LA TROBE
UNIVERSITY

LIVING WITH DISABILITY
RESEARCH CENTRE

Supporting Ageing People with Intellectual Disability in Group Homes: Past, Present and Future

Dr. Tal Araten-Bergman & Prof. Christine Bigby

Background: Ageing with intellectual disability

- Changing demographics: increases in life expectancy of people with intellectual disabilities.

- People aging with intellectual disabilities make up a small but significant proportion of all disability service users in most countries with advanced economies.

  - For example, in Australia, 7.6% (11,306) of all adult participants with intellectual disabilities (53,328) in the National Disability Insurance Scheme (NDIS) are aged 55 years or older (NDIS, 2019).

  - 81.3% of NDIS participants over the age of 65 are people with intellectual disabilities (NDIS, 2019).

  - People with intellectual disabilities are a very large group of the 17,000 people who live in groups homes and many are in their 50s and 60s.

LA TROBE
UNIVERSITY

Ageing with intellectual disabilities – social phenomenon

- Ageing of people with intellectual disabilities emerged as a pressing social phenomenon in the 1980s, when researchers and advocacy groups began calling on public policy and service providers to adapt to the age associated support needs of this population (Anderson et al., 1987; Bigby, 2000, 2002, 2008; Janicki & MacEarchron, 1984; Monahan & Wolf, 2014).

- Researchers explored the unique age related support needs of people with intellectual disabilities, and proposed policy aims, funding mechanisms and an array of services necessary to address these.

LA TROBE
UNIVERSITY

Policy Trends

- Since these issues were first raised, the context of debates about policy, funding and services for older people with intellectual disabilities has shifted significantly, reflecting changing conceptualisations of both aging and disability, public policy trends, and philosophies of service delivery and practice.

- Theoretical conceptualisations of ageing and disabilities have evolved from individual models to socio-ecological frameworks focused on person/environment fit (Agmon et al., 2016).

- Public policy in Australia has embraced a rights based approach that puts greater emphasis on community living, consumer choice and quality of life as desirable outcomes.

- These trends have been manifested by the ratification of the Convention on the Rights of Persons with Disabilities (UNCRPD), the development of the National Disability Strategy 2010-2020, and adoption of Active Aging as a guiding principle for age care policy (World Health Organisation 2002; 2015)

LA TROBE
UNIVERSITY

Australian policy aims

- Australian aging and disability policies stress expectations that all citizens regardless of their age or impairment should have equal opportunities for healthy and active aging, and access to support necessary to achieve this goal (Bigby, 2008).

- Active and healthy ageing is defined as: A process of optimising opportunities for health, participation and security in order to enhance quality of life as people age (WHO, 2002)

- Based on the proposition: older people having choice and control across a range of issues that are central to their lives are directly or indirectly influenced by how services and support structures are created, funded and managed (Tesch-Römer & Wahl, 2017).

LA TROBE
UNIVERSITY

Ageing in place

- The Australian government has adopted the World Health Organisation's definition of aging in place:

  - "Meeting the desire and ability of people, through the provision of appropriate services and assistance, to remain living in the community in their current home ..." (WHO, 2004, p. 109).

- Aging in place goes beyond physical space of residence, encompassing social relationships with others, psychological identity and a sense of belonging (Bigonnesse, & Chaudhury, 2020; Gitlin, 2003).

LA TROBE
UNIVERSITY

WHO - Policy directions: Determinants of active and healthy Ageing

- The Australian government adopted the UN principles of rights of older people:

