****

**Supporting ageing in place for people with**

**and into disability: An exploration of rural and**

**metropolitan perspectives**

**Professor Emeritus Trevor R Parmenter, University of Sydney**

**Co-Investigators: Dr Marie Knox, Professor Matthew Janicki, Professor Rafat Hussain**

**Introduction**

Assisting older people to *age successfully* is a major priority within the community services sector. In addition, people with lifelong disabilities are living longer and there is a major crisis within the disability sector for people with lifelong disabilities who are ageing. They can face being prematurely - and often inappropriately -‘institutionalised’ and placed into Residential aged care when no other community residential support is available. This problem has been noted by the Commonwealth Senate Community Affairs Reference Committee (2007), however, no resolutions have yet been proposed.

There is limited Australian research available to understand the challenges faced by older individuals with and without lifelong disabilities, and their carers, on how they cope with health and well-being issues.

This study explored the key issues that either help or block older people, both with and without lifelong disabilities, to age in place. The study looked at what options older people felt they had and how they might differ in metropolitan and rural regions.

The study had two phases:

1. Interviews with 57 older people, with and without lifelong intellectual disability, explored their understanding of ageing-in-place. They discussed their goals and what services were needed to achieve them. Participants living in the community and in aged care facilities came from both rural (Parkes) and urban (Liverpool/Illawarra) areas of NSW.
2. A survey looked at the knowledge and skill base of the existing workforce in aged care, generic health and specialist disability services. Opportunities to train and grow the skill-set of workers providing community-based support were also examined. The survey also identified gaps in the health support systems for both groups of people who were ageing.

**Figure 2: Barriers to a good life**

**Results**

**Participant interviews**

The complexity of the idea of ageing-in-place was a key theme. Participants felt ageing-in-place is not just about staying in their home or living in the same place they have lived for some time. Ageing-in-place is also about where to live and how to live life as an older person. It is about how to have a good life as an older person, with a quality lifestyle. Participants shared what helped and what prevented a good life.

Figures 1 and 2 show the key facilitators and barriers to a good life, as described by participants.

****

**Figure 1: A good life**

**Figure 2: Barriers to a good life**

**Choice/Control**

***“Ageing in place is more than bricks and mortar”***

Participants clearly said that having control over important decisions, such as where they live, was vital to a good life. “Home is where I want it to be” was said many times. Participants felt they made the best housing decisions, considering their future needs (health and mobility) and lifestyle wishes (close to valued relationships and activities).

*“I had an operation that went wrong …*

*I could not get up the sixteen stairs of my unit,*

*so I thought I may as well come here”*

Participants liked having choice and control to do activities that were of interest to them as individuals, rather than do things that others assumed would be enjoyable.

*“He doesn’t like to play scrabble or cards …*

*he just likes to be around men”*

Having control over how services were delivered was also important. Participants wanted to control who provided their services, not just in what they were doing. A mixture of paid and unpaid support was preferred. Relationships with paid support workers were seen as just as important as the tasks the support person performed.

*“My family wants to help out and things …*

*but I like to do it myself where I can”*



Lack of choice and control in these areas affected having a good life. Service-centred, rather than person-centred, approaches to quality support led to a lack of control or choice, in many instances.

 “*We need all the players around the table*

*to work XXX’s case through”*

**Relationships**

***I like having a joke with my friends, I do a bit of stirring…***

While paid support workers were important, participants valued unpaid and informal relationships the most. Building and maintaining friendships, and the ability to grieve for lost relationships, were key to a good life. Maintaining family and key relationships was essential.

*“I find it’s family all the way”*

Participants found loneliness and isolation from valued relationships were significant barriers to a perceived good life. Fear of these losing valued relationships affected decisions around where to live. Loss of mobility and declining health were connected with loneliness and isolation.

*“He talks about moving because he lives on his own and he’s very isolated. He does find the loneliness hard”*

***My friends are not where I live because people there are in their 70s, 80s and some 90s.***

Again, it was the person’s important relationships that were significant. A lack of harmony with co-residents or housemates was a barrier to a good life. Many felt out of control in this aspect of their lives. They might have had control over the home of their choice, but had little choice in the people with whom they lived.

*“Some people get on my nerves… push me round too much, and always speak to me about other people”*

***He gets pain that affects him …I think pain is the biggest thing in aged care.***

**Health and mobility**

Participants stressed the importance of maintaining their health and mobility. Health and mobility allowed participants to pursue activities and interests of their choice. Participants talked about their limitations in ways that were useful for them.

