

Panacea or Catalyst: Potential impact of the proposed National Disability Insurance Scheme on outcomes for people aging with intellectual disability.

Professor Christine Bigby

Department of Social Work and Social Policy

La Trobe University

C.Bigby@latrobe.edu.au

Social and Health systems

Policy vacuum and unprepared systems - Moss 1993– Bigby 2010

Not resolved re which system or level of government most appropriate or should bear the costs

Problematic service system interfaces

Disability system

- Few specific policies - ad hoc developments – particularly retirement
- Lives and services fragmented into sectors by funding mechanisms – day, accom, employment
 - Aging in place when home is a group home - States
 - Retirement from supported employment - Commonwealth
- Little expertise about aging – wariness of aged care services

Aging system

- Systemic barriers to aged care system - age , program , knowledge /expertise
- Issues of double dipping – are people aging or disabled or both?

Health and specialist health

- Systemic barriers to access –age, knowledge/expertise
- **Lack of decision making protocols for change**

Speculating on the future NDIS and changed foundations for aging

Entitlement – ‘reasonable and necessary support’

- No more waiting lists or rationing – capacity to plan for independence

Life time prudential not welfare approach – key driver costs across the lifecourse

- driver for early intervention, optimise potential for development and social inclusion
- proactive rather than reactive crisis based system

Individualised packages – consumer choice and control - providers or self management

- Person centred – across life domains – whole person support
- Flexibility – adapt to changed preferences and support needs over time
- More diverse support models – perhaps less shared living
- Case management/local area coordinator function – manager interface with NDIA

Tier one – Influencing major service systems external to the scheme

- Health systems
- Housing
- Transport
- Education
- Community attitudes and capacity
 - More accessible and adapted mainstream systems – better health outcomes?

Specific attention to interface of aging and disability

Long term aging from a less disadvantaged position

Ease of adapting support to changed health, mobility, preferences associated with aging

Filling in the cracks with clear policy positions –

The NDIS should put in place memoranda of understanding with the health, mental health, aged and palliative care sectors to ensure that individuals do not fall 'between the cracks' of the respective schemes, and to have effective protocols for timely and smooth referrals.

Funding responsibility not necessary delivery - purchase required supports from the market

States other than Vic National Health Reform Agreement 2011 – now those already in the system

- Federal responsibility to fund specialist disability support for people with disability aged over 65 years

NDIS Recommendation 3.6

At age pension age or any time thereafter choice of:

stay in NDIS service arrangements, where their support arrangements would continue as before, governed by its approach

move to the aged care system, where they would be governed by all of the support arrangements of that system, including its processes

Aims to

Ensure continuity of care for people with disabilities as they age, and allow them to choose services from providers who best meet their needs.

Continue to be supported by the system **best able to meet their care needs** as they age. Older people with disabilities can elect to stay with disability system or transfer to aged care system.

Potentially buy extra or different type of support to support aging in place -purchase aged care expertise with disability funding

People with disabilities should receive services from providers best skilled to meet their needs, however funded. So, for example, a person with a severe long term disability, such as multiple sclerosis, may be best served by specialist disability service providers to the end-of-life. On the other hand, people who experience younger onset of disabilities normally associated with ageing, such as severe dementia, might be best served by providers skilled in the support of older Australians. 182

If over 65 move into aged care if need long term residential aged care

If a person over the pension age required long term residential aged care then they would move into the aged care system to receive that support, regardless of the age at which they acquired their disability

Receive aged care services funded by NDIS if under 65

For younger people with disabilities should they require access to aged care services then their costs of aged care and accommodation will be met by the disability care system (including where eligible, the NDIS).

Things to consider

In tandem - reform of aged care system – greater account of diversity

Representation and decision making – when is residential aged care appropriate

- may still lack external advocates or supporters
- safeguarding and monitoring

Potential market driven

- new accommodation and support options post living with parents – will they be evidence based to optimise independence and inclusion
- development of niche expertise in adapting support to aging
- support models within disability system for older people
- models in aged care – are large scale specialist facilities sustainable?
- what does good practice for retirement, aging in place look like
- what are the quality benchmarks
- what are reasonable costs