  - Independence, Participation, Care, Self fulfilment, Dignity

- Focus on three core pillars :Health, Participation, Security

- Takes account of intersectionality, diversity and culture

- Focus on Person/environment fit

- Looks at multiple levels, individual, community/organisational, society/policy

- Calls for top down policies and bottom up initiatives

United Nations Principles for Older People
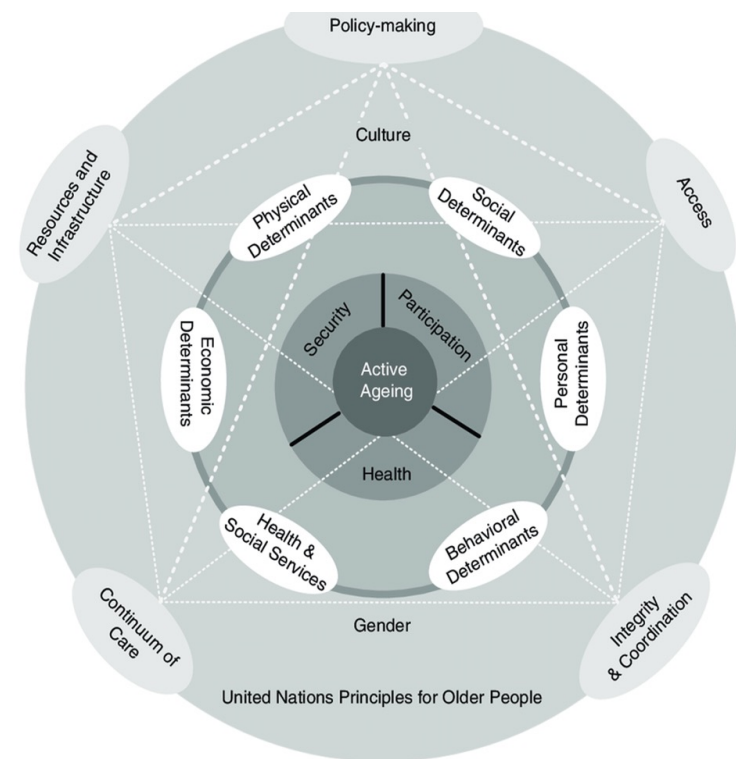
Ageing with intellectual disabilities: Access to service and funding

- Historically, at the federal level disability and aged care service systems have been divided according to age:

  - Access to aged care services for those aged 65 years and older.

  - Access to disability services restricted to those aged under 65 years.

- Both systems are complemented by mainstream services such as health care and social services.

Disability services

Aged care services

Person

Health care services

Social services

LA TROBE
UNIVERSITY
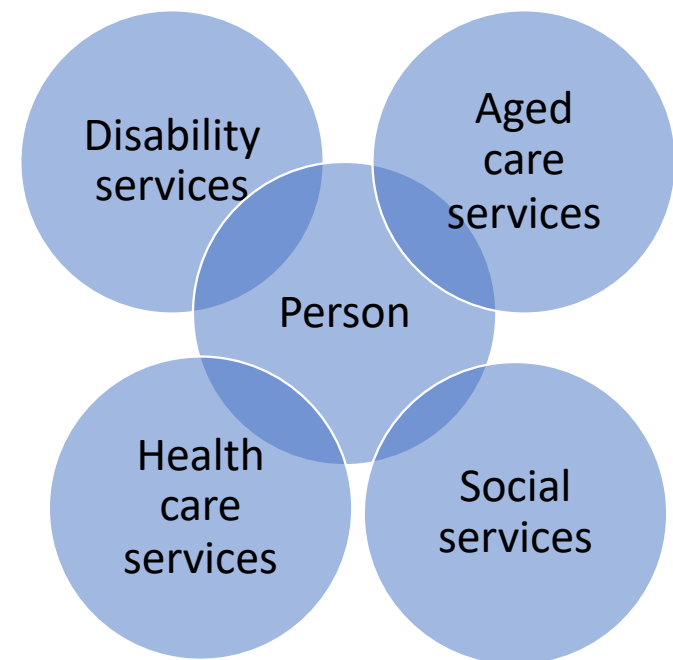
Policy Gaps - Prior to the NDIS

- Prior to the NDIS, Australian government responses to the phenomena of older people with disabilities reflected a sense of shared responsibility by the aged care and disability sectors.

- No firm policies stipulated which sector (aged care or disability), had responsibility for funding or service delivery.

- Policy remained at the level of general statements that neglected to define:

  - Mechanisms to translate high level policy intent into practice

  - Access to mainstream and specialised disability services

  - Financial resources for adapting physical, care and social environments as needs change (Bigby, 2004, 2008, 2010).

