Keeping my place in the community: Achieving successful ageing-in-place for people with intellectual disabilities

RECOMMENDATIONS FOR A BEST PRACTICE FRAMEWORK

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EXECUTIVE SUMMARY

This report summarises the findings and outcomes of a 4-year Australian Research Council (ARC) Linkage project looking at key policy issues and challenges associated with the health and social disparities across two cohorts of community-dwelling older Australians in two states – New South Wales and Queensland. The two specific population groups of interest were: People with Intellectual Disability (PwID) and those who were Ageing without lifelong disability (PwA).

An inherent underpinning of any framework that supports successful ageing, both of people with lifelong intellectual disability and those who may acquire a disability as they age, needs to take account of the particular circumstances, capacity, resources, experiences, interest, perspective and aspirations of each individual across their lifespan. This research found that the concept of ageing is no different for people with lifelong disability when compared to the general population. However, a significant difference is that people with lifelong intellectual disability experience multi-morbidities at an earlier age than their mainstream peers. A holistic focus is required; each person’s needs as they age will be different, depending on their life journey, as every individual has their own story and perceptions of a good life, and their ‘authentic’ self.

Though a “person-centred focus” is a legislated philosophy and objective across both the disability and aged-care services sectors in Australia, it does not appear to be translating into systems and practices that consistently deliver personalised service and good individual outcomes across the board. The achievement of successful ageing and an inclusive life is determined by a complex relationship between barriers and facilitators at the individual and systems/organisational levels, and through broader legislative and public policy instruments. A key finding of this research is that there needs to be a “seamless and integrated care system, across health, allied health, age and disability, and preferably across the life span”.

The Best Practice Framework provides a set of recommendations to mitigate the present issues and lead to improvements at the policy, programs and individual levels to enable successful community-based ageing of people with disability and those without lifelong disability.

INTRODUCTION

The aged care sector in Australia currently provides services to over 1.3 million Australians and operates with an annual expenditure of approximately $22billion. This figure represents a contribution of 1% of Australia’s GDP. Not surprisingly, the usage of aged care
increases significantly from age 65 onwards. Thirty-three percent of people aged 70 and over access some form of subsidised aged care and this rises to 70% for people aged 85 and over (Australian Institute of Health and Welfare [AIHW], 2018). Over the last 20 years the proportion of the population aged 65 years and over increased from 12% to just over 15%. The proportion of the population over 65 will continue to grow rapidly until 2030 and will represent approximately 21% of the population in 2066. People over the age of 85 currently make up 2% of the population and this is projected to more than double to 4.4% by 2066 (Australian Bureau of Statistics [ABS], 2017).

People with intellectual disability (PwID)\(^1\) are also experiencing this trend of increasing life expectancy and longevity. Many studies have shown that people with a mild intellectual disability, in the absence of any other medical conditions, are now expected to live as long as their peers within the general population (Bigby, 2008; Patja et al., 2000; Hwang, Foley & Trollor, 2017). Until the early 1970s, PwID were either supported at home by their parents or cared for, particularly for those with moderate to severe intellectual disabilities, in institutional facilities run by government or not-for-profit support agencies. The life expectancy of this cohort at that time was low, and for a variety of reasons, a majority simply did not live into old age.

PwID who are ageing constitute a unique group of Australians whose longevity was not expected nor planned for by either the aged care or disability sectors. There is evidence of widening health and social disparities across the lifespan for PwID with increased vulnerability as they age, both in relation to health, well-being and quality of life (QoL).

The ageing of PwID presents a national problem on several key fronts:

i) Not-for-profit support agencies are experiencing critical challenges in supporting ageing PwID in supported accommodation settings with current staffing knowledge and skills;

ii) Parents who are ageing and still supporting a family member with PwID, are seeking a satisfactory provision for their son/daughter, who may be simultaneously experiencing ageing issues, before they become too frail to continue support in the family home;

iii) PwID tend to age prematurely in comparison to people in the general population,

iv) Inappropriate and premature institutional admissions can lead to costly long-term care and compromised human rights;

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\(^1\) The Research Team does not normally use the acronym PwID, as it is considered to be problematic. However, the need to refer to people with intellectual disability numerous times, has led to reluctant use of the acronym, due to space constraints.
v) Aged care facilities are ill-equipped to meet the complex health, behavioural and aged care needs of PwID, many of whom will be placed in nursing homes at an early age, and

vi) Support service inadequacies and health disparities among sectors and between high density (urban) and low density (rural) population areas are notable.

The Best Practice Framework is based on findings of a 4-year ARC Linkage project titled *Keeping my place in the community: Achieving successful ageing-in-place for people with intellectual disabilities*. A key focus of the ARC-Linkage project was to identify the organisational and sectoral barriers and suggest facilitators to support ageing-in-place and ageing successfully for PwID, with the *cumulative aim* of all the components of the project being the development of a set of recommendations for a *Best Practice Framework*. The recommendations are grounded in conceptual theoretical constructs integral to person-centred approach using Brofenbrenner’s systems model, with empirical findings of the multi-method research project.

