“IT’S DIFFERENT IN THE COUNTRY” SUPPORTING AGEING-IN-PLACE FOR PEOPLE WITH DEVELOPMENTAL DISABILITY: AN EXPLORATION OF RURAL AND METROPOLITAN PERSPECTIVES

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Disclaimer

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Executive Summary

The past century has seen a dramatic improvement for the life expectancy of people with an intellectual or developmental disability (PwIDD). While there is a growing body of research in this area, it is recognised that policy and practice frameworks have not as yet managed to effectively adapt to the changing demographics for the sector (Bigby 2002; Bigby 2008; Wark et al. 2014a). This lack of coordination for support is particularly problematic in rural areas (Wark et al. 2013a); however, there is little research that specifically focuses on individuals living outside of major metropolitan locations.

The current project was funded by the Disability Policy and Research Working Group to undertake an assessment of gaps that exist in current disability and aged care sectors, including generic and specialist levels of care, that are required for successful ageing of people with developmental disabilities in both rural and urban regions of NSW and Queensland.

Phase One of the study utilised a semi-structured conversational style interview format with consenting older individuals with lifelong intellectual disability living in the community (either in their family home or in small group homes) and those who have moved to residential care facilities. Carers, both paid and unpaid, of these individuals were also interviewed. Participants from both rural and urban areas of NSW (Wollongong and Parkes) and Queensland (Redbank and Toowoomba) were included. In total 68 interviews have been completed.

With the consent of the participants, interviews were audio-recorded and transcribed by an independent transcriber. The transcripts were reviewed several times by three members of the team – initially individually to identify potential themes and later as a group to verify the emergent themes. The process was in accordance with the steps identified in analysis of qualitative data by Patton (2002) and Creswell (2007).

Phase Two of the study was a quantitative survey that used a purpose-developed tool. The target group for the survey were health professionals who may be expected to interact and/or support individuals ageing with an intellectual disability. A total of 439 health professionals from across NSW and Queensland completed the survey. This cohort either worked in the disability and aged care sectors, or were employed in other relevant health disciplines such as medicine, nursing, psychology, physiotherapy and speech pathology. The data were analysed using a combination of SPSS (V22) and Microsoft Excel.
The analysis of both the qualitative and quantitative data has led to the formation of four key recommendations from the study. These recommendations are:

1. **There was a strong preference of participants (both metropolitan and rural) in having autonomy in choosing to age where they want to and with whom they want to.**

   Such a change will require a review of policies around design of accommodation for PwIDD who are ageing. Furthermore, there needs to be greater autonomy in options around selection of co-residents. We acknowledge that both these issues pose a number of logistical challenges for residential accommodation options. Using a person-centred philosophy [which underpins the NDIS as well as most current programs supported by public funds], the concept of Ageing-in-Place needs to be reviewed and revised as **Ageing-in-my-Chosen-space.**

2. **There is a need for greater and more meaningful consultation in any decision-making processes.**

   For PwIDD who do not have family support and have increasing needs for some form of assistance with activities of daily living, the current model of integrated group homes with independent individual rooms and some level of residential support staff is appropriate. However, many participants felt marginalised and alienated in such environments due to lack of consultation in decision-making of co-residents. Much of the distress felt by participants can be ameliorated, which in turn will improve their sense of belonging and contribute to positive ageing, if there was flexibility in selection of co-residents and more importantly their personal space [room]. Many individuals considered their room as their “home”, and expressed the need for greater respect by fostering within the group home environment a sense of privacy for the sanctity of their personal belongings. Such changes can be easily incorporated in review of ongoing training of disability support staff and reinforcement of these concepts that influence perceived sense of belonging and ageing-in-my-chosen-space.

3. **There is an urgent need for the up-skilling of professional staff.**

   There is a clear need to review the skill base of professional staff in relation to the additional needs of PwIDD who are ageing. Such up-skilling would allow older residents to stay in their “chosen place”, rather than be moved due to a lack of adequate skills amongst current staff to deal with additional age-associated issues which are not yet of a magnitude to require residential aged
care. Many participants and their carers felt that “they had no options” because the easiest decision is to send them to large congregate facilities, which thereby cuts down on their social connections and diminishes the concept of “ageing-in-place”. This is a particularly important issue in rural regions and up-skilling of staff working in these areas would be of benefit in promoting greater confidence to support emerging age-associated issues as well as indirectly aiding the retention of staff through staff development.

4. *Individuals with intellectual disability who are able to stay in family homes should be encouraged and supported to do so.*

Some of this cohort’s age-associated needs could be met with some simple and low-cost home modifications using tele-health and e-technologies. The rollout of the NBN across both rural and metropolitan Australia provides an opportunity to connect individuals with support staff as well as help PwIDD who are ageing to maintain social connections through social media. These issues are particularly relevant for rural residents, as they are at great risk of both premature and inappropriate admission to residential aged care that is often located at considerable distance from their familiar community.

As a pilot study, the current project has also identified a number of key areas that require additional follow-up research. Some of the issues include:

1. The perspectives of carers were limited in the present research, particularly in relation to a better understanding of the impact of care-giving on their own health and well-being.

2. More focussed research is needed to elicit the perspectives of disability support workers. The present study has provided some interesting findings in relation to differences between inner and outer regional staff skill base, experience of dealing with PwIDD who are ageing and perceptions of their own abilities in relation to confidence in managing age-associated issues.

3. There is a need to undertake a gaps analysis in relation to available health, community and social support services and accessibility of services for PwIDD who are ageing. This is particularly of value in rural areas.
Introduction

The Australian Government has, since 1997, adopted the ‘ageing-in-place’ support notion to complement the existing residential and community based models to facilitate older people being able to remain in their own home and familiar local community (AIHW 1999; Forbat 2006). Additionally, national reforms to Aged Care (Productivity Commission, 2011a), Disability Services (Productivity Commission, 2011b), and the imminent advent of National Disability Insurance Scheme [NDIS], have changed the policy and funding landscape from a service-centric to an individualised funding focus.

There is increasing evidence of improvements in life expectancy of people with intellectual disability [PwIDD] (Coppus 2013; Bittles et al, 2002). The number of PwIDD in Australia who are now over the age of 65 is steadily growing and was conservatively estimated at 150,000 in 2008 (AIHW, 2008). No new national-level figures exist but many support agencies report that nearly 50% of their client population is aged 50 or above (e.g. K.Mead [The Ascent Group], pers. comm., 16 March, 2013). Thus, PwIDD who are ageing constitute a unique group of Australians whose longevity was not expected nor effectively planned for by either the aged care or disability sectors (Futures Alliance 2012).

In line with improvements in life expectancy, there are an increasing number of research studies in the area of facilitating successful (or positive) ageing for PwIDD. The pioneering work of Janicki and others in the USA (e.g. Janicki & Dalton 1998; Janicki 2001) has been built upon in Australia by researchers such as Bigby (Bigby et al., 2004; Bigby 2008; Bigby et al., 2008; Bigby 2010), Buys et al. (2008), Ashman et al (1990), Young & Ashman (2004) and Parmenter (2001, 2006, 2008).

