Aging and Retirement for People with Intellectual Disability: Policy, Pitfalls and Promising Practices.

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Outline

- Changing demographics – people with intellectual disability living longer
- Unhelpful assumptions about people aging with intellectual disability
- Aspirations for retirement - Active Aging as a useful framework
- Complicating factors for this group – aging with rather than aging into disability
- Retirement programs –
  - what's been done
  - what’s been learned
- NDIS - solving with policy wrangle
- Challenges that remain
Changing demographics people with intellectual disability

- Dramatic increases in life expectancy – 22 years in 1931
  - Tripled for people with Down Syndrome from 15 years in 1960 to 50 years in 1995 (Haveman, 2004)
- Becoming more similar to the general population
- Still disparity based on degree of impairment
  - People with mild, moderate, and severe levels of impairment expect to live for 74.0, 67.6, and 58.6 years respectively compared to a population median of 78.6 years (Bittles et al. 2002)
- Baby boom generation – increased cohort size
- Difficult to pin down figures – service users - 152, 500 (6.1%) were aged 65 years or older (AIHW, 2008)
  - Victoria more than doubled from 321 (3%) in 1982, 559 (4%) in 1990, 1,327 (6.7%) by 2000 (Bigby, Fyffe, Balandin, Gordon, & McCubbery, 2001).
- Increasing numbers of older people – still small proportion of both people with life long disability and aging population (0.4% of 55+ population)
- Projections of ADE older employees
  - by 2025, over half will be over the age of 50 (McDermott et al., 2009)
Unhelpful Assumptions

- **Assume homogenous** - are a diverse group - most younger old
  - significant differences likely in thinking about needs according to age, health, life course stage, middle age (40-60) younger old or third age, old old (85+)
  - literature and policy ignore middle-age – focus on older parents planning for future

- **Assumption of premature aging**
  - not necessarily
  - age related health conditions early - associated with genetics, eg. People with Down Syndrome – sensory, musculoskeletal (Holland, 2000), early onset dementia (36% between 50–59 years, and 54.5% between 60–69 years (Prasher, 1995)
  - impairment progression time since injury – spinal chord injury, post polio
  - onset of secondary health conditions associated with impairment, or long term poor health care or chronic conditions - people with cerebral palsy mobility decline, pain (Haveman, et al., 2010)
  - high proportion frail at an earlier age – but associated with preventable reversible factors such as low levels of physical activity, social relationships and participation (Evenhuis et al., 2012)

- **Many people do** not age prematurely – expectations of this will impact

- **Assume want to retire** – put their feet up – but enjoy working – see retirement as a risky proposition – isolation and loss of support (Bigby et al., 2010)
WHO - Active Ageing – A Useful Framework

‘process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age’. (WHO, 2002)

Focus on three core pillars

- Health
- Participation
- Security - care when necessary based on autonomy, dignity

Similar to disability policy - emphasis on rights, participation, choice, inclusion

Ageing of people with intellectual disability can be a time of real opportunity – post parental phase of life (Bigby, 2000)

- Expansion of social world
- Building new relationships
- Cessation of child role
- New roles of aunt, great aunt, sister in law
- Change in sibling relationships as replace parents in “caring about” (73%)
- Increased importance of siblings, closest family, longest relationship
Muted Voices re aspirations

“Rod and Isobel married when they were in their 50s, several years after their respective parents had died. They lived together independently in the community for about 24 years, supported informally by members of their church community. The family friend who managed Rod’s affairs since his parents died said, "of course they [his parents] never expected Rod to marry. That's the last thing in the world they ever imagined" (Bigby, 1997, p. 100).

People who are aging want to

• Exercise choice, remain active and engaged (Edgerton & Gaston, 1991; Mahon & Mactavish, 2000; Buys et al., 2008)
• ‘keep on keeping on’ (Bigby & Knox, 2009)
• Remain connected to peers from work or day programs
• Reluctant to retire

Their Views and Perspectives often ignored or frustrated by broader social forces

– Contrary views of staff, parents
– Group based imperatives or resources
– Compartmentalisation of lives
Multiple determinants of Active Ageing

- Economic determinants
- Health and social services
- Behavioural determinants
- Personal determinants
- Physical environment
- Social determinants

Gender

Culture
Complicating Factors to Active Retirement

Individual

- Need for support – choice, location, negotiation, participation
- Disability services play a key role in access and linkage to community activities and connecting with friends (Bigby & Knox, 2009; Buys et al., 2008)
- Complex and often separate networks of support to be renegotiated

Social networks - legacy of segregation and exclusion

- Live in distinct social space - family, peers and paid staff
- Little social contact outside formal programs
- Lack informal avenues for social participation and purposeful activity

Discrimination and low expectations of others

- Limited visions of others - complacency or contentment – with existing arrangements
- Low expectations of inclusion and use of mainstream programs (Bigby, et al., 2011)
- Obstacles to use of mainstream programs – attitudes, knowledge, conditional entry, worse case scenarios (Bigby & Balandin, 2004; Bigby et al., 2011; Ingvaldsen & Balandin, 2011; Craig, 2013))
- Identified need among mainstream for resources, training, extra support

