The Critical Policy Issues In Serving An Ageing Population With Intellectual Disabilities In An Equally Aging World

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Outline

Major risk factors

Knowledge about necessary components – interventions and models

Assembling and delivering high quality care and support in different policy contexts.

Exemplars - from Australia

Based on Bigby, McCallion, McCarron, (forthcoming Serving an elderly population in ***21st Century Issues for Individuals with Severe Disabilities: Ensuring Quality Services and Supports in Challenging Times*** edited by Martin Agran, Ph.D., Fredda Brown, Ph.D., Carolyn Hughes, Ph.D., Carol Quirk, Ph.D., and Diane Ryndak, Ph.D. Paul H Brookes.

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 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)

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

Major risks to quality of life

Physical wellbeing - early onset dementia, frailty, undiagnosed and poorly treated health conditions, secondary health problems

Emotional wellbeing – loss and grief re parents, frequent moves, high rates of mental health problems, end of life support

Interpersonal relationships - small and shrinking networks, loss of peers on retirement, few outside family or service system

Material wellbeing - loss income from work, little wealth, no private option

Personal development – non replacement of work or day program with meaningful activity – low expectations of others, lack informal networks as vehicle for participation

Self determination – resource driven or best interest decision making, crisis driven few safeguards

Social inclusion – re-institutionalisation – difficulties of aging in place with family or supported accommodation – poor social connections low participation in mainstream volunteering or community organisations.

Rights - loss of parents as advocates, few enforceable rights to service

Wider group and system issues - risks

Diversity - different aging trajectories, primary care providers, age cohorts, as well as uniqueness of every individual

Minority group of older people – very small, different characteristics from other groups (age composition, wealth, networks etc)

Equity - among people with ID with different access to ID services

Equity - between people with ID and general population – cost differentials – expectations re size of congregated settings

Ill defined - pathways to specialist age health and care services

Undeveloped Capacity –mainstream and ID systems to respond, and staff knowledge

Attitudes – low expectations of continued engagement and value of life and treatment

Disadvantages from support and life style earlier in the life course

Supporting carers and future carers – siblings

Forgotten middle age

Evidence base of intervention – components

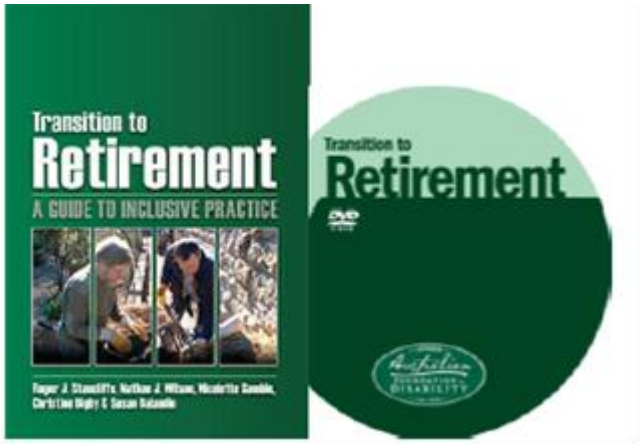
Derive from evaluation and demonstration programs

Self development & social inclusion – participation in community groups TTR program - Access - Linkage – Mentoring to support volunteering or membership of community group

- One person each group replace a day at work

- Selling idea of retirement to older adults and families
- Getting to know local communities – what are the possibilities
- Constructing reality -
  - Person centered planning re interests
  - Locating and negotiating with a potential group
  - Mapping new routine, travel, change to support
  - Recruiting and training mentors
  - Ongoing support and monitoring
- Better outcomes than group who stayed at work
- Importance of coordination with others in persons life
- Dynamic situations - ongoing support to group and person (Stancliffe et al)

Transition to Retirement Program Resources



The *Transition to Retirement* manual and DVD is available online at http://purl.library.usyd.edu.au/sup/9781743323274

Online preview of the TTR manual available at http://books.google.com.au/books?id=rC9ZAgAAQBAJ&pg=PA6&source=gbs_selected_pages&cad=2#v=onepage&q&f=false

Participation and inclusion people with higher support needs

More intensive groundwork needed than ADE employees

Analyse and work with group capacity

- influenced by social processes in groups
  - initial response of leaders re viability and differentiation
  - fitting in - manageable – disruptive?
  - working with conditions imposed
  - discernment process – expectations, responsibility, accurate feedback, familiarity, kindness
- skills and characteristics of participants with ID,
- access to expertise
- presence of an integrating activity
- Presence v meaningful participation – equal membership, mutually rewarding, working to a cooperative goal, effective use of expertise (Craig and Bigby in press)

Ageing in place - topping up supported accommodation - where staff untrained in health

Social inclusion, emotional wellbeing, physical wellbeing

2003/2004 by the Department of Health and Ageing - Disability Aged Care Pilot initiative (AIHW,2006b)

Specialist additional supports for supported accommodation residents eligible for residential aged care

- Additional funding in partnership with aged care providers
- Comprehensive care plans drawing on Allied health assessment
- Projects demonstrated improved quality of life for older residents and the feasibility of supporting them to age in place largely through additional health planning, access to allied health care, and day-time community support.
- Demonstrated the potential of cross-sector partnerships when resources are made available to support
- Additional cost less than residential aged care but greater than disability supported accommodation

Dementia Care

Physical wellbeing - attention to unique needs

- Diagnosis and broad components (Burt and Alyward, 2000)
- McCallion & McCarron, 2003 –three core elements
  - maintaining function
  - managing comorbid conditions and pain,
  - access to relationships and community participation,
    - absence of pain maintenance of health
    - psychosocial well-being
    - skills maintenance and support
    - absence of and supportive responses to problem behaviors
    - Leisure and community participation
    - Family and friends
    - Dementia-focused programming
    - supportive environments
    - alleviation of caregiver burden

Components of good dementia care of care

- Specialist memory clinics
- Multidisciplinary and clinical support
- A mix of services able to respond to changing needs, including day, respite, and specialist residential and family support services
- Services located where needed and not where available
- Clear person-centered understanding on what each service offered is intended to achieve
- Sustainable services
- Education programs for staff, family, and generic health care professionals
- Located in mainstream or in ID sector ?

