

Aging with a life long disability: issues, evidence and solutions

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Issue 1. Increased life expectancy: Absence of policy and unprepared service systems.

Increased life expectancy

- Those with mild to moderate intellectual disability comparable life span
- First sizeable cohort of older people with intellectual and multiple disabilities

Increased numbers – bulge as the baby boom generation age –small minority grp

(est, 2003, 152,500 people, or 6.1% over 65 yrs, Wen, 2006)

Included in disability policy aspirations of choice, inclusion, participation and rights

Absence of specific policy development or implementation strategies

No funding mechanisms to adjust for changed support needs

Recognised as an issue

- CSTDA -interface between sectors – health –disability –aged care
- 2009 NDA agreement improved access to aged care –has not progressed beyond scoping

Included in age policy aspirations Active/Healthy Ageing and Aging in place (SCARC, 2005)

Few policies

- Restricted access to aged care system –basis of age or use of disability services, ACAS, CACP's
- Recognition that access to aged care system is difficult – may need specific provisions ((Andrews, 2001).

Issue 1. Absence of policy and unprepared service systems

Pilots have demonstrated possibilities

- combining disability support with aged care expertise - support aging in place - increased quality of life (AIHW, 2006, aged care innovative pool disability aged care interface)
- extra cost for Federal govt - less than cost of support in residential aged care

Stalled policy and program development— under Howard

2007 Labor election policy support 'top up' - to extend aged care packages to people in shared supported accommodation

Un Preparedness of Disability Service Systems – Retirement eg.

Services flagging issues for many years

Ad Hoc developments – retirement programs off shoots or within existing day programs – 2004 survey identified 7 models variable outcomes (Bigby, et al, 2004)

No clear retirement pathways from either system or individual planning perspectives

Impact on older people with lifelong disabilities

2005-2007 ARC Linkage study, Qld and Victoria

All older people had purposeful but unsupported ideas about their future

Malcolm for example, who lived in a rural accommodation services said, “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”.

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 are 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.

Fear of retirement – desire to remain active and connected to friends

Disability services play a key role in access and linkage to community activities and connecting with friends

(Bigby & Knox, 2009; Buys et al., 2008)

Constraints and inability of services to adapt to aged related changes

Service centered decisions and control by others

Operational service requirements often take 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.

Decisions made by others can jeopardise relationships and purpose

I'd rather be doing stapling. I know that I want to do stapling again ... I've told the supervisor so many times ... I don't like it here and I've got no friends here and I'd like to get paid again

No one with the mandate to know or support planning for the future

– assumptions made - limited problem sharing

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

Issue 2. Not just an older person: Problematic service system interfaces

Having a life long disability and being an older person - access difficulties

Age barriers - no account of premature aging – early onset and high prevalence of AD

Complex unusual health needs - disability progression, long term impact of disability or simply aging (Cooper, 2009)

Diagnosis AD more complex – no simple pathway (Torr, Bigby, Iacona, in progress)

Difficult access health/aged care services – ACAS, memory clinics, falls clinics – and ill prepared if do (Hales 2007)

Hospitals ill equipped to provide care, communicate, mis match of expectations of medical staff and group home carers (Webber, Bowers, Bigby, 2009)

Very limited specialist knowledge within health care system

Compounded by other characteristics - social networks, income, wealth, health

- limited consumer power
- aging within formal services - health access mediated by staff
- services have to adapt not informal carers
- absence of informal advocates allies to navigate service systems (Bigby, 2008)

Limited knowledge of this group in Aged care system

Creating obstacles

Quest to distinguish between Aged Needs and Disability Needs

- Administrative imperative Fed- States
- Avoid double dipping

Pointless and Impossible Task

- Diversity of people with disabilities and starting points of aging
- One person's aged care need can be another person's disability need
- The degree of change as people age is what matters rather than objective needs
 - Jo, always high support needs, limited occupation, high level of support.
24 hour staffed small group setting with staff knowledgeable re health needs and accessible for wheelchairs – retiring, heart condition, sensory loss little impact other than increased personal care
 - Jim, mobile, fairly independent, supported employment , lower ratio staff, no active night staff, no accessibility issues – for him retirement brings needs for day time support, fall and arthritis brings need for increased health care, early onset dementia need for 24 staff - yet still comparable or lower support needs compared to Jo's preexisting needs
- Is it aging or disability? depends on philosophy
 - early onset dementia for a person with DS a disability related need (genetic cause) or aging issue, citizen who is experiencing different needs as gets older .
- Why waste energy on this issue – impossible to untangle (Hales, 2007)