Policy Gaps - Prior to the NDIS

The consequence of this were:

- People aging with intellectual disabilities and carers were left to navigate a complex pathway between the systems to find appropriate services to meet support needs.

- Failure by disability, aged and health care schemes to respond adequately to their unique combination of support needs

- Unmet needs

- Inconsistency and uncertainty about access

• People with intellectual disabilities admitted prematurely and inappropriately to residential aged care facilities (Bigby & Knox, 2009; ; Webber et al., 2010).

Critical review of Australian policy between 1999-2010

- Policy structured in such a way that implied support needs were either disability or aged related but not both at the same time.

- Three broad issues often led to unmet need for people ageing with intellectual disabilities:

  1. Knowledge gaps: Neither the aged care or the disability sector had appropriate services or skills to provide quality support

  2. Access: Rigid demarcation between aged care and the disability sectors restricted access to aged care programs by group home residents under the age of 65, preventing access to aged related expertise and supplementary support for residents to age in place

  3. Funding: Responsibility for service delivery and funding

     Double dipping

- The split of funding, responsibilities and rigid boundaries hampered inter and intra-sector collaboration (BIgby, 2008; 2010)

LA TROBE UNIVERSITY

Supporting ageing with disabilities in group homes

- Lack of clarity: What is ageing in place in group home

- Lack of consistent policy and standards

- Challenges in providing support to ageing in place:

  - Barriers to accessing disability, health and aged care services.

  - Time constraints on staff having to balance contradicting demands such as coordinating services and managing paperwork required by funding bodies

  - Lack of adequate resources to accommodate age-related support needs: Service and physical environment modification; staffing levels, staff training; inter and intra-sector collaboration (Wark et al., 2014a, 2014b, 2015).

- Despite expectations that people in group homes should have the right for active ageing and to age in place, there has been little funding to accommodate their additional support needs.

LA TROBE
UNIVERSITY

Policy reforms – Aged care

- Aged care and the disability sector have undergone significant reforms that has changed the Australian policy and funding landscape.

- The reforms are marked by shifts to a more competitive, market-based service system, moving away from block funded service delivery towards individualised funding and person-centred approaches.

- In the aged care arena:

  − Policy has shifted to individualised and consumer directed services in the community.

  − Shift in balance in funding residential and in-home aged care.

  − Home Care Package (HCP) Program: This program enables individuals to purchase subsidised in-home care supports with funding levels determined by the person's needs which are assessed through Aged Care Assessment Team/Services (ACAT/S) (My Aged Care, n.d).

LA TROBE
UNIVERSITY

Policy reforms - Disability sector

- Disability sector: the NDIS which consolidated a fragmented system into a demand driven market model, in which services are funded from individuals' packages rather than through block funding or commissioning.

- Responsibility for funding disability services is centralised and rests with the federal government.

- The NDIS provides individualised funding packages to eligible people to purchase services according to their disability related needs and self-defined goals.

- The NDIS is restricted to people aged 65 or under. The legislation provides for existing participants to remain in the scheme past the age of 65 or choose to transfer into the aged care system at aged 65 or later.

- If a person remains an NDIS participant after the age of 65, they may purchase supports to meet their age related needs from private or non-government organisations registered as NDIS providers.

- However, if an NDIS participant aged over 65 enters a residential aged care facility or receives an aged care HCP on a permanent basis, they are automatically transferred to the aged care system and from that time will be unable to access the NDIS funding (NDIS, 2013 section 29 (1)).

LA TROBE
UNIVERSITY

The NDIS: promising policy and emerging issues

- These reforms have addressed some of the tensions between the aged care and disability sectors, assigning uncapped federal funding to the disability sector. In hindsight, this assigned the responsibility for addressing the needs of older people with disabilities solely to the disability sector and provided people with disabilities control over which sector better addresses their needs.

- People with intellectual disabilities in theory can purchase a wide array of services to accommodate their needs.

- Supports are available until a point in time where the person makes an informed choice to move into aged care residential care.

LA TROBE
UNIVERSITY

Underlying assumptions

- Disability service system has the capacity, knowledge, skills and expertise to adequately respond to the changing needs of people with intellectual disability as they age.

