questionnaire)
6.5 Interview questions for carer whose person who is living at home
6.6 Interview questions for carer whose person who is living away from home
6.7 Plain language statement and consent for carer interview
6.8 Interview for person with intellectual disability who is living away from home
6.9 Interview for person with intellectual disability who lives at home
6.10 Participation consent form for person with intellectual disability
Dear Parent/Carer,

We are a group of parents/carers who formed a Toowoomba based association in February 2004. We recognise the problem of safe supported accommodation for our people with intellectual impairment as an acute one and believe that it will worsen as we all age. We aim to investigate this need and hope to provide some suitable options.

We require information from you to better understand the present and future accommodation needs of your son/daughter/relative/friend. This information will be of vital importance in planning for the best outcomes for our folk in need. Please help us by completing this questionnaire.

We can assure you that all information you provide will be treated as strictly confidential and any personal information will be removed before analysis.

Due to privacy concerns, this questionnaire has been kindly distributed by a service provider. We know that some of you have contact with more than one service and will receive more than one questionnaire. There is no way to avoid this. **If you happen to receive more than one, please send only one back to the researchers.** Either dispose of the others or pass them on to a friend who should have received one.

We hope you will complete this questionnaire and return it in the stamped addressed return envelope as soon as it is convenient.

Thanking you in anticipation.

Yours sincerely

Diana McKay
Research Officer
Dear Service Provider,

Thank you for offering to help with the distribution of the TIDSA questionnaire. This questionnaire has been designed to be completed by the carer of a person with an intellectual disability. This carer does not have to live with the person they care for.

The population we are specifically concerned about accessing are:

- those people who care for someone over the age of 18 with an intellectual disability
- carers of those people who have another type of disability that may include a component of intellectual disability (e.g., Autism, Down Syndrome)
- those that fit into the above criteria AND either the carer OR the person with an intellectual disability reside in any of the below shires
  - Rosalie
  - Crows Nest
  - Toowoomba
  - Cambooya
  - Pittsworth
  - Jondaryan
  - Gatton

Postcodes: 4350, 4352, 4353, 4354, 4355, 4356, 4358, 4359, 4360, 4363, 4364, 4400, 4401, 4402, 4403, 4404, 4614

If you have any questionnaires left over or require more please contact me on the below number.

Regards

Joanne Boyes
Research Officer
CRRAH, USQ
Phone: 4631 5458
E-mail: boyes@usq.edu.au
CRICOS No 00244B
6.3 Questionnaire

Toowoomba Intellectual Disability Support Association Inc Questionnaire

Which organisation forwarded this questionnaire to you? …………………………….

DETAILS OF THE PERSON YOU CARE FOR

Name: ………………………………………………
Address: …………………………………………….
Postcode: ………………………
Phone: …………………………….
Year of Birth: ……………… Male / Female (please circle)

• Do you think the person you care for would be happy to be contacted for a follow-up interview?    Yes / No (please circle)

PRIMARY CARER DETAILS

Name: ………………………………………………
Address (if different from above): ………………………………………………
Postcode: ………………………
Phone: …………………………….
Year of Birth: ……………… Male / Female (please circle)
E-mail address: …………………………………………………

What is your relationship to the person being cared for? (please circle or give details)

Parent     Sibling     Relative     Friend     Other………..

How many years have you cared for this person?…………………………

Is there someone else who also helps to provide care for the person above? Yes / No

Parent     Sibling     Relative     Friend     Other………..