Issue 3: Aging in place when home is a group home

NDA study 2007

Staff and organisations challenged by changing support needs

- Health problems - access and support in hospital
- Day time support on retirement – more staff
- Different types of knowledge re health and aging issues
- Impact on other residents

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

Strong commitment from disability providers to aging in place

Different interpretations of what this means

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

Question when existing capacity be stretched too far

(Fyffe, Bigby, McCubbery, 2008)

Unprepared for changing needs

Relatively few people had to move

- Within shared supported accommodation
 - 56 (3.4%) over 50 yrs older people moved between group homes last year
- From shared supported accommodation to Residential Aged Care
 - 27 (1.6%) residents over 50 years
- Masked by moves from hospital

No indication of the quality of care –is it the best option?

A closer look in recent study

Unclear what's needed - additional resources for what?

even if we did get extra staff, how could we organise the house without severely impacting on the quality of life of the other residents,

III informed responses

'She took him to the police station, and asked the policeman to show him the cells because that's where he'd go if he hit George and stuff.....this is a 54 year old man with Down Syndrome and early stages of dementia'

'I went one day to the centre and George was sitting there and he was depressed out of his mind, you know, he was just sitting there, and he'd been misbehaving so he'd been kicked out of class sort of thing, you know, just sitting there on his own looking so miserable'.

Lack of decision making protocols

ARC Linkage grant 2007-2009 transition to residential aged care. (Bigby, Bowers, Webber, 2009)

Professional decision making by staff

So Paul told me to more or less start to look for alternative accommodation because they couldn't manage in the house, you know? 15 F 2

She said he needs high level care and she gave me the form and she said I want you to go now and look at nursing homes 18 F

No sense of rights of family or person

he said: "Do you think we should ask a solicitor?" but I don't want to fight anybody, I just want to know what the rights are as far as the bureaucracy is concerned...I mean they can't just say: "Look, he has to go this afternoon", can they? 10F 3

Often hurried at time of acute health crisis

Absence process, family involvement or independent advocacy

Such things are critical in face of health improvements and sense of puzzlement by aged care staff

- Why is he here?
- We can't provide the same level of care
- Much higher staff resident ratios in group homes

Irreversible decisions once taken

Potential inequities in decisions to move

Similar objective needs different contexts

Move driven by degree of change not needs per se

Variable capacity by person or family to challenge, delay or avert

Variable access to flexible resources by organisations

Issue 4: Inappropriate residential age care

(Bigby, Bowers, Webber , 2008)

Small proportion of residents in any one RAC

- 40% RAC at least one resident with ID over age of 50

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

High proportion directly from the family home sometimes with family member or other types of supported accommodation (SRS's, institutions)

Necessity not choice: low capacity to respond

Entry not particularly associated with ill health or severity of support

- 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.

Different from other residents - difficulties in social aspects of care.

- age, interests, difficult behaviour, care needs, social isolation
- fitting in to activities
- need more individual attention
- negative attitudes other residents
- lack staff expertise
- lack resources to respond
- no positive relationships with other residents

Low capacity – Different population- Don't need high nursing care

Develop Policy Directions & Articulate Commitments

- Aging in place where ever home is - if appropriate
- Right to retirement But continuing support for purposeful activity
- Equitable access to health and specialist aged care services if appropriate.

Implementation Strategies.

- Acknowledge premature aging -remove age barriers to ACAS, CACP's
- Acknowledge as 'special group within Aged Care legislation - eg specialist wings in RAC- build expertise within –numbers too small for specialist accom
- Establish specialist clinics to deal with complex health issues and diagnosis (Postpolio, CP, AD)
- Measures to make health system more accessible – liaison nurses, nurse practitioners to bridge gap – longer term allied health training
- Funding Mechanism to take account of changed needs as age for those within the disability system – Fed 'top up' - based on age profile to States,
- State mechanisms to adjust funding based on age profile of service
- Specialist consultancy back up to health/ aged care/ disability services
Mandate, decision making processes and individualised planning

Solutions - Disability Service System

Develop Organisational Policies and Capacity for Aging

Articulate organisational approach and commitments

What does aging in place/retirement mean in this organisation

What models will it put in place

Adopt a life course approach to aging – healthy life style, occupation, relationships across all ages and programs

