Ageing-in-Place: Perceptions of people with intellectual disability and those without lifelong disability in rural and metropolitan NSW

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Part of wider study that aimed to provide an assessment of gaps currently preventing the successful ageing in place of both people with and without life-long intellectual disability in rural and urban areas of NSW.

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This focus of this paper is an exploration of the individual’s own understanding of ageing-in-place and the features that facilitate or impede the achievement of this goal.
Background

- Dramatic improvements in life expectancy has led to a large cohorts of people with and without an intellectual disability who are ageing.
- There is a significant social welfare context emerging in ageing of people with intellectual disability who may face a double jeopardy of getting older and facing further discrimination.
- In the general population people who are ageing acquire disabilities later in life.
- People with lifelong intellectual disabilities may age earlier and may have earlier onset of complex health needs, and thus may require aged care support for longer periods.
- Retirement may come earlier for people with life long disabilities.
- People with life long disabilities have often had a different life trajectory, including seldom acquiring substantial assets.
“Aging in place” is a popular term in current ageing policy, defined as “remaining living in the community, with some level of independence, rather than in residential care” (Davey, Nana, de Joux, & Arcus, 2004, p. 133).

Ageing in place generally refers to opportunities for people to remain in their own home regardless of their increasing care needs (Bigby, 2008, p. 77).

But how do the older people themselves understand ageing-in-place?
What was our Method?

In depth interviews in rural (Parkes) and urban settings (Liverpool, Wollongong) in NSW with the following people, all of whom were receiving services, on their perceptions of life as an older person, including notions around ageing in place.
Who were the Study Participants?

- **20 Older people with lifelong intellectual disability (55+ and showing signs of ageing)**
  - 17 in group home, family home, own home; 3 in aged care facility
  - 21 Carers nominated by the person (family member or support worker)

- **18 Older people without lifelong intellectual disability (55+ who had ACAT assessment)**
  - 10 in aged care facility, 8 in own home
  - 9 Carers nominated by the person (family member or support worker)

- **Totals: Older people: 38  Nominated carers: 30**
What Did We Find?

Ageing in Place
*It’s More than Bricks and Mortar*

Preliminary themes identified
- Ageing in a place I choose
- Relationships that are important to me
- Keeping my health and mobility going
- Support as I would like it
- Having a role in life I value
Having a say in *where* I want to live myself

- “I want to stay here” (ID participant)

- I like it here; it is my home. I’ve lived here all my life (ID participant)

- Down where I used to live at YYYY, there was rowdy and all of that and I didn’t like it. Colin came along and said there’s a place up at ZZZZ. I mean I had a visit up here up...(ID participant)

- I had had an operation that went wrong ... I could not get up the 16 stairs of my unit, so I thought I may as well come here (non-ID participant)

- I won’t leave Parkes because my husband and daughter are buried here (non-ID participant)
Ageing in a Place that I choose

Having a Say in who I live with

- Some people get on my nerves... push me round too much, and always speak to me about other people (ID participant)

- It’s good living here except that R... teases a lot. It’s not very nice. He gets very nasty. He upsets J... she can’t speak ... it’s not right. I just keep well away; I just go to my room.

- Love being on my own and I love being here (non-ID participant)
Maintenance of relationships I value

- I like having a joke with my friends, I do a bit of stirring… my friends are at XXX, not where I live because people there are in their 70s, 80s and some 90s (ID participant)

- “I go for lots of walks…I have friends in town…just say hi to them”.

- “I am just happy as long as I have my family and friends and I think they are a blessing and I think friends particularly living in a place like this it is very important I would hate to be at logger heads with anyone. (non–ID participant)

- I have friends here who come and have a beer with me. I don’t get a chance to get lonely (non–ID participant)

- I miss the people from …. (non–ID participant)
Opportunities to pursue new friendships

- "I find here that you always find your own friends and I am quite happy here" (non ID participant)

- "... the people here I like, even the arseholes aren’t too bad" (non-ID participant)

- "I enjoy all the people coming through my life" (ID participant)

Missing lost relationships

- "One of my best friends passed away – I was a bit upset over it" (ID participant)

- "My wife .. She changed me, she was very smart" (non-ID participant)
Keeping My Health and Mobility Going

Health Issues Experienced

- If I can control the pain, it’s fine (Non ID participant)

- I can’t ride my bike any more ... that’s why I had to stop playing bowls (non-ID participant)