Nonetheless, the issues in providing appropriate health- and social-care support for people with intellectual disabilities, particularly as they age, is problematic in both Australia and more widely in the world (Emerson & Hatton, 2012, Wark et al., 2013b, Wark et al, 2014b). One of the major factors around the world that limits access to appropriate services has been found to be a rural location. It was specifically noted that geographic location has a great impact upon the availability of intellectual disability services in Australia (WHO, 2007, Dew et al., 2013). In particular, there is a wide research gap between the philosophies embraced by the proposed national reforms and their articulation into practical, achievable outcomes.

The 2010 Intergenerational Report forecasts a dramatic increase in the number of older people [> 65 years] in Australia, from around 13% in 2010 to over 25% by 2050.
The Commission’s Report on Ageing identified significant problems within mainstream aged care systems and recommended that ‘ageing-in-place’ should be seen as an integral component of successful ageing. It is anticipated that by 2050, more than one in 20 healthcare workers is likely to be working in aged care (Commonwealth of Australia, 2010).

The disability services sector in New South Wales and Queensland is currently faced with serious policy- and program-level challenges associated with having to manage the first large-scale cohort of people with intellectual and developmental disabilities who are aged 65 years or older. It is also cognisant that many more people with intellectual and developmental disabilities will be added to this ageing cohort in the next few years. There is growing concern that without adequate problem identification involving all the major stakeholders no effective long-term solutions can be found, and the current ad hoc management of ageing of people with disabilities will continue and potentially result in considerably worse outcomes. It is recognised that allied health professionals are vital in the provision of appropriate ageing support for the mainstream community; however, how best to fill the role of allied health staff in assisting people with intellectual disabilities to age successfully is an area of research that is currently lacking.

Traditionally most research in disabilities has been conducted using quantitative methods with a few notable qualitative studies (McVilly et al., 2008). Much of the research in Australia on PwIDDD who are ageing has been conducted in metropolitan areas (Bigby & Knox, 2009) and there is limited information on needs and aspirations of those residing in rural communities (Wark et al., 2013a). Also while there are recent studies that have explored issues in recruitment and retention of allied health workforce (Lincoln et al. 2013), many of these are focused on PwIDDD but do not investigate these issues in relation to comparing issues relevant to PwIDDD who are ageing and mainstream ageing groups.

In the remainder of the report we present findings from the pilot project entitled:

“*It’s Different in the Country*” Supporting Ageing-in-Place for people with developmental disability: An exploration of rural and metropolitan perspectives.

We first overview the project’s Purpose & Aims and then outline the conduct and findings of the mixed-method study sequentially. Phase One focuses on methodology and findings of the Qualitative component of the project based on in-depth interviews with PwIDDD who are ageing and their carers. Phase Two focuses on
methodology and findings of the health professionals survey undertaken across NSW and Queensland. In the final section of the report we present the limitations of the present study and provide a series of recommendations based on findings of the research.

Purpose & Aims (as articulated in the original proposal)

The aim of this seed grant proposal is to undertake an assessment of gaps that exist in current disability and aged care sectors including generic and specialist levels of care that are required for successful ageing of people with developmental disabilities in both rural and urban regions of NSW and Queensland. A particular emphasis will be upon what measures enhance the viability of successful ageing-in-place for people with developmental disabilities and prevent unnecessary institutionalisation. This project will focus upon a collaborative exploration of the experiences of people with developmental disabilities who are ageing and their families/carers.

a) Explore their understanding of ageing-in-place, their aspirations and needs for services that allow this goal to be achieved. In some instances, carers take on the role of proxy respondents due to limited verbal skills of some of the people with developmental disabilities.

b) In collaboration with partner disability agencies, identify strengths and gaps in the knowledge and skill base of the existing workforce in aged care, generic health and specialist disability services. The gaps in training needs and the skill-mix of the workforce required providing community-based support will also be systematically examined.

Ethics approval & Pilot-testing

An initial step in the conduct of the study was the preparation of an application to the University of New England’s Human Research Ethics Committee. Approval was gained in two stages first for the qualitative interviews (HE13-045) and later for the survey component (HE14-019).

Pilot-testing was undertaken both for the qualitative and quantitative components of the study in Lismore with the help of MultiTask. The support from MultiTask CEO Graham Mapstone and his staff, particularly Kim Vincent, is greatly appreciated in ensuring the pilot phase was completed efficiently.
Phase One: Qualitative interviews with PwIDD & carers in New South Wales and Queensland

Consistent with this overall aim, the purpose of this first component of the study was to explore the understanding of ageing-in-place by older people with developmental disabilities and their nominated carers, as well as the aspirations and needs for services that would facilitate this concept to be achieved.

To this end, semi-structured conversational style interviews were undertaken with consenting individuals with lifelong intellectual or developmental disability living in the community (either in their family home or in small group homes), people who have needed to move to residential care facilities, and a nominated carer. Carers were identified by the participants, and were either a family member or nominated direct support worker who knew the person well. Participants from both rural and urban areas of NSW (Wollongong and Parkes) and Queensland (Redbank and Toowoomba) were included. In total 68 interviews were undertaken, as outlined in Table 1 below.

The transcription of interviews with people and their nominated carers living in community settings has been completed and analysis of the transcript data has been undertaken for the purposes of this report. The project team will continue to further refine the analysis with a view of developing manuscripts to be published in high quality peer-reviewed journals. The emergent themes from the in-depth interviews are presented below. Further details of methods including data analyses techniques are described below before presenting the findings.

Methodology

Recruitment of Study Participants

The recruitment of study participants took place in the following stages:

i) Seeking assistance of organisations supporting people with disabilities

Members of the research team have strong connections with non-government organisations across both Queensland and NSW. Thus, an initial step in the recruitment process was to seek the assistance of local disability and aged care support organisations to invite people with disabilities who met the below criteria to an information session to discuss the proposed research, and to outline what their participation would involve, should they choose to participate.
The selection criteria included:

• being aged 55 years and older, or persons aged 50 to 54 who experienced premature ageing\(^1\)

• currently live either independently or with their family, or in a community-based residential support option

• do not have a legal guardian appointed under the NSW Guardianship legislation as a substitute decision-maker, and

• have adequate communication and interaction skills to participate in an interview process.

\(\text{ii) Conduct of information session for potential participants}\)

Information sessions for potential participants were held across both states (Toowoomba, Redbank, Brisbane, Wollongong and Parkes). At these sessions, details of the study and the implications of participant involvement were outlined. Information packages detailing the study were left with the meeting attendees. Those people interested in participating were asked to contact the researchers directly. Thus the researchers did not have any identifying details of those who chose not to participate, while at the same time, coercion to participate from either the researchers or the organization was minimized. In effect, these measures provided safeguards for both potential and actual participants.

\(\text{iii) Recruitment of carers}\)

The individuals with an intellectual or developmental disability who chose to participate were asked to nominate a carer (either a family member or a direct support worker) to the research team member who then followed up with that person to request their participation. Table 1 outlines the numbers of participants

\(^1\) Note: We are cognisant of the Australian government use of 65 years or older to define ageing. However, many disability research studies have shown that signs of ageing start appearing earlier in PwIDD, particularly in people with Down syndrome (e.g. Carr & Collins, 2014). This matter was discussed with various members of the Project Advisory Committee as well as executives of disability organisations prior to commencement. It was initially recommended by the Project Advisory Committee, and then agreed to by the research team, that the broader definition should be used to ensure that no sub-groups were disadvantaged.
resulting from this recruitment process. The highlighted section represents the participants who are the focus of this interim report (i.e. those participants living in community settings in NSW and Queensland).