*Our volunteers would have had to have special training to deal with these sort*

*It’s also a case of knowing what to do when things go wrong*

*Seniors are for seniors… I know we’ve got members who would be very much against it.’*
Policy and Service System Obstacles

Fragmented under resourced service system (PC report, 2011)

- Siloed system
  - Funding sources - state – federal
  - Service type - accommodation - employment
- Which part of the system is responsible for retirement support – who should pay
- Which part is responsible to knit retirement together other aspects of peoples lives
- Potential impact on state funded day support and accommodation programs with retirement
- Potential on older or family carers – increased demands for respite as regular activity reduces
- Is retirement applicable to people who have not worked but attended day program
- Low wages and pensions, lack of super – cannot afford to loose additional income,
What been tried

Reconfiguring day programs for existing aging clients
Similar aims different models

• Choice and flexible support to enable participation in social activities and relationships, little importance accorded to development, maintain skills independence, health or fitness (Bigby et al., 2004; Bigby, 2005)

Relatively poor outcomes -

• Limited use of technology from other parts of life course
• Low expectations, entrenched, discrim attitudes, fewer opportunities than younger
• Segregated groups continued
• Including other groups complex needs, much younger and middle age

Difficult to access for people from ADE’s who are not part of a state funded system

Employment focused - range of pilot Retirement Programs – last 10 years

– tend to be centre or group based
– recent pilots adopted varying approaches
– primarily transition rather than longer term – sustainability not clear
– adhoc small pilots
– TTR AFFORD – Active mentoring - unique – capacity building - individual – solid evidence & similar more intensive model for people retiring for day programs

Multiple meanings of community inclusion and participation
What has been learned

• People with intellectual disability and disability services little knowledge about aging or retirement options.

• Viewed with trepidation - Limited expectations or conceptualisation of what might be possible.
  - High need for education, preparation, trial and error.

• Push may come from employer rather than pull from employee – whose interests.

• Planning can be complex and multifaceted –
  - Person centred whole of life approach no one takes responsibility.

• Inclusion in mainstream is feasible and enjoyable – some just do not work – not limited by individual capacity.
  - Locating and negotiating with mainstream organisations – skilled activity.
  - Capacity of mainstream can be increased with skilled support.

• People don’t have static lives.
  - People’s lives change –
  - Community organisations change membership.
  - Depth and longevity of engagement and support variable.
  - Need for long term intermittent support to participate – take account of change.

• Attendance costs low.
• Travel – transport can be problem.
• Little attention to health, fitness and lifestyle.
• Trend towards ‘special’ programs at local government level.
The Promise of NDIS

One system of funding – greater volume - curtail unmet need

Flexible tailored support – consumer choice and control

*Reasonable and necessary supports for people with disability should:*

- (i) support people with disability to pursue their goals and maximise their independence; and
- (ii) support the capacity of people with disability to undertake activities that enable them to participate in the community and in employment

Individualised packages — providers or self management

**Capacity to adjust and change**

- Suggests relative ease to revise support plan to take into account changed health, mobility, preferences associated with aging – wish to retire or work part time
- Purchase support to participate in community rather than employment

Person centred – across life domains – whole person support

- Case management/local area coordinator function – interface with NDIA and other systems

**Growth of service types** – supporting participation

In the longer term people will be aging from a less disadvantaged position
Potential Pitfalls

Will the market provide?

- how long to develop
- quality of programs – ‘effective and beneficial and current good practice’
- limited evidence - eg TTR proof of concept – not long term implementation
- will the market risk demonstration programs and innovation
- danger of one to one companionship rather than supporting inclusion
- choice and options in rural, remote areas or for diverse sub groups?

Will every one be an ‘informed consumer’?

- tendency to favor those with social capital
- people need vision and raised expectations, 'raising the bar'

Where will responsibility for ‘collective’ need lie?

- education about retirement, people with disability and family members
- who funds capacity building in the mainstream
Where will the line be drawn?

Type of support

Scheme will only fund Reasonable and Necessary Supports not those that are not more appropriately funded or provided through other service systems, for example as part of a universal services obligation or in accordance with the reasonable adjustment requirements required under Commonwealth, State or Territory anti-discrimination legislation.

Similar needs to general aged population

- Some met relatively easily by mainstream health and aging services
- Some needs will be different, may occur at an earlier age, or may have to be met in a different manner or with a unique set of expertise that is not applicable to other older people (Janicki et al., 1985).

Age

Entry - must be aged under 65 -not people aging into disability

Exit Section 29

*A person ceases to be a participant in the National Disability Insurance Scheme launch when:*

(b) the person enters a residential care service on a permanent basis, or starts being provided with community care on a permanent basis, and this first occurs only after the person turns 65 years of age; or

Will need to develop a set of principles re commitment to people aging with intellectual disability to inform decisions for people over 65 re changing from disability to aged care system.
Long term change will take time

Five NDIS Launch sites only 26,000 people

Only 2 or 3 sites will include aging people limited capacity to explore the issues that may arise and seed program development

People are aging now in increasing numbers across all jurisdictions

Retirement and issues of aging more generally for people with intellectual disability require continuing attention over the next 5 years – cannot afford to wait.

Right to choose retirement AND continuing support for inclusion in the community and participation in purposeful activity