- I’m getting slower. I get tired if I walk fast. But I’ve got a good memory, I help Mum when she keeps repeating herself, so I remind her. She had a stroke (ID participant)

Using Devices or Aids

- I wouldn’t make it without my walker... my mobility has gone downhill (non-ID participant)

- I hang onto the rail going down the steps now (ID participant)
Keeping My Health and Mobility Going

Accessing Specialist services

- It’s hard to get an OT in P...... I don’t even know if we have an OT in P....... (non ID participant)

- AAA takes me to Dr BBB especially about my diet (ID participant )

Learning from Others Experiences

- When I get old I’ll pass away … like Dad (ID participant)

- Yes. Well, I didn’t know anything about dementia, until the last couple of years. Until somebody said, “Jo’s got dementia.” I said, “What’s that?” He said, “When your brain’s going, and they know no-one.” (ID participant)

- It’s important that I can get around and have my mind …I watched my poor mother for 5 years, she didn’t know us” (non-ID participant)
Support as I would like it

Control in who does what

- My family want to help out and things … but I like to do it myself where I can” (non ID participant)

- The staff changing is annoying. Changing my dolls and room around. I don’t like it … the ones that clean (ID participant)

- I say you do the bathroom and I’ll do the bedroom; I’ll do the dusting, and she’ll do the kitchen (ID participant)

Mix of formal and informal supports

- “I got a lady comes after I do the washing she does the wiping up for me” (ID participant) and we got a friend who comes and does the ironing when I do the washing…” (ID participant)

- We get help from Y … she packs the groceries away and we do the cooking (non-ID participant)

Coordination of support

- We need all the players around the table to work my case through (non-ID participant)
Role in Life that I Value

A worker
- *I’m the best worker … I love going to work, I like getting paid and the pay slips* (ID participant)
- *I used to be a union rep…. Easy to use these skills here* (non-ID participant)

A Helper
- *it’s a good life when I’m helping my dad and my uncles and my aunties, and feeding my dogs* (ID participant)
- *I’m involved in the home bound library… and group leader at the monthly meetings of the Parkinson’s group* (non-ID participant)
An advocate

- I must put it to them they have room upstairs and they could keep it like a visitors room and somebody could come and stay there ... like they could get meals and you could pay for them to stay over here. (non-ID participant)

- 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. (non-ID participant)

A carer

- I water the garden for my mum now, and I bath the three dogs...I do my mum’s things for her ... Who will look after mum when I’m not there? (ID participant)

- We look after one another. ... Check when we don’t see somebody for a while (non-ID participant)
Depiction of A Good Life

A GOOD LIFE

- A KEY PERSON
- QUALITY SUPPORT NETWORKS
- FAMILY
- RELATIONSHIPS OUTSIDE PAID CARERS
- FRIENDS
- HOME IS WHERE I WANT IT TO BE
- CHOICE
- CONTROL
- AUTONOMY
- MOBILITY
Depiction of Barriers to Good Life

- No Role in Life
- Isolation
- Loneliness
- Service Rather Than Person-Centered
- Lack of Coordination of Support Services
- Lack of Specialist Health Services
Some Conclusions

- Ageing-in-place a complex entity, more than just “staying put”
- Similar issues for people with and without lifelong intellectual disability
- Coordinated planning needed across the sectors; person-centred approaches needed
- Enabling expressed wishes of person to be taken into account
- Similar policy focus on the individual in both aged care and disability sectors – so why is this not possible?
More diversity or variation within groups rather than across groups

Theories of ageing need to take into account the diversity of the ageing population. Perhaps a more inclusive notion of ageing rather than seeing minority groups such as people with lifelong intellectual disability as a separate group. Minority groups, such as people with intellectual disability, in ageing literature not catered for very well (Bigby, 2008, p. 77).

Ageing as part of the life course with previous life experiences impacting on perceptions of ageing in place need to be considered. Consistent with Tornstam’s gerotranscendence approach to understanding ageing, including ageing in place
Tornstam’s Theoretical Approach

- Tornstam (2005) suggested a developmental theory of positive ageing termed “gerotranscendence.”
- Theory allows “old age” to possess its own meaning and character.
- Has subjective and objective elements.
- Includes older people’s perceptions of ageing.