**Table 1 Participants by location and rurality**

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<th>Rural</th>
<th>Metropolitan</th>
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<td>Queensland</td>
<td>NSW</td>
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<td></td>
<td>Toowoomba</td>
<td>Parkes</td>
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<tr>
<td>Community home</td>
<td>13</td>
<td>6</td>
</tr>
<tr>
<td>(group home or</td>
<td>participants with</td>
<td>nominated carers</td>
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<tr>
<td>family home)</td>
<td>intellectual disability</td>
<td></td>
</tr>
<tr>
<td></td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>carers*</td>
<td></td>
</tr>
<tr>
<td>Aged care</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>facilities</td>
<td>participants with</td>
<td>nominated carers</td>
</tr>
<tr>
<td></td>
<td>intellectual disability</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>carers</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>19</td>
<td>16</td>
</tr>
<tr>
<td></td>
<td>participants in rural</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Queensland</td>
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* Several participants nominated the same carer
** One nominated carer declined to participate

NOTE: Although considerable effort was made to locate and recruit participants in aged care facilities in Queensland, it did not yield any consenting participants. This was because of issues pertaining to general ill-health as well as “gate-keeping” within certain facilities.

**Data Collection**

Following the gaining of informed consent, an individual semi-structured conversational style interview was undertaken with each participant in locations of their choosing. These were in private settings either in the participant’s home or in a separate room within the organisation with which they were associated.

An interview guide was used to canvass the following topics with both the older person with lifelong intellectual disability and their nominated carer.

- Perceptions of current life as an older person
- Feelings about getting older
- What is needed for a good life
- What are the barriers to a good life
- Other issues about life as an older person considered important

**Data Analysis**

With the consent of the participants, interviews were audio-recorded and transcribed verbatim by a transcriber unknown to the participants. The transcriber was required to sign a confidentiality agreement. The verbatim transcripts were reviewed several times by three members of the research team – initially individually to identify potential themes and later as a group to verify the emergent themes. The process was in accordance with the steps identified in analysis of qualitative data by Patton (2002) and Creswell (2007).

A thematic analysis was undertaken to highlight core concepts and categories around participants’ perceptions and aspirations for:

- Ageing
- Ageing-in-place
- Concept of home
- Social connections
- Transition to retirement
- Access to and satisfaction with social and health services
A schematic representation of the key issues as voiced by people with intellectual disabilities who are ageing and their carers is presented in Figure 1. Given that in some instances several participants chose the same carer [a paid disability support worker] and in other instances the issues raised by carers were very similar to those highlighted by individuals, the findings presented below have not been segmented into individuals’ views versus carers views. By providing a composite analysis, we have been able to retain the focus on core issues without incurring the risk of considerable repetition that would have occurred in presenting the views of these two groups separately.

**Figure 1 Emergent Themes of Ageing in a Chosen Place**
Major themes emanating from the interview data

Ageing-in-my-chosen-space

A key theme identified was the complexity and richness of the *ageing-in-place concept*. Participants indicated that ageing-in-place is not simply about remaining in their home or staying in the same place they have lived for some time. Ageing-in-place was seen to instead relate to having autonomy over both where and how to live life as an older person. In essence it was about ensuring a quality of lifestyle as an older Australian, and making one’s own choices about that lifestyle. Participants described various elements that made them feel ‘at home’ in their accommodation setting. **Accordingly the term ‘ageing-in-my-chosen-space’ has been chosen to encompass the variety of ageing-in-place circumstances experienced by participants.**

Participants were very clear that having **choice in housing options** and **control over the decisions concerning their lives** were **crucial to ageing successfully**. However, some participants indicated that they had not chosen to live in the situation they were currently, while others could not articulate why they had moved or even who made the final choice. Often family members or support staff made those important decisions on their behalf, typically after a triggering event such as the death of a parent carer. There were occasions when the person with a disability was included in the conversation and decision-making process, but ultimately any decision came down to a compromise between the support needs of the person, availability of placements, and what other people considered “best” for the person at the time.

In spite of these issues, most participants indicated that they were happy with their current living situation, and when asked said they would not prefer to be anywhere else. Michael feels a strong sense of home and connection to his housemates: “*I aren’t (sic) going to move anywhere else…. It’s family to move I’d miss my friends, I love it*”. There were exceptional cases where some participants were heavily involved in the decision-making process and the choice of place to live was not always as expected. Joanne and her mother made a joint decision to move together into an aged care facility which Joanne genuinely referred to as ‘home’.
Choice of co-residents

While choice in location may have been available, often the choice of who to live with was not as feasible. This issue became particularly pertinent as dedicated ‘seniors residential homes’ are seeming to become more commonplace within disability service organisations, with these models created to provide maximum support with the increased needs as people age, but with sometimes a trade-off being little focus on the compatibility of housemates:

None of them actually choose to live together, but that happens across the board everywhere, which I suppose, we don’t do that in our lives, we choose who we live with, we choose where we live and things and I suppose one of the biggest constraints on the people we support is that they don’t really get a choice who they live with (Fiona, paid support worker, urban seniors service home).

Participant Glenda spoke of having had no choice in where she lived and was in fact incredibly unhappy with her current living situation due to the lack of independence and common interests with other housemates: “It’s not independent” she says, “like we get told to do things, but half of them (housemates) sit on their backsides and watch the idiot box” (Glenda, rural, group home).

This is not dissimilar to those living in high care aged care facilities where the choice of person to share a room with was also not always available. Robyn discussed these issues: “the woman [she shares a room with] is deaf and does not hear when my daughter tells her to ‘shut up’ as she says what she thinks”, she goes on to say “It would be nicer if she was in her own room. The other lady is dying….. I think she’d be pleased if she went” (Robyn, 90, carer of Lisa, 57, rural, aged care facility).

Creating ‘my-space’ in a shared environment

For those living in a congregate residential situation (low/high care aged care, a senior’s service disability house, community-living disability group residence or with family or friends) having a defined personal space that they could call their own within the larger home environment appeared crucial to a positive ageing experience. For some, retreating to their room was a key strategy employed to cope
with wider personal incompatibility within the home. As Ruth explains: “it’s good living here except that Simon teases a lot. He gets very nasty. He upsets [another housemate]…. she can’t speak…. It’s not right. I just keep well away; I just go to my room” (Ruth, 66, urban seniors service home).

Furthermore, this space was also considered by participants to be an ultimate site of autonomy; a place where they could organise their belongings as they wish and engage in activities of their own choosing without the need to compromise: “See, I’ve got my TV, I’ve got my DVDs, got my computer, my bedroom…. Have peace and quiet in the room.” (Shirley, 57, regional family home with parents). A strong sense of ‘my-place’ or ‘home’ was felt by participants who were able to include their own elements in the shared space: “She has all the things she loves from home…. Many photos of family” (Robyn, 90, carer of Lisa, 57, rural, shared room, aged care facility).

