

The aspirations of older people with intellectual disability about their future: How the system is failing them.

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Aging and Intellectual Disability: Big Picture Context

Increased life expectancy

Bulge in numbers as the Baby Boom Generation Age

Still predominantly younger old

High use of formal services, increases after loss of parents as primary carers

Included in broader disability policy visions of choice, inclusion, participation and rights.

Few specific policies within the disability sector

Recognition that access to aged care system is difficult

Issues of double dipping – are people aging or disabled or both?

Demonstration that partnerships between aged and disability do work and increase quality of life – policy and program development stalled

Election promises to extend aged care packages to people in shared supported accommodation

Focus on the little picture, what's happening on the ground, program responses and lived experiences.

Findings recent research: Aging in place

NDA study (Fyffe, Bigby, McCubbery, 2007)

National study of shared supported accommodation

Total population 11,308 people across all states

Sample: 3912, (34.6%) of total residents

- » 1647 (42%) over 50 years 68% intellectual disability
- » 285 (7.3%) over 65 years (56% of all people over 65 years)

Quantitative & Qualitative case study data- adaptations, issues re aging in place

Challenged by changing support needs - Not only among older age group – another story

- Health problems - not always associated with age.
- Problems associated with progression of disability
- Clearly age associated

Adapt through

- » Staffing
- » Negotiated day program changes – replace employment with day support/respite
- » House modifications
- » Variation to service design – residents grouping – internal planning
- » Organisational mind set - Combinations rather than single strategies

Views and experiences of disability providers

Strong commitment from disability providers to aging in place

- Uncertain as to meaning
 - staying within the disability sector, but moving house often to 'be with like people'
 - staying in one's own home - regardless of the cost - until a certain level of medical or complex care is needed - until the service provider can't or won't continue to provide support - until death - when palliative care is required

Few people have to move

- Within shared supported accommodation
 - » 56 (3.4%) over 50 yrs older people moved between group homes last year
 - » Of these 18 to group homes arrangements exclusively for older people.
- From shared supported accommodation to Residential Aged Care
 - » 27 (0.7%) total residents
 - » 27 (1.6) residents over 50 years
 - » 5 (1.%) residents over 65 years

Going it alone own resources – limited funding or external expertise or linkages

What is the quality of care –is it the best option? When is it appropriate to move?

The picture from residential aged care

Survey of 826 residential aged care in Victoria (Bigby, Webber, McKenzie-Green, Bowers in press)

Mailed survey telephone follow up to directors of facilities

Qualitative and quantitative data on facility and residents with intellectual disability

Sample 286 facilities 35% (representative, size, metro/rural)

40% (114) at least one resident: 207 residents with intellectual disability over 50

Most small number and proportion of total residents, 1-3 (two exceptions 17 & 23)

Much younger than other residents

- 46.8% under 65 years v 4.1% under 65 years
- 4.4% 85 years or over v 52% 85 years or over

Stay for longer

- Uncompleted length of stay 5.6 years 44% more than 8 years v completed length of stay 2.7 years

Lower rate of dementia 10% v 60%

Similar dependency profile approx 60% high care

- Artefact of assessment tools- lack experience
- Or reflection of early aging – but small % DS

Reasons for entry and experiences of RAC

Where from

- 37% from family home 10% of these with family member
- 25 % from previous supported accom
- 6% from group home, (masked by hospital 9%)

Entry do not seem to be associated with ill health or severity of support needed

- Inability to continue support those in supported accommodation
- Death or ill health of carer those at home
- Lack of other options for those at home or lack knowledge

He probably could have gone somewhere else because he is fairly independent. It seems to me that families hit a crisis (when the person has to be hospitalized). They don't know what to do so they decide on aged care as the only option but with good care the person often starts to feel better. Poor Planning – Lack of Alternatives

Social rather than Care issues in RAC

- 28% no positive relationships with other residents

75% respondents identified this group as different and referred to difficulties

- Fitting in to activities provided for all residents 48%
 - Different in terms of age, interests, difficult behaviour, care needs, social isolation
 - Needed more individual attention (24%)
 - Negative attitudes other residents (6%)
 - Lack staff expertise (6%)
 - Lack resources to respond (10%)
- Low capacity – Different population- Not High Nursing care

Perspectives and experiences of people with intellectual disability

In- depth qualitative study 16 people with intellectual disability aged over 50

Qld & Vic – ARC Linkage (Bigby & Knox; Buys et al.,)

Experiences and idea of aging, themselves and those around them

In depth interviews with person, staff member and family member/friend

All used day support/ employment and or accommodation support services

Most life long connections to disability services

Busy Active Lives

- Regular activities based on routines

“Ooh yeah, I love it, then Wednesday’s I go bowling again, twice bowling. ..and Thursday’s we go shopping. .. last week we went in the country. ..and we go different places. ..Friday’s we go to the country for a drive. .. sometimes we go for a barbeque

- Focus of support services

“keeping them occupied, that’s the best”.

- Activity - not always related to individual interests

“they always say you have to do what everybody else does. ... well say when everyone else is dancing they say “you’ve got to dance” ... And you do it ... Yes”.

Sense of belonging & significance

Valued Roles – Known as an individual

“I’m the second one up in command. I’m the supervisor ... He [staff member] said I was perfect ...He leaves me in charge”.

“Julie [service user] idolises him, everybody loves him, he’s a grumpy old bugger he is, but he’s everybody’s favorite”.

Close and long-term friendships with other service users,

Josh plays bowls at the weekends in a bowling team with other service users

They have travelled widely to participate in competitions. He said, “when we don’t bowl in the afternoons, we just go to Sizzlers or something. Gary and Trish and all the others from bowls...”.