- Provides a theoretical lens for research efforts to gain the perspectives on ageing, including ageing in place, of older people with and without lifelong intellectual disability.
The research team has just begun a three-year comparative study of ageing with and without an intellectual disability across two states covering both rural and metropolitan areas funded through the Australian Research Council (ARC) Linkage Grants.

**Investigators**
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**Partner Organisations:** Ability Options Limited, Endeavour Foundation, UnitingCare Ageing NSW.ACT, The Ascent Group Australia Ltd
Thank you

Questions and Comments?
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Ageing and Disability: Are we getting it right?
The Futures Alliance and Australian Association of Gerontology (NSW Division)
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Ageing in place is more than bricks and mortar
Complexity of the ageing in place concept
Quality of life or good life for older person
Their views on good life – and its facilitators and barriers
Relationships
Health and Mobility
Support
Role in Life
Wanting to move – e.g. Judith
Two distinct populations

In the general population people who are ageing acquire disabilities later in life

People with congenital disabilities may age earlier and have earlier onset of complex health needs

High level of aged care facilities generally cater for people at end of life stage

People with life long disabilities may require aged care support for longer periods

Dementia support is common to both populations

Retirement may come earlier for people with life long disabilities

People with life long disabilities seldom acquire assets
Interview Guide

- 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

MAYBE SIMPLIFY AND INCORPORATE INTO PREVIOUS SLIDE
The Current Research Project - Methods

NSW Metropolitan area (South Western Sydney and Illawarra) 13 people with lifelong disability and 15 carers nominated by the older person were interviewed. Eleven of these people lived in either a family home, group home or own home, whilst two lived in a aged care facility.

Five people who were ageing without a life-long disability and who lived in an aged care facility were interviewed as well as four nominated carers. Four people who were ageing and living in their own home with an aged care package were interviewed.

In the Rural sample (Parkes, NSW) six people with lifelong disabilities living in either a group home or their own home were interviewed, together with one living in an aged care facility. Seven carers of these people were also interviewed. For those who were ageing without a lifelong disability, five who were living in an aged care facility and four were living in their own home with aged care support packages, were interviewed, as well as two carers (see Table below).
<table>
<thead>
<tr>
<th>Ageing with ID and carers</th>
<th>Ageing without lifelong disability (ACAT) and carers</th>
<th>Ageing with ID and carers</th>
<th>Ageing without lifelong disability (ACAT) and carers</th>
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<tbody>
<tr>
<td>Illawarra</td>
<td>Liverpool/Illawarra</td>
<td>Parkes</td>
<td>Parkes</td>
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<tr>
<td>13 participant &amp; 15 carers’ interviews</td>
<td>5 participant interviews (Aged Care Facility)</td>
<td>6 participant interviews</td>
<td>5 participant interviews &amp; 2 carer interviews</td>
</tr>
<tr>
<td>– 11 in home (family home, group home, own home)</td>
<td>4 carer interviews</td>
<td>7 carer interviews</td>
<td>4 in own home with package</td>
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<td>– 2 in ACF</td>
<td>4 in own home with package</td>
<td>1 Aged Care Facility participant.</td>
<td>4 in own home with package</td>
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Is ageing-in-place as important as choosing who I age with?

- Some people described choosing to stay with their significant other or family as more important than staying in their own home

  *Quote from Colin and Denyse*

  *Linda?? -- Marie’s one*

- Having control / choice over where I live and when I move appears to be very important to both PwID and members of the general community
Ageing in Place – More than bricks and mortar

- Home is where I want it to be
- Denyse and Colin
- Want to stay here
- Marie’s one about moving when I get older
Key points??

- Person centred – versus service-centred
- Key person

- The two groups similar – and little difference in rural settings – other than specialist services
- Similar outcomes
- Also similar philosophies of aged care and disability sectors???
Recent Reports and Reforms

- Two (2010-11) significant national reports by the Productivity Commission: one on Ageing and one on Disability.

- National reforms and the advent of National Disability Insurance Scheme (NDIS) have changed the landscape from a service-centric to an individualized funding focus.

Nonetheless, there are substantial gaps in policy & practices between the philosophies embraced by the proposed national reforms and their articulation into practical, achievable outcomes.
The Project Team

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(a) Successful Ageing

- Avoiding disease
- Maintaining high cognitive & physical function
- Engagement with life

Rowe & Kahn (1998) suggested that when all three components overlap, successful ageing is represented.

But, can all people who are ageing maintain high levels of functioning? This approach lacks subjective elements. Is it a tangible or an elusive concept?