Details:……………………………………………………………………………………………

• Are you happy to be contacted for a follow-up interview?    Yes / No  (please circle)
THE PERSON YOU CARE FOR
1. Level of support required (please tick one)

<table>
<thead>
<tr>
<th>Level</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Low</td>
<td>He/She can perform most daily living activities on their own and requires only limited or occasional support.</td>
</tr>
<tr>
<td>Medium</td>
<td>He/She requires regular support with daily living activities most of the time.</td>
</tr>
<tr>
<td>High</td>
<td>He/She requires continual support and assistance with most of their daily living activities all of the time.</td>
</tr>
<tr>
<td>Very High</td>
<td>He/She requires intense and sustained levels of support and assistance with most daily living activities all of the time.</td>
</tr>
</tbody>
</table>

2. Generally, what level of support does the person you care for require for each of the activities below (please tick one for each activity)

<table>
<thead>
<tr>
<th>Activity</th>
<th>Very High Support</th>
<th>High Support</th>
<th>Medium Support</th>
<th>Low Support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td></td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

3. Occupation: What does he/she do to occupy their time (e.g. Endeavour, therapy centre, school)

…………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………………
How many years has this person been living in this accommodation? 

6. How suitable is this accommodation for this person? (please circle one)

Very Suitable  Suitable  Not Sure  Unsuitable  Very Unsuitable

Would you like to tell us more about your reasons for this choice? Please comment on both positive and negative aspects.

...........................................................................................................................
...........................................................................................................................
...........................................................................................................................

8. As a carer, how satisfied are you with this accommodation arrangement? (please circle one)

Very satisfied  Satisfied  Not Sure  Unsatisfied  Very Unsatisfied

Would you like to tell us more about your reasons for this choice? Please comment on both positive and negative aspects.

...........................................................................................................................
...........................................................................................................................
...........................................................................................................................

9. How do you think the person being cared for feels about his/her accommodation arrangement? (please circle one)

Very Happy  Happy  Not Sure  Unhappy  Very Unhappy

Would you like to tell us more about your reasons for this choice? Please comment on both positive and negative aspects.

...........................................................................................................................
...........................................................................................................................
...........................................................................................................................

FUTURE ACCOMMODATION NEEDS

10. Do you foresee a change in this person’s accommodation needs in the future? (please circle one)

No  Yes within 1yr  Yes within 2-5 yrs  Yes in 5-10 yrs  Yes over 10 yrs

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

...........................................................................................................................
...........................................................................................................................
...........................................................................................................................

11. Would you like to see the person you care for continue to have the opportunity to become progressively independent in their accommodation and living arrangement?

Yes / No (please circle)
Would you like to tell us more about your reasons for this choice? …………………
..............................................................................................................................
..............................................................................................................................
..............................................................................................................................

12. What type of accommodation do you think would best suit the needs of the person you care for? (please tick one)

<table>
<thead>
<tr>
<th>Dwelling</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ Large residential</td>
<td>accommodating more than 20 people</td>
</tr>
<tr>
<td>□ Small residential</td>
<td>accommodating 7 to 20 people</td>
</tr>
<tr>
<td>□ House/Unit</td>
<td>Living alone or sharing with other people with appropriate amounts of support</td>
</tr>
<tr>
<td>□ Village style</td>
<td>Several people in unit accommodation in a supported village style environment which provides various facilities (eg. social, recreation)</td>
</tr>
</tbody>
</table>

Other:..............................................................................................................

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

13. How involved would you like to be with the support of the person you care for in his/her accommodation? (please circle)

Totally involved      Moderately involved    Slightly involved      Little or no involvement

Would you like to tell us more about your reasons for this choice? ………………………
..............................................................................................................................
..............................................................................................................................

Please proceed to the questions on the back of the page
ADDITIONAL INFORMATION

It is important for us to know of the problems, obstacles, choices, difficulties and concerns you have now or had in the past with accommodation needs. Please comment on both positives and negatives of these needs.

Please tell us what you see is impacting upon the future accommodation needs of the person you care for.

