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LIVING WITH DISABILITY  
RESEARCH CENTRE

# **Supporting Ageing People with Intellectual Disability in Group Homes: Exploring Staff Perception**

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## Background: Ageing with intellectual disability

- The life expectancy of people with intellectual disabilities has increased dramatically over several decades. Currently, people ageing with intellectual disabilities constitute a significant proportion of all disability service users:
  - 81.3% of NDIS participants over the age of 65 are people with intellectual disabilities (NDIS, 2021).
  - Many reside in shared-supported accommodation services, such as group homes that provide 24-hour support (NDIS, 2023)
- The increased longevity means that a growing number of residents experience age-related changes that impact the everyday work of group home`s staff and managers (Alftberg et al., 2021).

## Ageing with intellectual disabilities – social phenomenon

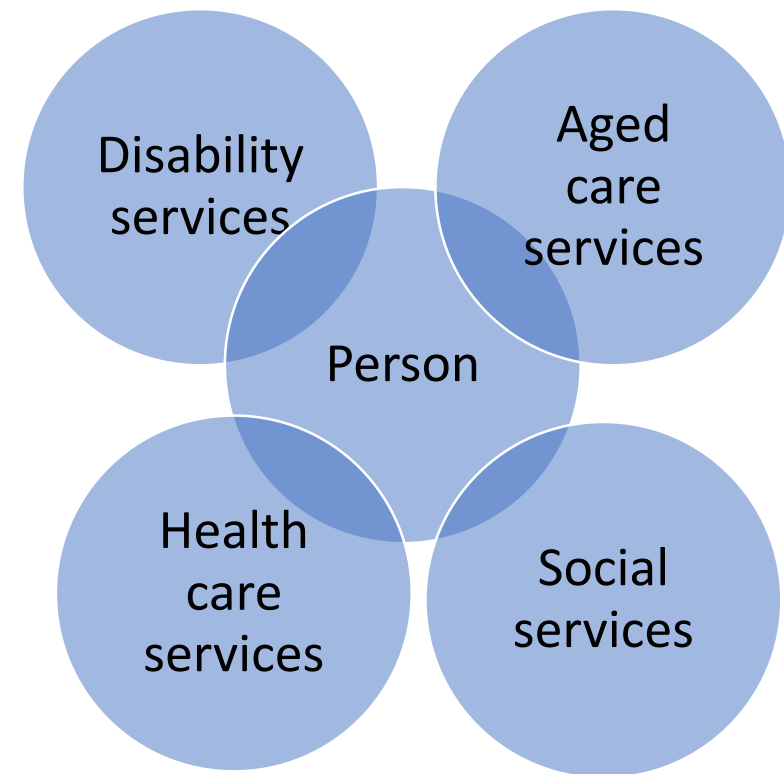
- changing conceptualisations of ageing and disability, public policy trends, and philosophies of service delivery and practice.
  - Theoretical conceptualisations of ageing and disabilities have evolved from individual models to socio-ecological frameworks focused on person/environment fit
  - Public policy 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 Australia's Disability Strategy 2021-2031 and the adoption of Healthy Aging as a guiding principle for the National aged care reforms

## Australian policy aims

- Australian ageing and disability policies stress expectations that all citizens regardless of their age or impairment should have equal opportunities for healthy ageing, and access to the support necessary to achieve this goal (Bigby, 2008).
- Supporting healthy ageing involves providing opportunities and an enabling environment to promote the maintenance of well-being, independence, self-determination, and active engagement in life, despite changes in health and functional abilities (WHO, 2015).
- Ageing in place : supporting people to remain in their preferred environment with adequate funding and services to meet changing support needs (WHO, 2004).

## Ageing with intellectual disabilities: Access to service and funding

- Historically, 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.



# Supporting ageing with disabilities in group homes

- Lack of clarity: What is healthy ageing and ageing in place in group homes
- Lack of consistent policy and standards
- Challenges in providing support:
  - Barriers to accessing disability, health and aged care services.
  - Limited knowledge and understanding of service providers
  - Time constraints on staff having to balance contradicting demands
  - 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).

## Policy reforms

- In the last decade, Australian aged care and the disability sectors have undergone significant reforms, changing the policy and funding landscape towards individualised funding and person-centred approaches.
- Access to 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.
- If a person remains an NDIS participant, they may purchase supports to meet age-related needs from services registered as NDIS providers.
- However, once a person enters a residential aged care facility and receives aged care funding permanently, they are automatically transferred into the aged care system and are no longer eligible for NDIS funding (NDIS, 2013 section 29 (1)).