Put on place planned organisational response

- Build knowledge and expertise through staff recruitment, training, specialist positions cross programs/ organisations
- Develop organisational capacity –supervisors and managers
- Build health advocacy skills to leverage for health related resources, as a right
- Develop mechanisms for individualised planning and decision making processes re transitions.
- Education for people with disabilities about middle age and aging
- Build circles of support and ensure external advocates involved in decisions
- Seize rather than avoid responsibility at individual and organisational levels

And Finally What Outcomes are Sought

Greater clarity about outcomes sought for older people, what meant by aging in place – retirement – active healthy aging

A sense of security: attention to physical and psychological needs, to feel safe from pain or discomfort and receive competent sensitive care.

A sense of continuity: recognition of the individuals biography and connection with their past.

A sense of belonging: opportunities to maintain or develop meaningful relationships with family and friend and to be part of a chosen community or group.

A sense of purpose: opportunities to engage in purposeful activity, identify and pursue goals and exercise choice.

A sense of achievement: opportunities to meet meaningful goals and make a recognised and valued contribution

A sense of significance: to feel recognised and valued as a person of worth, that you matter as a person. (Nolan et al. 2001, p.175)

Useful Resources

Bigby, C. (2004). *Aging with a lifelong disability: Policy, program and practice issues for professionals*. London: Jessica Kingsley.

Bigby, C., Fyffe, C., Ozanne, E. (2007) *Planning and support for people with intellectual disability. Issues for case managers and other practitioners*. London: Jessica Kingsley

Kerr, D. & Wilkinson, H (2005). *In the know. Implementing good practice information and tools for anyone supporting people with a learning disability and dementia*. Brighton: Pavilion Press

Fyffe, C., Bigby, C., & McCubbery, J. (2007). *Exploration of the population of people with disabilities who are ageing, their changing needs and the capacity of the disability and age care sector to support them to age positively*. . Canberra: National Disability Administrators Group.

Wilkinson, H., Kerr, D., Cunningham, C., & Rae, C. (2004). *Home for good? Preparing to support people with a learning disability in a residential setting when they develop dementia* Brighton, East Sussex Joseph Rowntree Trust/Pavilion.

Bigby, C. (2000). *Moving on without parents: Planning, transitions and sources of support for older adults with intellectual disabilities*. New South Wales/ Baltimore: Mclennan+Petty/ P H Brookes.

- Bowers, B., Bigby, C., Webber, R. (2009). Intellectual disability and ageing. In Nay, R & Garrat, S., *Interdisciplinary care of older people: issues and innovation* (pp. 60-77). Sydney: Elsevier
- Bigby, C. (in press). A five country comparative review of accommodation support policies for older people with intellectual disability. *Journal of Policy and Practice in Intellectual Disability*.
- Bigby, C., & Knox, M. (2009) 'I want to see the Queen', The service experiences of older adults with intellectual disability. *Australian Social Work* 62, 2, 216-231
- Buys., L., Boulton-Lewis, G., Tedman-Jones, J., Edwards, H., Knox, M., Bigby, C. (2008). Issues of active ageing: Perceptions of older people with lifelong intellectual disability. *Australasian Journal of Ageing* 27 (2) 67-71.
- Bigby, C., Webber., R., McKenzie-Green, B., Bowes., B (2008). A survey of people with intellectual disabilities living in residential aged care facilities in Victoria. *Journal of Intellectual Disability Research*. 52, 404-414
- Bigby, C. (2008). Beset by obstacles: A review of Australian policy development to support aging in place for people with intellectual disability. *Journal of Intellectual and Developmental Disabilities*, 33 (1), 1-11.
- Bigby, C. (2008). Known well by no one. Trends of the informal social networks of people with intellectual disability five years after moving to the community. *Journal of Intellectual and Developmental Disabilities*, 33, (2) 148-157.
- Bigby, C. (2005). Comparative programs for older people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disability*, 2, 2 75-85.
- Bigby, C., & Balandin, S (2005). Another minority group: A survey of the use of aged care day programs and community leisure services by older people with lifelong disability. *Australasian Journal on Aging*, 24, 1, 14-18
- Bigby, C., Balandin, S., Fyffe, C., McCubbery, J., Gordon, M. (2004) . Retirement or just a change of pace. : An Australian national survey of disability day services used by older people with disabilities. *Journal of Intellectual and Developmental Disabilities* 29, 3, 239-254