The central tenet of Brofenbrenner’s (1979) ecological systems theory is a person-centred approach to human health and social issues, where the “person is at the centre of the system” surrounded by four environmental levels: the microsystem, the mesosystem, the ecosystem and the macrosystem, with each level exerting a different impact on the development of each individual person with reciprocity effect across each of these levels.

This is important in the context of the development of the *Best Practice Framework* as one of the fundamental flaws of the current systems is bureaucratic segmentation of people with disability due to fragmentation of services and resources. *Hence, the notion of a “seamless life journey” through various life stages is essential in the examination of the interface between disability and aged care support systems.*

The empirical findings from the ARC-L project provide a scaffolding to theoretical constructs that underpin the key recommendations of the Best Practice Framework. Details of the project methodology and key findings are provided in appendix 2 and 3 respectively. Briefly, a mixed-methods approach was adopted including both quantitative and qualitative data aspects.

*The two main data sets from the current project were:*

i) A health and quality of life survey distributed to a sample of people without a lifelong disability and a sample of PwID. Both samples were drawn from people living in community-based settings in NSW and Queensland (described below).

ii) Key informant semi-structured interviews with a sample of relevant policy makers and senior managers across the Commonwealth and relevant states and NGOs in the disability and aged care sector.

Additionally:

- The project draws heavily on results of two pilot projects. They include data from several face-to-face in-depth interviews with older PwID and carers as well as older
people in community-based settings in both metropolitan and rural regions of NSW and Queensland. One of pilot projects included a health professionals survey and some of the findings of that survey identified particularly relevant issues in training at various levels to ensure better fit-for-purpose integrated content and care across the disability and aged care sectors. (Hussain et al., 2018; Wark et al., 2015; 2016; 2017).

- The findings from a National Summit on Ageing and Disability and a Discussion Paper *Improving the Interface Between the Aged Care and Disability Sectors* developed by the National Aged Care Alliance (NACA) were drawn upon in preparation of recommendations for BPF.

- The Partner Organisations – namely Ability Options, Uniting, Endeavour Foundation and The Ascent Group – were asked to provide case studies or vignettes that reflect the current service environment in 2018/19. This request was in recognition that, as the primary data collection for the ARC-Linkage project was completed in 2017, some further examination was required regarding any changes experienced by either PwID or mainstream ageing groups associated with the formal introduction and roll-out of the National Disability Insurance Scheme (NDIS) in July 2017.
The Best Practice Framework, as outlined over the subsequent pages, has been developed specifically with the individual at the centre. This concept is core to service provision within both the aged and disability sectors, enshrined in state and national legislation. All figures and diagrams should be viewed within this lens of person-centred care – while some of the discussion and recommendations reference policies and practices aimed at structural change or population-level interventions, the focus must ultimately always remain on ensuring each individual receives the most appropriate level of assistance to support their current life circumstances.
Goal: Seamless Integration of Disability & Aged-Care Services for older PwID & non-ID people

Older Population (with and without ID)

Choice & Autonomy
Health, Well-being & QoL
Social Inclusion

Improvement in Services (Disability and Aged-care)

National Standards:
- Registration & Compliance

Workforce Strategy (National & State-based)

Training & Upskilling of Professional Staff

Communities of Practice
Place-based Collaboration
Retention of Health workers

Purpose & Means - Enable, Promote, Sustain

Physical & Mental Health
Prevention, Promotion & early Rx across the lifespan

Reducing silos

Outcome: Achieving / Promoting Successful Community-based Ageing
BEST PRACTICE FRAMEWORK: RECOMMENDATIONS

The majority of this project was undertaken either during or just prior to major reforms across both the aged and disability care sectors. The partner organisations’ feedback was that both the old and newly reformed systems were, and are still, difficult to navigate. The concept of a seamless, integrated care system represents a seismic change in the way services are regulated, resourced, managed and delivered. Successfully implementing this change will require a significant effort to overcome the existing and longstanding ‘silo’ approach across Federal and State/Territory jurisdictions.

A first general over-arching recommendation is to:

- Re-align every government department and authority overseeing what are currently disparate service systems.

This would also include a renewed focus on the life journey approach to allow people to easily navigate and access services. Such a change will, of necessity, need to consider how funding instruments and other initiatives can facilitate equitable outcomes, with a particular focus on rural and regional areas. A key barrier is the adequate resourcing of individual community care. Any such easy-to-access service system will critically need to address the concept of ‘good’ and ‘shared’ information to facilitate informed decision-making. It also needs to minimise the need at a system level for people to have to repeat their life story at every service level interaction, but without compromising each person’s confidentiality and data integrity.

Changes are required to improve the experience and outcomes of individuals and their support networks, including focusing on the following key considerations to facilitate successful ageing. Specific recommendations and suggestions for change are outlined below under four headings.
1. People require choices and the expectation of individual agency/autonomy to engage in decisions at any given point in time.

A. Provide Choice in Living Options

Participants across metropolitan, regional and rural areas clearly articulated wanting to have agency about where they lived with, and with whom. This is a fundamental human right. A key issue for people across both metropolitan and rural areas was the absence of choice, engagement in decision-making and co-design opportunities.