Changing family relationships & roles

Family avenue to wider group of acquaintances

On the weekends I help George ... and when he’s not around I go shopping with Gloria (sister) and Sunday we go to church at Chersey. .. Last Sunday we went over to Redland and I met my great nephew and Gloria and I and a couple of friends of ours went out with the church group.

Purposeful ideas about the future

Seldom conceptualised as aging

But clear ideas and preferences based on interests

“I’d like to live with my girlfriend - that’s what I’ve got in the back of my mind. I’d like to have my own house with her. I’ve worked out how I can move .. but it’s not happening”.

Janine did not want to stay in the retirement village, because of the social ostracism she experienced, she said, “I’d like to live near Alison’s house. Because about 8 years ago I was renting there in the same street. I was happy there.

Rachel who lived with her elderly parents had a vision of what she wanted for her future.

I’d like to move somewhere where there’s no stairs and somewhere where there lots of shops and trains ... I’ve had too much of here ... Forty years nearly forty-one. I’d like to live near my sister – that would make it home.

I want to go to England.. to see the Royal Family, I love the Royal Family... I could tell you about the children, the dates of their birthdays, anything like that.

Controlled lives and un-actioned plans

Control exercised by staff and family

- **where to live - who to live with - where to work and activities they could participate in**

All of a sudden they told me they didn't want me anymore. [they said] you can ring up and go to the Willows and have a coffee and a chat, and I said "what's the point in doing that? Catching a bus all the way out to Willow's just for a coffee and a chat".

My sister-in-law's got different plans for me. ..When I get old, really old and Donna [service provider] told me this too I have to go to a nursing home because they can't take care of you.

"I just keep on my own way ... always doing things the way other people want me to do"

Service centered & present focused

Operational service requirements took precedence

Donna used to take us shopping on a Wednesdays but now she can't do it for some reason. When I first came over here we used to have Aged Care at our place every day. They closed down that service because they can't afford to send anybody else.

Frustrated by the absence of an orientation to the future.

Hilda, a service provider “they don't think about, when people get older, where are they going to put them you know, they could put them anywhere you know”.

Jules, another service provider, felt powerless to challenge what she saw as the only alternative for older people provided by her organization, “ And then what? They put her into a nursing home like they did with Tracy ... She won't cope with that”. “We've never had that discussion [with families]. I don't think any of them would think of the future, they just go along with the flow you know”

Rachel's mother unlike Rachel had no clear ideas about the future, saying, I just take each day as it comes. I know the girls [her other daughters] will do the right thing ... Yes, I don't like to think about it. What's going to happen to her? It's a terrible feeling... I'm quite happy with her here ...She loves all her things around her

Living in separate worlds

Lives split between two distinct worlds

The Service World

- formal programs, large organisations, paid workers, and other service users,

The Informal World

- populated by family members, volunteers and acquaintances unconnected to formal services.

Unconnected worlds

- Little knowledge or communication passed across the boundaries.
- Family members had only a fleeting involvement in or knowledge of life in service world
“We’re continually forming relationships with different staff”,
“We don’t know that much that goes on there”
- Staff knew little of the person’s history or their life beyond the service confines.

He only sees them once a year they pick him up and he goes out to have dinner with them ever year.
Family? I don’t know who they are. ...They were friends of his family or something like that....they’ve
been doing it for years lost opportunities

- Only volunteers straddled

Impact of unconnected worlds

No one from either of their two worlds had a mandate to know the whole person or the right to do so?.

‘I wouldn’t have a clue of what he’s got in money and I’m not interested in that money, that’s got nothing whatsoever to do with me.’ (friend)

My role is limited in a certain way ...Laura’s been in Algester about 30 years I think ... see I’m not too sure of her history. I think she was 18 when she went to Algester, I think. I’m not too sure. (staff)

Limited shared problem-solving

Each made assumptions

Unsure of mandate re crossing boundaries or future planning

“I think the family have got that sorted out. Least I think so”

“we’re aware of boundaries with family, and we can’t do it we can only suggest it”

No one was aware of the complete picture of each older person’s life.

Why can't Janie Visit the Queen

A typical example is Janie who, as she points out, needs support to pursue her goal of going to see the Queen, “but I can't do that on my own ... I'm not allowed I'm not allowed to travel.” Despite her dream being acknowledged by both the service world and the informal world, “she wants to go to England” (family member), “she wants to visit the Queen and that's part of her goals, her long term goals” (service provider), and having sufficient personal funds for herself and a carer to travel to England, it is not addressed.

Like the realisation of most goals for people with intellectual disability of all ages, Janie's required skilled effort, collaboration and advocacy. But for her like the other people in this study, there is no collaboration between her separate worlds, and advocacy does not figure strongly in either.

Fractured sense of continuity

Why does no one have the complete picture?

- Divided lives between parallel unconnected worlds
- Fragmented biographies and support
- No responsibility for boundary crossing
- No responsibility to challenging piecemeal present focussed decisions
- No responsibility for focus on the future
- No Responsibility to support refinement and implementation of ideas for the future

Where should the responsibility lie?

For individual whole of life planning - commensurate with own preferences and ideas

Commitment to aging in place is not sufficient – needs to be in the context of individual plans.

Do the problems stretch beyond the issue of aging to planning for individuals earlier in life course

Will Person Centered Planning address this

Can Services seize the responsibility at least for planning

Bigger picture unanswered questions

How will effective PCP be funded and plans implemented for those in services

How can better alternatives be planned and entry as a last resort to residential aged care be tackled

What is the quality of care in shared supported accommodation for those with Changing needs – is it the best option?

When is it appropriate to move?

When will the existing capacity of services be stretched too far to adapt to changing needs

How can ACAT assessment be improved/resourced to take account of life long disability

How can the capacity of residential aged care be improved for this population.