Entry into the market of large for profits - recent fire- UK Winterbourne

Workforce issues –building size and capacity

Policy commitment to aging people

Will the market provide ? - rural, remote, diverse sub groups

Will every one be an 'informed consumer' and benefit equally

Inequities of information and knowledge

Change will take time -what about people who are aging now

Articulate Commitments

- Accommodation options to optimise inclusion and independence
- Aging in place where ever home is - if appropriate
- Right to retirement **But** continuing support for participation in purposeful activity
- Equitable access to health and specialist aged care services if appropriate.
- Transparent and supported decision making

Retirement - a Risky Proposition

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Not resolved re which system or level of government most appropriate or should bear the costs

Few specific policies – unplanned unfunded developments in day programs

Aging of workforce in supported employment

-- by 2025, over half will be over the age of 50 (McDermott et al., 2009)

For services - declining productivity

For workers – stamina, health issues – right to retire

Anxiety about retirement

‘I’ve got my friends here (at work) you know I go home and I go to work that’s enough for me
...no-one thinks of retiring...’

Absence of alternatives

–No funded mechanisms to support the transition to retirement

–Ad-hoc retirement programs - resemble disability-specific day program and reflect existing service models

Limited conceptualisation of what might be possible

Disconnection with prevailing ideas about social inclusion (Bigby, Wilson, Stancliffe and Balandin, 2011)

Community groups willing but hesitant about inclusion



Overview of Study

Aim Develop and Test a Model of Service - Transition to Retirement

- Increase capacity of community groups to include older adults with intellectual disability
- Enable people with disabilities to “join in” their local communities
- Older people (45+) to cut down work or day program days
- Support to join a community or volunteer group based on their interests

Action

- Supported 30 older people (46 – 72 years, Mean = 57.4) to drop one day at work and join a mainstream community or volunteer group
- Based on adapting technologies of Active Support and Co-worker training
- Pre - Post Intervention Study with Control Group

Outcomes

- **90%** of intervention group participants participated in a mainstream community or volunteer group 27 people attended for 6 mnths 21 still attend
- **Significantly more socially satisfied** than comparison group members.
- High levels of social interaction while attending the group,
- Almost no examples of contact with other group members outside the group.
 - The model was **largely very successful** in bringing about sustained membership of community groups.

Older person and their support network

Thinking about possibilities

- Translating the notion of retirement as a positive thing
- Giving ideas of what the possibilities are in retirement

Seeking the trust of others

- Establishing strong relationships with people, their families and staff
- Exuding confidence that retirement was not setting people up to fail

Promoting the Model

- Selling the idea of dropping one day at work
- An insurance policy - guaranteed right of return to work
- Provide concrete examples of group and activity types

Laying the groundwork

Local communities

Getting to know local communities

- Knowing what is available in each community
- Identifying group dynamics including entry criteria (e.g. age, gender, address)
- Getting to know key leaders in seniors community

Becoming a trusted community ally

- Strong existing relationships lead to easier access to groups for people with a disability
- Two-way process of give and take
- Adapt to different sub-cultures (e.g. Men's Shed, knitting group)

De-mystifying disability

- Help de-mystify “disability”
- Work through previous bad experiences with people with disabilities, or disability services
- Minimise any perceived “threat” as an advocate for people with disabilities

Constructing the reality

5 parts multiple players

TTR case manager

Person with intellectual disability

Family

Accommodation Service

Vocational service

Community group

1. Planning

2. Locating

3. Mapping a new routine – 6 months

4. Recruiting mentors

5. Monitoring and ongoing support



Conclusions: Supporting meaningful change

Change is difficult and complex

Change means establishing new routines to replace long-standing lifelong patterns

Recognise the 'work' that sits behind community participation of people retiring from supported employment – building capacity over time of mainstream community or volunteer groups

Requires significant initial groundwork with local communities, marketing to potential retirees and their families, and person centred planning with people and their families.

Long term support and monitoring of varying intensity as individual or community group needs and circumstances change

Requires significant investment of resources – both time and skilled case manager

Variable – 70 hours – 100 plus over a 6 month period



Useful Resources

- Transition to retirement model program DVD see <http://www.afford.com.au/employment/transition-to-retirement>
- Bigby, C. (2004). *Aging with a lifelong disability: Policy, program and practice issues for professionals*. London: Jessica Kingsley.
- 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. (2012). I hope he dies before me. Unravelling debates about aging with intellectual disability. In, Watson N, Roulstone A and Thomas C (eds). *Routledge Companion to Disability Studies* (pp. 426-439) London, Routledge.
- 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.
- 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