Immense dissatisfaction can occur when the privacy and autonomy of this space is disrespected. Leonie describes the frustration she feels when her needs regarding her space are not respected by staff: “[staff] changing my dolls and room around I don’t like it…. the ones that clean” and other housemates “some [other housemates] come into my room and change my dolls around” (Leonie, 60, urban group home).

Frank reiterates this frustration: “I’ve got this room. [I have] peace and quiet on my own. But everybody’s always coming in here all the time…. I like my space, on my own. I can’t get it through to them! (Frank, 52 with T21, urban senior’s service home). Various elements were described as important:

“Living in the group has meant she no longer celebrates her culture. She is Italian but no one else is. She does not have cultural foods or go to church. She doesn’t celebrate her cultural beliefs that were important to her and her mother.” (Joan, carer of Leonie, 60, urban group home).

Retirement – still need something to be proud of

Some of the study participants were either employed full or part-time in formal business services provided by a disability service provider [Australian Disability Enterprises], or had retired from employment completely.

A change in health conditions was one of the key instigators for retirement. The participants still working full-time perceived no changes in their health, and they
wanted to continue to work. Mark’s wish “to keep going” was articulated by his co-workers. This notion is consistent with much of the literature (e.g. Bigby et al. 2011), with the workplace as their social hub and providing a forum for the enactment of often long term friendships “I’ve got all friends here”. However, other participants indicated they had clear retirement goals, were happy to cease work, and indeed were actively looking forward to it. The concept of partial retirement seemed common, and was usually phased in by changing from full-time to part-time.

The importance of having a role valued not only by others, but also by themselves was readily apparent. For some people, this need was fulfilled by work. For example, Dennis spoke proudly of his role: “I do the shredder with J…”. For others it was fulfilled in their new daytime activities. Bob told of his role in building wooden articles, maintaining the house herb garden, and overseeing the larger garden. Mark identified his emerging role as an actor with the local drama group. This new role supplemented his worker role, now that he had changed to part-time employment.

Claire… a carer, encapsulated this sentiment with her comment: “I can understand why his days at work have been reduced, but at the same time it’s such a shame….. To me, if you take the ability away to achieve, then you’ve got nothing to be proud of”

Lardeen…, another carer, however, pointed to the difficulties in older people with intellectual disability accessing community activities. She described her experiences: “Cause some a lot of places that are out there they have issues in dealing with someone who has a disability whether it be physical or mental or there are a lot of people who just can’t handle it. Even a men’s group with disabilities. Being able to cope with the different varieties of disability. Some people can’t handle it.”

Is it different in the country?

Limited differences were seen between rural, regional and urban participants in terms of their thoughts on what is a good life, what it means to age in place, changes in health and aspirations for the future. However, there were some major divergence in identifying specific factors that were recognised as potential barriers to a good life. Some of the main differentiating features included:
• Access to medical services, particularly specialist medical services. Similar availability for both GPs and specialists was reported across regions, but the actual process of ‘getting there’ in terms of accessing services was much harder for people in the rural sites compared to large regional and urban study sites.

• Limited service provision in regional and rural areas. There were concerns relating to the availability and choice of service providers in rural locations. This issue manifests particularly if there is only one service provider or major operator in the town, with any choice and control limited not only to what is available but also to what is the best fit for all clientele of the organisation (which might not be best for the individuals):

“[This] is the only place where they put me. I was planning to stay at [the other house] and things like that but [my housemate] got a hold of me and thumping Christ out of me one time….. They should’ve moved him at the time but they couldn’t….. They said ‘well [he’s] got no place to go.” (Glenda, regional, Group Home)

Facilitators and Barriers to Ageing-in-my-chosen-space

Relationships and a good support network

Considered essential to successful ageing-in-my-chosen-space was access to people and relationships that participants viewed as important to them. Support to maintain existing friendships when a change of residential or occupational circumstance had occurred was critical to a feeling of ‘home’ or ‘my-space’. A crucial element to a successful transition into a new place can be the continuation of daily activities such as work, social groups or day services. As Joanne explains she has trouble making friends at the aged care facility and day service because “just when I come here that is all because people here have their own lives”. Joanne has a strong desire to return to her workplace because that is where her friends are: “You said you would like to go back to [workplace] to visit”. “Yeah, retirement you know when everybody, what you retired year ago, that is what I’d like to do” (Joanne, 65, aged care facility). Moreover, continuance of desired or preferred family relationships was of utmost importance for some participants. As Malcolm explains “I have to [keep those contacts]
because she’s the only mother-in-law and my only family I’ve got.” (Malcolm, 62, regional, retirement village).

Creating and supporting opportunities for new and meaningful friendships, as well as allowing time and space to grieve lost relationships with both friends/family as well as of paid support staff (through staff turnover and organisational changes), was central to a continued sense of well-being. Witnessing a declination in health of close friends and/or family was often a trigger for self-reflection and contributed to participants’ understanding of the ageing process and what successful ageing meant to them. Conversely some participants were unable to understand the death of a parent (primary carer) and struggled emotionally as a result. Grief counselling and support for participants through transitions both during and after bereavement was regarded as lacking by some paid support staff.

Emotional, mental and physical health maintenance

The group was somewhat heterogeneous when it came to the importance of maintaining their health and mobility. Some participants had a good understanding of the decline in their health and mobility due to the ageing process like Joanne: “Just slower you know. I get tired if I walk fast” (Joanne, 65, urban, aged care facility) and Dennis: “Because my body told me..... Telling me, stop working. Stay here. And it’s time to move on” (Dennis, 56, regional group home). In contrast, it appeared that other participants had little understanding of what the future held or what changes in health were the result of age.

Access to a good doctor was viewed as important, and the characteristics of what makes a good doctor included:

- someone who listens and takes the time
- someone who doesn’t talk down to the participants and takes a genuine interest in their needs
- someone with an understanding of the complex needs of someone who is ageing with an intellectual disability.

Carers [both paid and unpaid] raised issues around mental health support for this group of participants, as many had been diagnosed and medicated for treatment of depression [often following a bereavement]: “Trying to keep the depression under
control…. He tends to isolate himself a lot” (Kaye, carer of Russell, 63, urban family home). There were also many participants who were taking a lot of medications for a myriad of both minor and significant health conditions:

“Staff have to take them to doctors…. I think there is a general concern that GPs probably don’t have enough time” (Patricia, carer of Stephen, 79, rural, family home).

“Someone who can understand his complex needs. With most people with disability it’s not just one disability, it’s a number of things and they need to understand the whole total package” (Kaye, carer of Russell, 63, urban family home).

Having a purpose or a role in life that is important to me

The individuals who were occupied, kept themselves busy and had something they considered meaningful to do with their time tended to speak more positively about the ageing experience. Feeling that they were still capable of doing good things, or had some role within the home, was also an important element of ageing-in-place. Sometimes organisational issues got in the way of this – (e.g. forced workshop retirement, moving to a ‘seniors home’):

“I can understand why his days at work have been reduced, but at the same time it’s such a shame……. To me if you take the ability to achieve, then you’ve got nothing to be proud of” (Fiona, paid support worker, urban group home).