- Ageing People with intellectual disabilities have equal access to mainstream services.

- Ageing People with intellectual disabilities (and the people who support them) can articulate, claim and manage age-related support services within the disability system.

- Aged care system can accommodate for older people with intellectual disabilities with complex needs.

- Ageing People with intellectual disabilities (and the people who support them) have the knowledge and skills to successfully navigate between the disability, aged care and health systems.

LA TROBE
UNIVERSITY

Assumption: Disability service system has the capacity, knowledge, skills and expertise to adequately respond to the changing needs of people with intellectual disability as they age.

- Research suggest that the NDIS had increased the level and types of supports available to older people with disability (Araten-Bergman & Bigby, in press).

  - Increased the accountability and flexibility of services for delivering positive outcomes for ageing residents.

- Research with service providers revealed that individualised support plan with attached funding and the opportunity to review the plan regularly provide flexibility and new opportunities to adjust services as needs change.

- This provided security and confidence that services will be able to secure adequate funding for support as long as these are part of the residents NDIS plan.

"I would like to say that it's more personalised services. I mean the fact that we are able to increase the staffing and support to our ageing clients and know that we've covered the cost of staff to do that, …. knowing that we can react and support clients in the way that they're needed by, basically, quoting for exact hours that we need. To have clients be support by an OT every year for however long. I just think we're providing a better service because of that" (manager).

LA TROBE
UNIVERSITY

Assumption: Disability service system has the capacity, knowledge, skills and expertise to adequately respond to the changing needs of people with intellectual disability as they age.

- Knowledge gap

- Lack of consistent policy and service standards on how to support people ageing with intellectual disabilities

- Ad hoc strategies

- Funding/NDIS pricing: Fails to take adequate account of the non-face to face costs associated with quality services, such as administrative costs, internal planning to adjust supports as needs change, staff training, professional development, advocacy, and building partnerships with other services and sectors (Disability Services Australia, 2017)

- Provides few incentives to support participants with multiple and complex needs, such as those aging with intellectual disabilities

- The inherent systems segmentation and split funding mechanism between the aged care and disability sectors continues to hamper collaboration and knowledge transfer

LA TROBE
UNIVERSITY

Assumption: Ageing People with intellectual disabilities (and the people who support them) can articulate, claim and manage age-related support services within the disability system.

Concern about the implementation of the NDIS, particularly the nature of NDIS planning and review processes and the place of the services' input.

- NDIS participant can purchase support associated with age related changes using their NDIS funds. Making this happen relies on: knowing what's possible, making a claim, providing evidence (reasonable and necessary supports; related to the person disabilities), NDIS agreeing to fund the support, finding suitable providers (register as NDIS service provider).

In reality

- Ageing people with intellectual disabilities often struggle to clearly articulate, either directly or through their families, their needs, ask for sufficient funding and identify and engage with adequate services once required support funding is agreed.

- Aging people with intellectual disabilities, particularly those who previously lived in institutions, frequently lack informal supports to assist them in articulating needs and manage the support plans.

- Serves providers, families and Planners' limited understanding of the unique combination of age-related disability and health needs, as well as gaps in their knowledge about available community services and support outside of the disability service system (Araten-Bergman & Bigby, in press; Mavromaras et al., 2018).

LA TROBE
UNIVERSITY

Assumption: Ageing People with intellectual disabilities (and the people who support them) can articulate, claim and manage age-related support services within the disability system.

- Plan review: service providers and advocates reported challenges in getting NDIS plans reviewed in a timely manner to accommodate changing needs as people age.

- Staff highlighted some of the challenges in getting the NDIS plans reviewed in a timely manner to accommodate changing needs as people age, resulting in providers operating at a loss.

"We had a client that had a fall no broken bones but she was confused a bit and we were like, "We need to react quickly to this." So, we just started rostering on staff to be with her 24/7 from that moment…. So We needed more hours so we went for her plan review … it meant that the funding hadn't quite come through yet, and the service had to pick up the tab … We applied for NDIS Change of circumstances It took 6 weeks and we had to provide evidence GP OT which also took some work …, we had to pick up the tab for two staff permanently with them, …. We are not-for-profit… But we can't permanently run at a loss" (manager)

LA TROBE
UNIVERSITY

Assumption: Aged care system can accommodate for older people with intellectual disabilities with complex needs.