If you have some more information that we have not covered, please feel free to attach extra pages.
6.4 Plain language statement and consent form (for questionnaire)

PLAIN LANGUAGE STATEMENT

The Centre for Rural and Remote Area Health, the University of Southern Queensland (USQ) and The Toowoomba Intellectual Disability Support Association (TIDSA) are collaborating on a project that is investigating the accommodation needs of persons with intellectual disabilities and their carers. The principal researchers in this study are Dr Diann Eley and Professor Desley Hegney from the Centre for Rural and Remote Area Health at the University of Southern Queensland. The aims of this study are to ascertain the present accommodation situation of persons with an intellectual disability and their carers and then assess the needs of these people so that the accommodation situation might be improved and future needs might be met.

Your participation in this important study will provide us with the information necessary to address the accommodation problem in the Toowoomba region and help inform future policy decisions in this area of need. Your participation will involve the completion of a short questionnaire that asks you about your present accommodation situation and your opinions and views on how your situation might be improved.

Participation in this evaluation is entirely voluntary. If you fill in the questionnaire and later change your mind you may withdraw by advising Dr Diann Eley (07 4631 5459) at the Centre for Rural and Remote Area Health and quote the number above. If you do withdraw, the information that you have provided in this questionnaire will be destroyed and any data provided by you will be deleted from the researcher’s computer data files and not used in any analysis.

To ensure confidentiality, all information relating to your participation in this project will be immediately de-identified by the researcher upon receipt, and held securely in this de-identified format. Your comments will be kept completely confidential with no identifying information appearing with them. At no time will TISDA have access to any information that could identify your questionnaire response. The report which USQ will supply to TIDSA and any publications of the research results will contain no data which would identify individual respondents. All questionnaires for this study will be kept in a locked filing cabinet at USQ for a period of five years after which they will be shredded and disposed of as confidential waste.

If you would like to know the outcome of this study, we will provide a brief report that will be available on the Centre for Rural and Remote Area Health website http://www.usq.edu.au/crrah. Alternatively, you can contact TIDSA for any additional information. Any questions regarding the study can be directed to Dr Diann Eley on (07) 4631 5459. Additionally, if you have any concerns regarding the implementation of this study please feel free to contact the Human Research and Ethics Committee at the University of Southern Queensland on (07) 4631 2956.

This research adheres to the guidelines of the ethical review process of the University of Southern Queensland and has been approved by the University of Southern Queensland Human Research and Ethics Committee (reference number H04REA416). If you wish to participate in this study please read and sign the Consent Form below and return it along with your completed questionnaire in the stamped addressed envelope provided. Please retain one copy of this Plain Language Statement for your future reference.
CONSENT FORM

The investigators conducting this research project abide by the principles governing the ethical conduct of research and at all times avow to protect the interests of all participants. This Plain Language Statement has been given to you for your own protection. Your signature below will indicate that you agree to participate in the study. If the completion of this questionnaire causes you some distress you may wish to speak to someone at Lifeline (131 114) for support. Thank you very much for your time and assistance with this important research.

__________________________________           ___________________________________
Participant’s Name     Signature

__________________________________
Date
6.5 Interview questions for carer whose person who is living at home

**People living at home**

Name

Knowledge
Can you tell me how much you know about accommodation choices in Toowoomba for people with an intellectual disability?

**Current situation**
Is your child still at home through choice or lack of services?

If you could wind back the clock with no restrictions, how would you like your situation to be handled differently by services?

**No longer able to care**
How will you know when you are no longer able to care?
- plans
- transition period
- sibling assistance

What would you like your life to look like after your child moves to alternative accommodation?
- level of involvement
- child coming home?

**Future accommodation**
Can you describe the type of accommodation that you would like for your child?
- staffing ratio?
- small residential, a house/unit or village- pros and cons
- family/homely environment
- cooking/cleaning etc
**Independence**
Could you describe what type of independence you would like your child to have?
- indicators of independence
- Independence—what is it?
- Support needs vs. independence

**Ageing**
Do you think accommodation services for people with an intellectual disability should also cater for them as they age or should they go into the aged care system?