## Policy reforms - Disability sector

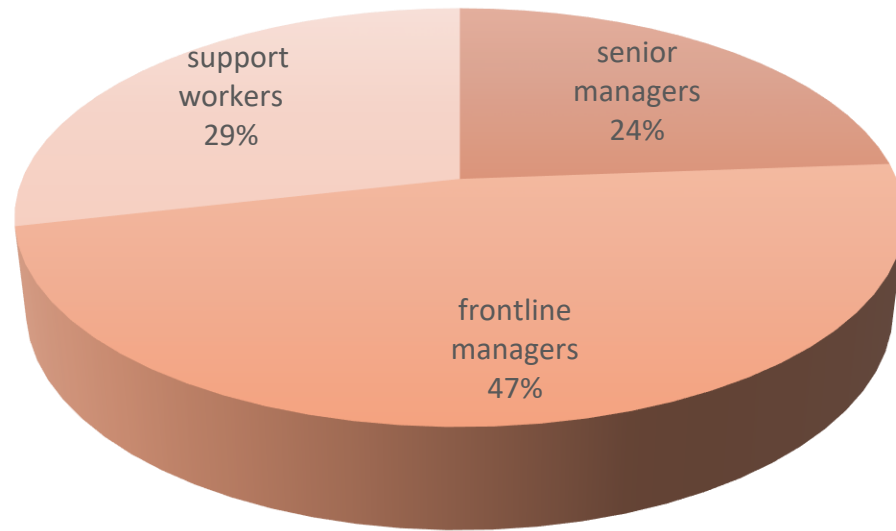
- the NDIS provides opportunities to address all needs of ageing NDIS participants solely within the disability sector.
- Holding significant promise for enabling people ageing with intellectual disabilities to experience healthy ageing while continuing to reside in group homes.
- However, this interpretation of policy has yet to be fully tested.

## Study Aims

- To explore the perceptions of direct support workers and their managers about ageing and the support needs of people ageing in group homes.
- To explore the experiences of direct support workers and managers in responding to and adjusting services for ageing residents' needs within the new policy context of a fully implemented NDIS.

## Method

- Qualitative interviews with 21 group home staff from 11 group homes



- Participants` experience working in the disability sector ranged from 5 to 20 years (M=13.2; SD=3.5).

## Interview guide

- Separate but interrelated interview guides for managers and direct support workers sought to elicit:
  - Perspectives on the support needs of ageing residents
  - The practices and adjustments made to provide support
  - The facilitators and challenges of providing support
- The managers' interview guide included additional items about
  - Organisational-level processes contributing to or impeding the effectiveness of supporting people with intellectual disabilities (funding, workforce skills, training, and cross-sector collaboration)

## Medicalisation and uncertainty about age-related changes

- Participants described ageing as multidimensional, encompassing physical, functional, social, and psychological domains, but focussed primarily on the biological and physical aspects of ageing and the impact of these on support needs. Hence, they associated ageing with the emergence of diseases and saw all changes as originating solely from medical conditions:

**“You see the changes as they become older if it’s dementia, I notice when it comes to remembering things ... If it is fatigue or mobility I need to check for arthritis or osteoporosis ... Any change we need to go to the doctor to check....it could be anything blood pressure, maybe they need glasses or hearing aid ...” (direct support worker).**

## Medicalisation and uncertainty about age-related changes

- Staff struggled with the uncertainty that surrounded the timing and nature of each individual's age-related changes, finding it challenging to anticipate the impact on support needs.

**“We just were noticing small things, like forgetting things that she wouldn't normally forget. But it wasn't every day, it was just coming and going ... It is hard to know what's going on, one day she can't get out of bed without us ,next day she can take the bus and go shopping “(frontline manager).**

## Ad hoc adaptations to age-related changes

- Age-related changes were conceptualised by all staff as requiring adjustments to the type and intensity of support a person needed.
- Staff described how age-related changes called for significant adjustments in the practice
  - Nature and scope of support
  - Hours of support
  - Adaptive equipment (hearing aids or walkers)
  - Changes to the physical environment to ensure accessible and safe surrounding

## Ad hoc adaptations to age-related changes

- Both direct support workers and managers perceived themselves as **reactive** to the changed needs of ageing people, making ad-hoc adjustments on a case-by-case basis as needed

**“We are learning how to do this as we go ... we were supporting this client one way and then, all of a sudden, she literally fell and knocked her head twice in two days, and then, surprisingly, her support needed to change.... We found it quite hard to know, what process we should be following here, to ensure that we are keeping this woman safe ... we don't have a simple process or policy of what we need to do or who's doing what... we need to figure it out as we go” (direct support worker).**

## Ad hoc adaptations to age-related changes

Staff described how as people aged their social network faded away, thus reducing opportunities for social support and advocacy. As a result, staff saw older people as increasingly dependent on them, and felt the need to compensate for these losses by providing additional support for decision making, service coordination, and social outings:

**“As they get older the parents disappear, sometimes they die, or have their own problems, I don’t know ... So, we are all they have to take care of them, take them to doctors and activities, you know they have no one else” (direct support worker).**

## Ad hoc adaptations to age-related changes

Direct support staff described using their personal and professional knowledge and experiences of caregiving together with their amassed social capital about aged-related support and services:

**“I have built up a huge network in the community services, so that does make my life easier. For example, palliative care, I have worked with them before. ..., I supported my Mum to die in a home a couple of years ago, So I know everyone. If someone here needs this or that... I know what to do, I know where to go ... So, it is my personal systems and my professional systems ... You know it is a network that I have gained over many years that has allowed me to support my guys” (direct support worker).**

## Navigating a complex service environment

- Staff felt that introduction of the NDIS had increased the level and types of support available to ageing residents and the accountability of services for delivering positive outcomes.
- Staff observed that individualised plans with attached funding and the opportunity for regular reviews provided them with the flexibility to adjust services as needs changed.
- Managers reported that the NDIS contributed to their confidence that they would be able to secure adequate funding for supports as long as it was incorporated into a person's plan:

**“I would like to say that it's more personalised services now . I mean the fact that we can increase staffing and support to our ageing clients is reassuring....., knowing that we can react and support clients in the way they need, by basically, quoting for exact hours that we need..... I just think we're providing a better service because of that” (frontline manager).**

## Navigating a complex service environment

- Staff described the complexities the NDIS had created and their frustrations in having to navigate these.
- Achieving good outcomes, they thought, came at a considerable cost to organisations and staff, requiring advocacy, knowledge, skills and capacity to fill unfunded service gaps. They described uncertainty and confusion arising from the complex context.

## Navigating a complex service environment

- Managers found it difficult to get timely and clear guidance from the NDIS about people ageing in group homes which often left them baffled.
- Complex NDIS processes were compounded with constant changes to many NDIS policies, regulations and guidelines, and the lack of detailed NDIS policies around ageing issues.

**“My understanding is that this [NDIS] is always changing, it’s a massive system to get your head around anyway. The guidelines and requirements for evidence and what have you are not clear, pricing is challenging ... once you understand how this work and whom to talk to, or how to apply for this or that, the guidelines change ...” (senior manager).**

## Navigating a complex service environment

- Some staff felt that the move from block to individualised funding hampered their flexibility and left some costs of providing quality support unfunded. Specifically, NDIS pricing failed to take account of non-face-to-face costs:

**“Before [the NDIS] we had staff meetings ... I could arrange for the nurse to come and explain how to work with a feeding tube ... Or we could ask our OT to help with group activities ... But now we can’t do that, every hour is accounted for, we need to provide evidence that every hour of support is with the person ...”**  
**(frontline manager).**

## Navigating a complex service environment

- Staff thought getting good NDIS planning outcomes was dependent on either the person themselves or someone on their behalf being knowledgeable about their needs and able to advocate for them. They were concerned, however, about the capability of ageing residents to advocate for their own needs and the availability of family members who can do so on their behalf:

**“I think that NDIS package depends on people’s connections to community and family. I think if people are well-connected, then more people can support the argument that they need support... Whereas if we’re working with people who don’t have anyone - particularly older people from institutional backgrounds, it comes down to me as the service provider to act as an advocate on their behalf, to get the right supports in place.. this takes a lot of time” (frontline manager).**

## Navigating a complex service environment

- Adjusting support prior to securing NDIS funding also added to the costs borne by organisations.

**“We applied for NDIS change of circumstances, it took 6 weeks and we had to provide evidence, GP, OT, which also took some work ... So overall it took about six weeks and because we were documenting everything, when we went to the plan review and showed the planner he said, “This is pretty accurate “and they approved it. but it took time and as the service provider, we had to pick up the tab for two staff permanently with the person ... we are not-for-profit.... But as a service provider, we can’t run at a loss (senior manager).**

# Conclusions

Findings have implications for future research policy and service delivery, looking forward there is a need to:

- Clearly articulate what is “healthy ageing” in group homes
- Develop clear guidelines on how to best support ageing residents and to maximise their choice and control over their support.
- Develop nationally consistent policies and standards for supporting ageing people with intellectual disabilities.
- Workforce planning and training strategy: Develop staff’s knowledge, skills and competence in identifying and fully addressing the whole spectrum of age-related support needs of people ageing with intellectual disabilities.
- NDIS pathway and pricing
- Form independent government-funded advocacy broker services to assist ageing people with intellectual disabilities to navigate NDIS, health and aged care services.

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