- Research indicates that Aged-care facilities are ill-equipped to meet the complex health and behavioural needs of older people with intellectual disabilities (Webber et al., 2014).

- Residential aged care providers may be skilled in meeting the health needs of older people but their capacity to meet their social needs or ensure their human rights are limited (Bishop et al., 2013 ; Bigby et al, 2008; Webber et al., 2014).

- Currently, the *Royal Commission into Aged Care Quality and Safety* has been set up to look at the quality of aged care services and whether those services are meeting the needs of the Australian community. This includes people with disabilities in residential aged care.

LA TROBE
UNIVERSITY

Assumption: People with intellectual disabilities (and the people who supports them) have the knowledge, and skills successfully navigate between the disability and aged care systems

- The decision whether to leave the NDIS in order to transfer to a permanent aged care package and move to aged care residential services is a critical one. In order to make such life changing decisions there is a need for accurate information and independent advice about availability and quality of care and support in both disability and aged care systems.

    - Research has highlighted concerns about serves providers, advocates and planners' knowledge about available community services and support outside of the disability service system (Araten-Bergman & Bigby, in press; Mavromaras et al., 2018).

- NDIS: There are to date no clear NDIS rules that translate the meaning of high level legislative provisions about shifting from one system to another or to provide guidance about doing so and issues to consider.

- No protocols for referral from the NDIS to the aged care system

- No monitoring of the transition process and outcomes

Disability Services

Aged Care

LA TROBE
UNIVERSITY
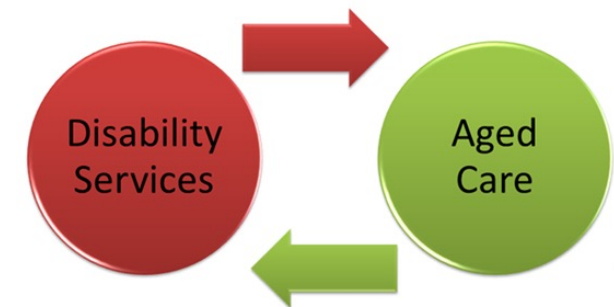
Moving forward

- NDIS Pathway and pricing

- Forming independent government funded advocacy or broker services to assist ageing people with intellectual disabilities to navigate NDIS, health and aged care services.

- Workforce Planning and Training Strategy: Mainstream and , disability service providers, Local Area Coordinators (LACs) and planners

- Nationally consistent policies and standards for supporting ageing people with intellectual disabilities

- Clear policies translating the interface with disabilities, health and aged care systems into clear rule and guidance

- Funding to build cross sector partnerships, knowledge and skills transfer.

LA TROBE
UNIVERSITY

Thank You

LA TROBE
UNIVERSITY

LIVING WITH DISABILITY
RESEARCH CENTRE

Dr. Tal Araten-Bergman

Contact:
E: t.araten-bergman@latrobe.edu.au

People ageing with intellectual disabilities support needs - is it different?

- People with intellectual disabilities experience a complex combination of disability and age-related changes.

- Health care needs: poorer health compared to the general population.

  - Genetics

  - Life styles (poor nutrition, low physical activity and high rates of medication)

  - Poor access to health care or advocacy

  - Dismissive attitudes of healthcare providers, diagnostic overshadowing, low rates of screening and communication challenges

LA TROBE
UNIVERSITY

People ageing with intellectual disabilities support needs - is it different?

Ageing from a disadvantaged position:

- Social environment: barriers to participation, attitudinal, structural factors.

- Life histories: The history of deinstitutionalisation and patterns of family care in Australia mean many group home residents were relocated from institutions between the 1970s and early 2000's, or have moved from their family home.

- Social support and informal networks.

- Employment and socio-economic status.

- Support for exercising choice and participating.

LA TROBE
UNIVERSITY