Something that people know me as, something people remember me for, what do I do after retiring. Stress again the importance of both retirement planning and also post-retirement options [not using an arbitrary retirement age of 65]. Some people talked about the importance of being known as something other than the ‘disability man’ (Ted – Toowoomba)

Summary

There are a number of clear themes that emerged from the interviews. In particular, it was evident that the desire to be consulted and to be an active participant in all important decisions was a key factor in an individual’s level of satisfaction with their life as an older person. This issue will become increasingly important as disability
services struggle to adapt to the increasing number of people with an intellectual or developmental disability who are ageing. Some disability organisations are moving towards specialist ‘aged care’ approach, however, while this model is cost-effective and can provide greater access to support through congregation of need, it simultaneously removes the individual’s right to choose who and where they live.
Phase Two: Health Professionals Survey

The second phase of the study was a survey of health professionals and sought to capture their thoughts about ageing with an intellectual disability, as well as their own preparedness to appropriately support this emerging cohort of the community. Health professionals were widely defined to include medical and allied health staff, as well as direct support staff from disability or aged care organisations.

Sample

The proposed target was 400 health professionals. The target group comprised workers who were directly employed in the disability and/or aged care sectors, as well as in associated but potentially distinct disciplines such as medical practitioners, registered nurses, psychologists, physiotherapists, speech therapists and so forth.

Recruitment

The disability and aged care workers were recruited through industry partners. Organisation-wide emails were sent to all appropriate staff within the company. The research team also used contacts with industry and other institutions to recruit further participants from organisations separate to the industry partners. A list of contacts was recorded and 208 people were emailed or approached directly on social media by the research team.

Details about the study were also shared through a number of newsletters such as the Global Disability Gazette and select Medicare Local newsletters. An email was also sent to 794 General Practitioners (GPs) using a consulting service called AMPCO. While 158 clinicians opened the link, only 15 actually completed the survey. Other medical doctors included in the survey were contacted through professional contacts of research team. Hard copies of the survey were distributed to relevant agencies. The cover letter contained the URL link for the online survey and potential participants had the option of either completing a hard copy or the online survey questionnaire. Most of the participants chose the online format. The online survey was open from April-July 2014 to allow adequate number of health professionals.

Pilot testing of the instrument

Before opening the online survey, the study questionnaire was pilot-tested with a number of health professionals in different fields including disability, aged care,
psychology, social work, and medicine. The feedback from pilot-testing was incorporated in the development of the final survey instrument.

**Results**

A total of 439 health professionals who worked in the disability or aged care sectors, as well as in associated disciplines such as medical practitioners, registered nurses, psychologists, physiotherapists, speech therapists etc, completed the online survey. Information was missing on a number of demographic variables for a small number of respondents. On further analysis, there were missing responses to some of the questions but no clear pattern emerged around reasons for skipping any specific questions. We postulate that some health professionals did not possess the knowledge and/or experience to answer some of the more detailed questions about issues affecting PwIDD, PwIDD-Ageing or the mainstream ageing groups, however, this remains as speculation.

**Demographic Information**

**Gender**

A majority of respondents for the health professionals’ survey were females. However cross-tabulation of data by state showed a more skewed distribution for NSW (86% females and 14% males) whereas in Queensland the gender distribution was more equal (78% males and 22% females).

![Sex of Respondents by State](image)

*Figure 2 Distribution of Health Professionals by State*
Age
The results are indicative of a mature-age workforce with a third of the participants (33.7%) in the 45-64 age group, 25% in the 55-64 age group and 6% in over 65 (combined 64.8% of the total). Only a third of the sample was under the age of 45 years with 2.6% less than 25, 14.2% were aged 25-34, and 18.5% aged 35-44 years.

Residence
The distribution of health professionals by location (using ARIA+ classification) across the two states is shown in Figure 3. Compared to NSW, relatively more respondents were concentrated in major cities in Queensland (35% for NSW and 42% of Queensland). There was almost no difference in the distribution of respondents in the inner regional areas across the two states but a marked difference was observed for outer regional location (38% versus 22% in NSW & Queensland respectively). In NSW, the proportion of respondents from remote and very remote regions was very low (3%) compared to 10% in Queensland.

![ARIA Classification by State](image)

**Figure 3** Distribution of Health Professionals across major cities and regional and remote areas in NSW and Qld

Occupation
The distribution of the health professionals who participated in the survey is presented in Figure 4 and Figure 5. To avoid repetition, the respective proportion of health professionals in each category is described with figures for Queensland in brackets.
The survey covered all the major professions involved in supporting PwIDD-Ageing. Breakdown of the various groups is as follows:

- Nurses comprised 20% of the NSW sample and 8% in Qld,
- Allied Health Professionals - (15% NSW & 16% Qld),
- Disability Workers - (7% NSW & 13% Qld),
- Aged Care Workers (10% NSW & 3% Qld),
- Team Leaders in Disability /Aged Care (18% NSW & 24% Qld),
- General Management (12% NSW & 20% Qld),
- General Practitioners (11% NSW & 8% Qld),
- Unspecified professional groups (7% NSW & 8% in Qld).

![Figure 4 Distribution of Health Professionals in NSW by Occupational groups](image)

![Figure 5 Distribution of Health Professionals in QLD by Occupational groups](image)
As the focus of this report is on issues associated with the ageing of PwIDD the following section concentrates on residential distribution of Disability and Aged Care staff in NSW and Queensland (see Figure 5 and Figure 6).

A different pattern was seen across the two states in relation to distribution of the above-mentioned categories of health professionals in metropolitan and non-metropolitan regions across the two states. In NSW, nearly half of the Disability Workers who completed the survey were working in outer regional areas (47%) and there were no respondents from remote/very remote regions of NSW (Figure 6). In comparison, the distribution of Disability Workers in Queensland was more evenly distributed across major cities, inner and outer regional areas as well as remote areas (Figure 7). With respect to Aged Care workers, they were more evenly distributed in NSW (Figure 6) compared to Queensland where all of them were either located in major cities regions (50%) or inner regional areas (50%) with no respondents from outer regional, remote/very remote regions (see Figure 7).

![Occupation by ARIA classification for NSW](image)

Figure 6 Occupation by ARIA classification for NSW

A different picture emerged in relation to Disability/Aged Care Team Leaders in NSW with nearly 73% of the respondents located in inner and outer regional areas, whereas in Queensland the distribution across inner and outer regional areas was 44%, with an equal proportion concentrated in metropolitan regions (see Figure 7).
Experience of working with PwIDD who are Ageing

In line with the age profile of the respondents discussed previously, which partially correlates with years of professional experience, we found that over half of the health professionals had more than 10 years of experience in supporting mainstream ageing groups (49%), and a little over a third of sample (38%) for PwIDD (see Figure 8).

However, the more concerning pattern is the proportion of individuals who have very limited experience. Ten percent of those working with PwIDD reported that they had no experience, and another six percent noted less than 1 year experience. The corresponding figures for experience of working with people who are ageing were 2% (none) and 6% (less than 1 year) [see Figure 6].