“ *I wouldn’t make it without my walker…*

*my mobility has gone downhill”*

Equally, lack of mobility, declining health and constant pain limited participation in preferred activities and contributed to loneliness and isolation.

 “*I can’t ride my bike any more …*

*that’s why I had to stop playing bowls”*

Access to specialist health services supporting the diverse needs of older people, in both rural and urban areas, was of concern for many participants.

*“It’s hard to get an OT in Parkes.*

*I don’t even know if we have an OT in Parkes.”*

**Support**

***I live by myself. Gerry comes Thursday and I have Homecare in the mornings and afternoon.***

Quality support was critical to participants, helping them to lead a good life. Yet, the support was often from different sources, and uncoordinated.

*“… it’s about understanding the whole total package”*

This lack of coordination of services was a barrier to leading a good life. A key person to coordinate and monitor support, ensuring a person-centred manner, was seen as essential to facilitating a good life for the older person.

*“I prefer to do shopping with my sister,*

*not with other people*

*And changing the room around,*

*I don’t like it – the ones that clean.”*

***I’m the best worker … I love going to work, getting paid and the pay slips.***

**Role in life**

Participants liked having a role for themselves and also being valued by others. The role could involve work or daytime activities.

“ *I take charge of the bingo.*

*Call out the numbers and take in the money*.”

For some, ensuring other’s well being provided a leadership/advocacy role.

*“He loves to get on his soap box. He has taken over the father role of a young man with intellectual disability and enjoys this role.”*

Lacking a role was identified as a significant barrier to a good life.

*“I don’t know how she would accept it if she got to the stage of giving up work.”*

**Results from support staff and health professionals’ survey**

Early analysis of the service provider’s feedback shows that people with intellectual disabilities appear to be worse off than those in the general population. This confirms the responses from the participant interviews.

On the issue of pre-service training, workers in general ageing reported greater satisfaction than those in the intellectual disability field.. A similar trend emerged on the availability of specialist services.

This may indicate the workforce in the disability field is not prepared to cope with the changing needs of their ageing clients.

**Recommendations**

The results of the study suggest:

 Services supporting people who are ageing require greater coordination.

 Support staff working in both community and in aged care facilities, especially those supporting people with lifelong disabilities who are ageing, need better training. A generic training program for both ageing and disability issues, including hands-on experience, would be ideal.

Better access to appropriate health and allied-health services, especially in rural areas, is required.

 People with lifelong disabilities require a more person-centred activity plan, especially if they live in an aged care facility where activities may not be appropriate for them, e.g. board games and crossword puzzles. Extra staffing or engaging volunteers who may be able to provide such support is needed.

 Long term planning for the future is required, including the needs and wishes of the person with input from family. There must be a balance between the wishes of the person who is ageing and other stakeholders, especially when considering relocation due to health issues or the death of a partner.

 Transport that helps people who are ageing access medical services, go shopping and meet friends and family, is essential.

**Summary**

People with intellectual and developmental disabilities are now living longer. Disability and aged care service providers now have to consider the special needs of this group. People with lifelong disabilities have previously been supported in out-of-family home care, or by their parents at home. Parents who have been primary caregivers are becoming increasingly concerned about the long term welfare of their sons or daughters.

Despite increased life expectancy, people with a lifelong disability often age earlier and experience more complex health issues. Age-related needs of people with a disability, including early onset of dementia, may often require support before the person is eligible to access aged care services. Similarly, aged care staff may not be equipped to assist people with a lifelong disability. Ageing people with disabilities face possible discrimination as they receive aged care services by workers who are not equipped to support their needs. However, ageing is the central issue, with the additional factor of having a lifelong disability.

This study identified factors which participants described as contributing to their quality of life, a ‘good life’. There were many similarities across people ageing with a disability and the general ageing group. The main theme appears to be a focus on positive ageing.

The major issues identified by carers and support workers are isolation, and lack of access to specialised services.

This project was funded through a grant from IRT Foundation. IRT Foundation (formerly IRT Research Foundation) directly aligns with IRT's mission to create communities of good health, lifelong learning, participation and security.

IRT Foundation has committed more than $1.4 million to research since 2009 and will build that commitment into three priority funding programs: a community grants program to fund local initiatives which improve the lives of older people; an education and advocacy program to influence policy and decisions which impact older people; and a research program where IRT will continue to fund important research into ageing



IRT Foundation

A division of IRT Group

Level 3, 77 Market Street

Wollongong NSW 2500

T: 1800 024 915 (freecall)

E: irtfoundation@irt.org.au