**Distance**
How far away from you would you be comfortable with your child living?

**Lifestyle**
Is a home-like atmosphere important to you in accommodation for your child?

What would that look like?

What type of social activities would you envisage for your child in their accommodation?
**Carer involvement**
Once in the accommodation, what sort of involvement would you like to have with your child?
- weekends
- medical appointments
- siblings

**Funding**
Is Govt funding an issue for you at the moment or for the future care of your child?

How much do you think would be a fair price for people to pay for accommodation?

**Respite**
Has respite been an issue for you?

Do you think it is important for accommodation services to also provide respite facilities?
6.6 Interview questions for carer whose person who is living away from home

**People living away from home**

Name

**The decision**
Can you tell me the story about how your child came to be living away from you?
- choice or forced
- involvement
- catalyst
- age
- right time for either of you
- health professional involvement
- financial and health plans?

If you could wind back the clock with no restrictions, how would you like your situation to have been handled differently by the services?

**Staffing**
How many staff are involved in your child’s life at the residential?
- Sufficient?
- Role of staff
- overnight staffing?
Future accommodation
Can you describe the ideal type of accommodation that you would like for your child?
- Independence—what is it?
- Support needs vs. independence
- Staffing ratio?
- Family/homely environment
- Cooking/cleaning etc

Ageing
What will happen to your child once they start to age and need more care?
- Your decision?
- Need help with this?

Distance
Is the physical location of the accommodation an important aspect?
- Same town
- Distances from services

Co-resident selection
How much say did your child or you have in deciding who they live with?

Independence
Could you describe what level of independence your child has?
**Lifestyle**
Is a home-like atmosphere important to you?

What do you see as contributing to this place as being like home/not like home?

Do you think your child is getting enough social interaction? What activities does he/she do?

**Carer involvement**
How often do you see CR?
- weekends
- medical appointments
- siblings

**Respite**
What do you think of respite accommodation being available in a permanent residential place?

**Funding**
Do you think residential services are adequately funded?
- Future concerns?

How much do you think would be a fair price for people to pay for accommodation?
The Centre for Rural and Remote Area Health, the University of Southern Queensland (USQ) and The Toowoomba Intellectual Disability Support Association (TIDSA) are collaborating on a project that is investigating the accommodation needs of persons with intellectual disabilities and their carers. The principal researchers in this study are Dr Diann Eley, and Professor Desley Hegney from the Centre for Rural and Remote Area Health at the University of Southern Queensland. The aims of this study are to ascertain the present accommodation situation of persons with an intellectual disability and their carers and then assess the needs of these people so that the accommodation situation might be improved and future needs might be met.

Your participation in this important study will provide us with the information necessary to address the accommodation problem in the Toowoomba region and help inform future policy decisions in this area of need. Your participation at this stage will involve a semi-structured interview addressing issues that have arisen from the questionnaire you completed recently.

Participation in this evaluation is entirely voluntary. If you fill in the questionnaire and later change your mind you may withdraw by advising Dr Diann Eley (07 4631 5459) at the Centre for Rural and Remote Area Health. If you do withdraw, the information that you have provided in the interview and/or questionnaire will be destroyed and any data provided by you will be deleted from the researcher’s computer data files and not used in any analysis.

To ensure confidentiality, all information relating to your participation in this project will be immediately de-identified by the researcher upon receipt, and held securely in this de-identified format. Your comments will be kept completely confidential with no identifying information appearing with them. At no time will TISDA have access to any information that could identify your questionnaire response. All questionnaires for this study will be kept in a locked filling cabinet at USQ for a period of five years after which they will be shredded and disposed of as confidential waste.

If you would like to know the outcome of this study, we will provide a brief report that will be available on the Centre for Rural and Remote Area health website http://www.usq.edu.au/crrah. Any questions regarding the study can be directed to Dr Diann Eley on (07) 4631 5459. Additionally, if you have any concerns regarding the implementation of this study please feel free to contact the Human Research and Ethics Committee at the University of Southern Queensland on (07) 4631 2956.