Taking into account the 1-5 year groups, which cannot be further disaggregated as data was collected in this format, we found that nearly a quarter (24%) of the health professionals in NSW reported having very limited experience of working with PwIDD, and 28% of health professionals had limited experience of dealing with PwIDD who were ageing.
Figure 8 Years of Experience of working with PwIDD and Mainstream Ageing groups across NSW and QLD

Survey respondents were also asked to rate their experience of assisting PwIDD on a five-point response category (ranging from none, very little, limited, significant and very significant). Due to small numbers, the category of ‘none’ and ‘very limited’ were merged together. Figure 9 shows the self-rated experience of health professionals for assisting PwIDD by location using the ARIA classification.

As can be seen from the figure below, some interesting results were observed. Amongst those who considered their experience to be “none/very little”, 46% were located in major cities, whilst 26% were in inner regional and outer regional areas. The responses by health professionals who stated that they had “limited experience” also showed regional variation with 36% in major cities, 21% in inner regional areas, and 38% in outer regional areas.
Conversely, those health professionals who considered themselves to have significant experience were equally distributed in major cities (38%) and outer regional areas (37%). Those in inner regional areas scored lower, with just 19% for very significant category. Health professionals in remote and very remote regions scored low on all aspects, which is consistent with the findings from the literature and anecdotal information from health service providers. It is also reflective of the small number of respondents in the present study.

**Confidence supporting PwIDD**

Available evidence has long suggested that a large number of health professionals neither have the experience nor the confidence in managing or appropriately supporting with people with intellectual disabilities (e.g. Lennox & Diggens 1999). There is limited information on how “comfortable” health professionals are in dealing with people with intellectual disabilities who are ageing (PwIDD-Ageing).

As is evident in Figure 10, there is some variation in responses. On the positive side, it was found that the combined figures for feeling confident in managing PwIDD “most of the time/ all of the time” was 64%, and the corresponding figure was 55% for PwIDD-Ageing. However the proportion of health professionals who did not feel confident was nearly a third of the sample (29% for PwIDD and 39% for PwIDD-Ageing).
Ageing). Such findings reflect both lack of experience [discussed below] and perhaps lack of access to ongoing training and mentoring support systems.

Figure 10 Self-rated Confidence in dealing with PwIDD and PwIDD-Ageing

Since aggregate figures are often unable to provide a fuller picture of the differentials in metropolitan versus regional and remote areas, we interrogated the data further in relation to area of residence of the survey respondents (see Figure 11). A very mixed pattern was revealed. In relation to PwIDD in general, health professionals in metropolitan regions had higher levels of self-reported confidence (77% for ‘all of the time’ and ‘most of the time’ response categories) compared to those in inner regional centres where the corresponding figure was only 36%. Perhaps surprisingly, 73% of health professionals in outer regional reported high levels of confidence.

In relation to PwIDD-Ageing, health professionals in major cities and outer regions reported relatively higher levels of confidence compared to inner regional areas. The proportion of health professionals working in remote and very remote sites was very low, which is reflective of the small number of respondents in the survey.
To further explore the issues, we then examined the data for the same question for three main categories of health professionals who are most involved in dealing with PwIDD and PwIDD-Ageing, i.e., disability support workers, disability team managers and aged care workers. The results presented in Figure 12.

The proportion of disability workers who felt confident (“most of the time / some of the time”) in dealing PwIDD was high (75%) but dropped to 63% for PwIDD-Ageing group. We had expected the Disability/Aged Care team leaders’ responses would score higher for confidence in dealing with PwIDD and PwIDD-Ageing groups, but the figures were similar to those of disability workers (73% and 62% respectively).

In comparison to the above two groups of health professionals, aged care workers rated their confidence high with 67% for PwIDD and 78% for PwIDD-Ageing groups. The survey did not ask for respondent’s previous work history and it is plausible that some of the disability care transitioned to aged care sector or vice
versa. Anecdotally, disability providers confirmed that many of their staff had previous experience in a residential aged care setting, and it was commonplace for casual staff to work across both settings (J. Bramble [The Ascent Group], pers. comm., 28 November, 2013).

Figure 12 Self-rated Confidence dealing with PwIDD, PwIDD-Ageing, mainstream Ageing by profession

Health Support Services

Respondents were asked as to “How would you characterise health support services in your local area (30 minutes travel) for “three groups”: PwIDD, PwIDD-Ageing and Mainstream ageing”.

For PwIDD it was found that the proportion of respondents who felt that services were “always available” were not very different across the metropolitan and rural regions. A similar pattern was seen for responses to availability of health services “available most of the time” in metropolitan and rural locations (see Figure 13).
Few differences were found in the response pattern for PwIDD who are ageing compared to PwIDD (see Figure 14). These findings are contrary to most surveys that show a limited availability of health services in regional and rural areas. It is difficult to postulate how the survey respondents understood the question, and whether their responses were made in the context of overall availability of services in their respective region. It is difficult to hypothesize why this is the case beyond some conjecture. It would be useful to explore these issues in greater depth in future research studies using a qualitative design which focuses on the views of different health professional in inner and outer regional areas to seek explanation of their perceptions and experiences of health services support.
We also examined the data specifically in relation to responses from three major groups of health professionals; disability workers, disability/aged care team leaders and aged care workers. These health professionals are closely involved in supporting PwIDD, PwIDD-Ageing and mainstream ageing groups and are likely to have a better understanding of available health support services.

As evident from the response bars in Figures 15-17, there were some marginal differences in responses by these three broad groups of health professionals for health support services for PwIDD, PwIDD-Ageing and mainstream ageing. We were unable to undertake a detailed analysis due to small numbers when the data is split by state.

As stated above, it would be useful to undertake a mixed-methods study, where some of these issues can be further explored and clarified with a special focus on these three groups of health professionals.

Figure 15 Health Support Services Availability for PwIDD by profession
Figure 16 Health Support Services Availability for PwIDD-Ageing by profession

Figure 17 Health Support Services Availability for mainstream ageing by profession

Training of Health Professionals

When health providers were asked about their training about providing health support for people ageing in the general community, for PwIDD, and for PwIDD-Ageing, a different pattern was noted. Some 77% percent of the respondents reported that their training was adequate “most of the time/ all of the time” for PwIDD. The comparative figures for PwIDD who are ageing and mainstream ageing was 64% and 54% respectively (Table 2).
We examined the data for differences in responses from health professionals across the two states for the three main groups of recipients of health services: PwIDD, PwIDD-Ageing and mainstream ageing groups.

PwIDD: Health professionals’ perceptions of adequacy of training varied. More respondents from Queensland (58%) responded that the training they received was adequate “All of the time/ most of the time” compared to 44% from NSW. The proportion of respondents who felt their training was “not adequate at all” was the same in both states (13%). These results show that there is considerable scope for ongoing training of health professionals through a series of well-organised training workshops with intermittent refresher opportunities.