Critical questions

- What needs can and should be met by mainstream aging and health care systems?
- How can the capacity of these mainstream systems be developed and supported to meet the needs of older people with intellectual and developmental disabilities?
- What needs do people aging with intellectual disability have that are met with difficulty or cannot be met by mainstream services?
- What should the associated cross-system training requirements for staff be to ensure that developed capacity in both service systems is effectively used?
- How should services—whether mainstream or disability specific—be resourced and delivered in a way that takes into account

  1) equity between people with intellectual and developmental disabilities with age-related needs who have differential access to disability services and

  2) equity between older people in general and people aging with intellectual and developmental disabilities?

- Will depend on context of existing health, aged and disability systems

Assembling and Delivering in Different Contexts

Australian –new developments –NDIS

Disability Reform 2011- 2013

National Disability Insurance Scheme –(DisabilityCare Australia) *significant disability*

- Entitlement – to 'reasonable and necessary support' not available in other service systems
- Life time prudential not welfare approach - emphasis on early intervention
- Individualised packages – flexibility to adapt to changed preferences and support needs
- Expansion - foreshadowed doubling of expenditure on disability services to *$13.5 billion*

Largely adopted by government – NDIS legislation 2013 – 5 launch sites 2013 full roll out 5 years

Reforms disability and aged care in tandem 'no gaps' disability – aged care interface

Reforms founded on different principles and target groups

- disability insurance no means test - aged care user pays (income & assets)
- disability prior to 65 years – aged care predom focus frail aged 85 plus

Similar mechanism and ethos – person centred, self directed, individualised funding

Similar values – support participation, rights, dignity, respect, choice

Promises for people aging with disability

Attention to continuity of care, long term service relationships

> services should be drawn from the sector with the most relevant expertise, irrespective of the funding source. (Caring for Older Australians)
>
> continue to be supported by the system **best able to meet their care needs** as they age. (Disability Care and Support). –irrespective of sector

At age 65 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. (*Disability Care and Support)

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

Market based demand driven system potential for development of niche services – aging people with intellectual disabilities

In the long term aging from a less disadvantageous position

Potentials Pitfalls and New Tensions

Cost differentials will remain between sectors higher packages in disability

NDIS a lifetime scheme - until? **- will forced transfer out occur at some point**

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;*

Will need to develop a set of principles to inform decisions about change in system

Will the market provide

- Small numbers – dispersed

Will every one be an 'informed consumer'?

- Tend to favor those with social capital

Inequities - Capacity of Aged Care system re disability

- Major advocacy Excluded over 65s
- New group over 65 'functional impairment in absence of aged related conditions'
- Argue disability related support not well developed in aged care - aids and equipment, mobility and orientation following vision loss
- Less focus on participation more on over 85s frail and dementia

Aging with a disability – Aging into disability

Huge step forward for people aging with intellectual disability – money follow person – support can cross sectors

Ongoing advocacy – over 65s with disability – potential to undermine tightly targeted insurance based system

For the first time attention focused on disability expertise required in aged care system

Attention to diversity among older people – potential for people with disability to lobby for special status on aged care now acquired by GLBT, CALD

Expansion of disability system will add expertise and capacity to benefit both older and younger people with disability – demand driven, individual funding open cross sector purchases

Skilled Workforce ? How to attract and develop?

Different contexts

Ireland

- concentrations, in geographic areas, committed charitable institutions to long term residents, relatively underdeveloped aged care system
- Specialist mobile dementia care service - diagnosis, support and consultancy to staff (already have health care training)
- Cluster specialist developments

US

- less investment in supported accommodation and more people remain at home with family
- inclusion in mainstream dementia initiatives re
- Renewed push to community living from Olmstead decision

Common elements - Bridging systems and knowledge

Greater consideration in policy development and policy implementation of opportunities for improved collaboration between aging and ID service systems, including:

- Requiring that the needs of people with ID be specified in every policy and every training program for mainstream services;
- Considering the needs of all persons with ID who are aging, and not just those who are in formal out of home services, and then supporting genuine aging in place
- Exploring the potential for ID resources to be used to purchase mainstream aging services for people with ID
- Developing specialized services by the ID system that complement rather than duplicate mainstream options or further create dual systems, and ensuring that aging systems recognize their need to access those services.

Useful Resources

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Bigby, C., Bowers, B., & Webber, R. (2011). Planning and decision making about the future care of older group home residents and transition to residential aged care**.** *Journal of Intellectual Disability Research 55,8, 777-789*

Health manual re aging for group home staff download from

http://www.latrobe.edu.au/health/about/staff/profile?uname=CBigby

Transition to retirement model program DVD see http://www.afford.com.au/employment/transition-to-retirement