This research adheres to the guidelines of the ethical review process of the University of Southern Queensland and has been approved by the University of Southern Queensland Human Research and Ethics Committee (reference number H04REA416). If you wish to participate in this study please read and sign the accompanying Consent Form and return it along with your completed questionnaire in the stamped addressed envelope provided.
CONSENT FORM

The investigators conducting this research project abide by the principles governing the ethical conduct of research and at all times avow to protect the interests of all participants. This Plain Language Statement has been given to you for your own protection. Your signature below will indicate that you agree to participate in the interview process of the study. If this interview causes you some distress you may wish to speak to someone at Lifeline (131 114) for support. Thank you very much for your time and assistance with this important research.

__________________________________           ___________________________________
Participant’s Name     Signature

__________________________________
Date
6.8 Interview for person with intellectual disability who is living away from home

- I am doing a study to see how some people in Toowoomba would like to live and I am interested in hearing what you think about it. Would you be able to talk to me about it for a little while?
- I am going to tape our talk, is that ok with you?
- I will not tell anybody else what we have spoken about, but I may write it in a report, but if I do, I will make sure nobody will know who said it.
- You can tell me to stop if you want and I will
- Could you sign this form that says I have explained all this stuff to you and you are happy to talk to me?

At the moment you live by yourself/away from your parents. How happy are you about living by yourself/away from your parents?

What kind of things do you do around the house?

Are there some things that other people help you with?

Are you working?

Do you have friends who also live away from their mums and dads?

Where do they live?

Do you where they are living?

If the Govt gave us a lot of money to build somewhere for you and your friend to live, what would you like us to build?
How many people do you think would be a nice number to live with?

Do you think it is a good idea for people to choose who they live with?

Do you think that some people would need some extra help to live in the place you have chosen?

Do you think that people who live with other people should help with the housework?

Do you think that people who live in the place you chose should be able to go shopping and do things by themselves?

What would you think of people coming and staying at a place you live to have a holiday?
6.9 Interview for person with intellectual disability who lives at home

- I am doing a study to see how some people in Toowoomba would like to live and I am interested in hearing what you think about it. Would you be able to talk to me about it for a little while?
- I am going to tape our talk, is that ok with you?
- I will not tell anybody else what we have spoken about, but I may write it in a report, but if I do, I will make sure nobody will know who said it.
- You can tell me to stop if you want and I will
- Could you sign this form that says I have explained all this stuff to you and you are happy to talk to me?

At the moment you live with mum and dad. How happy are you about living with them?

Do you help mum and dad around the house? What do you help with?

Are you working?

Do some of your friends live away from their mums and dads?

Have you seen where they live?

Do you think it would be a good place to live?

If the govt gave us a lot of money to build somewhere for you and your friends to live what would you like us to build?

How many people do you think would be a nice number to live with?

Do you think it is a good idea for people to choose who they live with?
Do you think that some people would need some extra help to live in the place you have chosen?

Do you think that people who live with other people should help with the housework?

Do you think that people who live in the place you chose should be able to go shopping and do things by themselves?
6.10 Participation consent form for person with intellectual disability

Researchers Dr Diann Eley; Prof Desley Hegney; Joanne Boyes

PARTICIPANT CONSENT FORM
For participation in the TIDSA Accommodation Needs Study

The TIDSA accommodation study has been explained to me.

The TIDSA accommodation study is for research at the university.

I have been able to ask the research person questions about the TIDSA accommodation study

I agree that people running the study can talk and write about what I have said about accommodation needs.

I understand that anything I say will be kept locked away in a safe place.

I understand that when the people running the study talk and write about what I have said, they will change my name so nobody can tell who I am.

If I don’t want to be part of the study I can stop at any time and everybody will still be happy with me.

Signed: __________________________ Date: ___________