Table 2 Adequacy of training for providing health support

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Not at all</th>
<th>Some of the time</th>
<th>Most of the time</th>
<th>All of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>PwIDD</td>
<td>1</td>
<td>18</td>
<td>46</td>
<td>31</td>
</tr>
<tr>
<td>PwIDD-Ageing</td>
<td>3</td>
<td>29</td>
<td>44</td>
<td>20</td>
</tr>
<tr>
<td>Ageing</td>
<td>3</td>
<td>39</td>
<td>39</td>
<td>15</td>
</tr>
</tbody>
</table>

Note: values are in percentages
Perceptions of training adequacy by state for PwIDD

Figure 18 Perceptions of Training Adequacy by state for PwIDD

PwIDD-Ageing: As shown in Figure 19 the perceived adequacy of training for supporting PwIDD who are ageing was low. Only 9% of the respondents from Queensland and 7% from NSW felt that the training was adequate “all the time” and an identical proportion (35%) stated it was adequate “most of time”. The remaining proportion (56%) of the survey respondents from Queensland and 58% of the respondents from NSW felt that the training had major gaps with 20% in Queensland (a fifth of the sample) and 23% in NSW stating that their training was “not adequate at all”.

Perceptions of training adequacy by state for PwIDD-Ageing

Figure 19 Perceptions of Training Adequacy by state for PwIDD-Ageing

Mainstream Ageing: While the analysis showed relatively more respondents who felt that training was adequate in all and most areas for providing support to
mainstream ageing groups, nonetheless that still left a fairly considerable proportion of the respondents who felt that training was inadequate.

![Perceptions of training adequacy by state for mainstream ageing](image)

**Figure 20 Perceptions of Training Adequacy by state for mainstream ageing**

In our final section of analysis of the data, we limited the examination to three specific sub-groups of health professionals; Disability Workers, Aged Care Workers and Disability/Aged Care Team Leaders. The results are shown in figure 21.

Thirty-one percent of the disability workers, nineteen percent of the aged care workers and fifty percent of the Disability/Aged care team leaders considered training to be sufficient for PwIDD. The corresponding figures for perceived adequacy of training by these three groups of health professionals for PwIDD-Ageing were 22% (disability workers), 33% (aged care) and 44% (team leaders). For mainstream ageing groups, the perceived adequacy of training was 14% (disability workers), 36% (aged care workers) and 50% (team leaders). Taking a more pragmatic position and reviewing the data for adequacy of training (“most of the time”) still shows considerable gaps in training at the level of direct care workers in disability and aged care.

These results indicate that training gaps exist at all levels of the disability and aged care workforce. A review of current training protocols is required. This issue is further discussed in the Recommendations section of the report.
Figure 21 Training Sufficiency by occupation for PwIDD, PwIDD-Ageing and mainstream ageing

Training issues: Some insights from comments provided in open-ended section of the survey tool

The last section of the survey tool provided open-ended response options for respondents to add further comments. We provide a dot-point overview of some of the comments made by various health professionals in relation to specific questions.

Part A: Specific training topics that would help you to support people who are ageing?

Some of the topics and issues that were frequently mentioned by many respondents include:

Health & Medical

- Mental Health Training
- Managing Emotional Health
- Training in various types of dementia
• Training in bereavement & loss
• Falls prevention
• Dual Diagnosis & Dementia
• Diagnosis of early onset of Dementia
• Trauma – loss of home, family, pets
• Impact of medication / multiple drug interactions
• What are variations in normal ageing

**Family and Community support**

• Carers support
• Social connections
• A whole of family approach

**Health Systems**

• Navigating the community service systems.
• How to access community services packages
• Knowledge of support services and palliative care system
• Advanced care directives
• Best Practice Guidelines changes
• Information on new research studies
• Rights of Older People / Human Rights training

Part B: Specific training topics that would help you to support PwIDD-Ageing?

Some of the topics and issues that were listed by many respondents include:

**Health & Medical**

• What are variations in normal ageing
• Diagnosis of early onset of Dementia / distinguishing depression and dementia; Down syndrome & dementia
• Managing other conditions in dementia – e.g., osteoarthritis
• Communication on various syndromes – e.g., autism
• Common illness associated with ageing in PwIDD
• Management of Behaviours
• Mental Health Training / Managing Emotional Health
• Training in various types of dementia
• Training in bereavement & loss
• Dual Diagnosis & Dementia
• Trauma – loss of home, family, pets
• Impact of medication / multiple drug interactions

**Family and Community support**

• How to support PwIDDD-Ageing who have no family/ friends as support
• More information for carers – that is medically and socially relevant
• Build/ Maintain social connections
• A whole of family approach
• Better Carers support

**Health Systems**

• Better understanding of upcoming changes (e.g. NDIS)
• How to effectively advocate for PwIDDD-Ageing
• Person-Centred planning
• Navigating the community service systems / How to access community services packages
• Information on best to support to prevent transfer to aged care
• How to discuss Death & Dying
• Knowledge of support services and Palliative Care
• Advanced care directives
• “Stranger Danger” – Elder abuse
• Best Practice Guidelines changes
• Rights of Older People / Human Rights training

“Training for both Staff and Family to accept the changes in PwIDDD-Ageing and the steps needed for a better life that is safe – but without requiring a huge document trail….By getting funding, to avoid hospital or nursing homes, so a person can stay at home [own/group home] and be cared for family or other PwIDDD”
Part C: Specific trigger points or crisis that lead to moving to residential facility?

Some of the specific comments made by respondents are reproduced here:

- “Physical care becoming too much for older carers. Ill-health of older carers.”

- “Death/ decline in health of carer. Declining health, mental health of PwIDDAgeing. Due to lack of community nursing availability… the person has to move.”

- “Community ability to support people with dementia and ID is variable. Agency staff providing accommodation and day support have difficulty with challenging behaviours. At times there is little awareness of basic health issues such as swallowing difficulty and aspiration. Therefore PwIDDD may be moved out.”

- “Usual trigger points occur around the need for nursing interventions (e.g. injections.”

- “Age-related depression, which is becoming increasingly prevalent as the population ages. Very limited home-based supports to enable people with depression to safely stay in their own homes.”

- “Lack of services available in the home due to insufficient packages available especially in rural and remote areas. Lack of family support / lack of family knowledge about what pathways are out there as it has become all IT [digital] based and most older Australians do not know or understand IT and how to use. Pathways are too hidden; and clients and families need to search to find a path that suits their needs. Lack of follow-up appointments by health staff to
ensure clients have ACAT assessments, assessments are happening much later.”

**Part D: Can you nominate any strategies that may prevent or delay PwIDD having to move into residential care facility?**

Some of the specific comments made by respondents are reproduced here:

- “Introducing flexible in-home care early”
- “family support; environmental modifications”
- “Set up age-appropriate facility for PwIDD”
- “Provision of additional support services to assist people with community support. Transport provision in rural areas.”
- “more home care for rural areas, more rapid assessment by ACAT teams and implementation of assistance”
- “Ensure the GP’s realise an aged care facility is not the first option but the last.”
- “Specialised ageing health clinics (like the one run by CDS for people with ID) to monitor people more closely when they are living in the community to help plan for increased supports rather than the person reaching a crisis and needing a sudden admission which often means they end up living somewhere that they wouldn’t have chosen, Better access to preventative sources such as allied health and other services such as home modifications to ensure the person’s environment is safe and accessible.”
• “If support workers are provided with necessary age related training and good leadership/ mentors they could feel confident in their ability to support PwIDD-Ageing to living in the community longer.”

• “Clear pathways that are promoted and publicised in medical surgeries, public domains that assist people to plan for old age (printed leaflets), better GP training on referring aged clients, more collaboration between Disability Services and aged Care Services / ACAT.”

Summary

While there are a number of limitations that result from the pilot nature of this project (as discussed below), there are some very interesting results from the Health Professionals survey that relate specifically to the readiness of the community services workforce to cope appropriately with the emerging phenomenon of people ageing with an intellectual or developmental disability. In particular, the lack of relevant and targeted training appears to be a significant gap in current services. Participants clearly indicated their lack of training in this area, and current frameworks do not appear to be proactively addressing this major concern. The survey respondents were able to clearly identify the main areas in which they believe they require additional specific education and knowledge. As the cohort of people with an intellectual or developmental disability who are ageing is predicted to continue to grow rapidly over the next few decades, a far greater priority on the provision of tailored training is clearly of high importance.

Limitations of the Study

Some of the limitations of the present study need to be acknowledged. In relation to the qualitative component, firstly the interviews had to be kept much shorter as respondents were not able to sustain any interview for long periods of time. In most qualitative research projects, if sufficient time was not available, a repeat interview would be undertaken or a copy of the transcript sent to the concerned individual to seek their feedback. Neither of the two options was viable for the present study, as the cost and logistics of organising another interview was not feasible.
Second while we had envisioned the availability of more carers, particularly family carers, in many instances it was not feasible as family carers either lived in another city or at some distance. More importantly, very few were directly involved in the care of the designated participant.

Another limitation of the study was the non-availability of people with intellectual disability who were ageing and living in residential aged care. A lot of time and effort went into trying to recruit a few individuals who fitted the profile. However, there were a number of issues particularly in study sites in Queensland, where it was difficult to gain access to participants as some staff in these institutions felt that an in-depth interview would place an additional burden on the resident.

In relation to the survey of health professionals, a lot of time and effort went into advertising the survey and seeking assistance from various health professional bodies to promote the survey. Although the overall response of 439 responses was above the study target (n=400), in retrospect we feel that a bigger sample is needed to elicit adequate number of responses across the various health professionals involved in the care of people with intellectual disability who are ageing, stratified by state and profession. Such an exercise is costly, and requires additional financial and human resources as well as a longer timeframe to undertake the survey.

**Dissemination of Results**

The findings of the current project have been presented at a number of national and international scientific conferences. Many of these have been outlined in the previous reports. A full list of conference papers and publications is presented in Appendix 1.

**Scaling up**

The project has provided foundational work which will be scaled up in a much bigger and longer grant through a recent ARC-Linkage Grant to be administered by the University of New England. Industry partners are Ability Options, The Ascent Group, Endeavour Foundation and Uniting Care Ageing NSW/ACT. This grant will enable the team to build upon the results of the DPRWG seed grant.

**Details**

LP130100168 (2013-2016; $344,500)

**Investigators**
Parmenter, Em/Prof Trevor R; Hussain, Prof Rafat; Knox, Dr Marie F; Janicki, Prof Matthew P; Hayhoe, Ms Nicola; Leggatt-Cook, Dr Chez M; Armour, Ms Pauline M; Kingstone, Mr Martin.

Recommendations

Implications for policymakers & program managers

1. There was a strong preference of participants (both metropolitan and rural) in having autonomy in choosing to age where they want to and whom they want to.

It is clear that participants across all locations wished to be consulted and have a greater say in any decisions being made around their accommodation. Such a change will require a review of policies around design of accommodation for PwI/DD who are ageing. Furthermore, there needs to be greater autonomy in options around selection of co-residents. We acknowledge that both these issues pose a number of logistical challenges for residential accommodation options. The person-centred philosophy inherent to most current disability models has been argued to underpin the concept of Ageing-in-Place, however it is seen that this belief needs to be reviewed and revised as Ageing-in-my-chosen-space, rather than simply ageing-in-place as this does not necessarily reflect the goals and aspirations of this group.

2. There is a need for greater and more meaningful consultation in any decision-making processes.

It is recognised that for many people with an intellectual or developmental disability, particularly those without strong family support networks or who have increasing needs, the current model of integrated group homes remains a very appropriate model. The structure of independent individual rooms and some level of residential support staff are often able to adequately meet individual needs. However, it is worth recognising that other participants felt marginalised and alienated in such environments due to lack of consultation in decision-making of co-residents. It is believed that much of the distress felt by participants can be ameliorated, which in turn will improve their sense of belonging and contribute to positive ageing. This is predicated on their being sufficient flexibility in selection of co-residents, and more importantly, by ensuring that their personal space [room] is respected by fostering within the group home environment a greater sense of privacy and greater respect for sanctity of their personal belongings. Such changes can be easily incorporated
in review of ongoing training of disability support staff and reinforcement of these concepts that influence perceived sense of belonging and ageing-in-place.

3. **There is an urgent need for the up-skilling of professional staff.** There is a clear need to proactively review the skill base of professional staff in relation to the additional needs of PwIDD who are ageing. Participants identified an obvious gap within their education and knowledge base regarding the provision of support for ageing-related issues. Such up-skilling would allow older residents to stay in their “chosen place”, rather than be subject to an enforced move as a consequence of either a perceived or real lack of adequate skills of current staff to deal with additional age-associate issues which are not yet of the magnitude that require residential aged care. Many participants and their carers expressed the belief that “they had no options” and that the simplest decision was to send them to large congregate facilities. Such a move was seen to greatly diminish their social connections and completely undermined the concept of “ageing-in-place”. This problem particularly evident in rural regions, and increased training of staff working in these regions would result in greater confidence in dealing with age-associated issues. A secondary benefit of increased retention of staff through staff development could also be a highly desirable outcome of such a change.

4. **Individuals with intellectual disability who are able to stay in family homes should be encouraged and supported to do so.** The rollout of the NBN across Australia has presented new opportunities for both individuals and services not located in close proximity. It would appear that at least some of this cohort’s age-associated needs could be addressed effectively and efficiently through simple and low-cost home modifications utilising existing tele-health and e-technologies. The availability of fast speed internet services provides new opportunities to connect individuals with support staff or specialists, as well as to assist PwIDD who are ageing to maintain their wider social connection through social media platforms. These issues are particularly relevant for rural residents, as they are at great risk of both premature and inappropriate admission to residential aged care that is often located at considerable distance from their familiar community.
Implications for Research

There are a number of areas and issues that would benefit from further research. Some of the key issues are outlined below:

1. The perspectives of carers were limited in the present research, particularly in relation to a better understanding of the impact of care-giving on their own health and well-being.

2. More focussed research is needed to elicit the perspectives of disability support workers. The present study has provided some interesting findings in relation to differences between inner and outer regional staff skill base, experience of dealing with PwIDD who are ageing and perceptions of their own abilities in relation to confidence in managing age-associated issues.

3. There is a need to undertake a gaps analysis in relation to available services and accessibility of services. This is particularly of value in rural areas.
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APPENDIX - Publications