The current reality is that there are limited opportunities in relation to accessing appropriate housing stock, resources and funding (for example, long waiting lists for community-based care packages, or discrepancies in NDIA funding). Often, there are only a few suitable options for an individual to consider. Unfortunately, this lack of options can mean that any sudden change in circumstances, such as a significant but temporary health crisis, can trigger an inappropriate but often permanent move into residential aged care designed primarily for end-of-life care.

Positively, our disability partner organisations reported seeing some improvements in access to appropriate plans and support resources in the NDIS. Yet people who require access to 24-hour support are being pushed into group homes as it is only housing option, particularly in rural areas. This is against the principles of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Also being observed are large discrepancies between supposedly ‘comparative’ packages allocated to people with a similar profile and need, across and within different jurisdictions. Being able to access the necessary funding is critical, and it is worth noting the Commonwealth Budget in April 2019 reported a $5Billion underspend on the NDIS.

Having appropriate housing options is critical. This is a risk for adults with lifelong disability, who in both rural and metropolitan areas, have limited affordable supported living options and accommodation configurations about where to live, and in which style of accommodation – a unit, shared living, or clustered.

2 Unless specified otherwise, also includes regional areas.

3 Clustered housing in this context refers to co-located housing within a discrete geographical area, and where there is capacity to offer some shared support resources. For example, two separate houses on a single site. Alternatively, it may be a few homes within a short walking or driving distance.
To achieve an objective of having a choice about where one lives – the bricks and mortar – requires an acceleration of appropriate community-based options. The National Disability Insurance Schemes ‘Supported Disability Accommodation’ (SDA) framework, with an estimated injection of $700 million in annual funding has, in the 2.5 years since its inception, failed to stimulate appropriate building options due to lack of operational clarity.

**People who are Ageing (PwA):** For the general population of people aged over 65, the critical issues are a shortage of community-based funding packages designed to support people to remain in their own home and community. For people who are ageing and who may have a home that they want to continue to live in, access to timely supports and services is a key issue.

- *For both groups, the key issue is capacity and autonomy to “age in my chosen place”.*
- *Again, there is a key risk that without access to timely in-home support, residential aged care may be the option of last resort.*
Public policy in aged and disability care now use common language. It is recommended that the concept of ‘Ageing-in-Place’ with its particular meaning in aged care, needs to be reviewed and revised instead as **Ageing-in-my-Chosen-Place** to better capture the diversity of need across our population.

There needs to be greater evidence of service delivery options, co-design in the development of options, and an authentic engagement around existing models, policy and service review, and evaluation. Some modelling and traction around shared equity concepts that work, and how they can work, would be useful to people who may have resources to collaborate in an equity arrangement. However, this emerging market is not well conceptualised or understood by government, the community, providers, developers or financiers.

A range of housing solutions, both in rural and metropolitan areas, requires promotion. These options must be accessible to public transport, community infrastructure and amenities. This needs to occur in conjunction with capacity for capital solutions to facilitate supports that respond to changing needs and underpin an individual to **age-in-my-chosen-place**. As noted, capital models that facilitate shared equity would benefit those who have some capacity to contribute to the cost of building a home and contribute to the range of co-designed options.

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**Ageing-in-my-Chosen-Place**

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B. There is a need for greater and more meaningful consultation in any decision-making processes

In order to achieve a truly seamless model, there is a need for greater and more meaningful consultation in all decision-making processes. In some instances, this begins with the complete lack of appropriate and amenable options for consideration as people age.

Total restructure is not required; for people with lifelong disability who may or may not have active family support (or even a desire to move out of the family home) and simultaneously have increasing needs for assistance with activities of daily living, the current model of integrated group homes with independent individual rooms and residential support staff may be appropriate. However, the research identified that *many people felt marginalised and alienated in these environments due to lack of consultation or viable alternatives*, feeling the impact of decisions made by or for co-residents.

The concept of home was fluid. The more important issue was *engagement in decision-making*, feeling as though they had influence in ongoing decisions and, if in a shared living situation, sanctity/respect/control of their room as a safe space and their ‘home’. A co-design approach is critical in decision-making, and for those in the situation living with others.

To address this issue, additional attention to systemic and funding issues, and organisational implementation, staff training and compliance, is required. The *National Disability Standards (2013)* specifically refer to individual rights, and include the promotion of freedom of expression, self-determination and decision-making and actively preventing abuse, harm, neglect and violence.

The research also identified that *within the general ageing population there was a shared feeling that they had no control over whom they resided with and the impact of the behaviours of others*. The use of mainstream ageing services by people with intellectual disability appeared to present concerns for both of our cohorts. Interestingly, there was a noted a lack of tolerance articulated towards people with lifelong disability when they were sharing accommodation settings, such as in a residential aged care facility or day activity centre, by the mainstream ageing population.

- The planned matching of co-residents is critical, as is being able to source alternative options if the matching does not work out in the short or longer term.

- Having appropriate staff-to-participant ratios is also vital to manage co-living environments.
This is currently a challenge in the disability and aged care sectors with funding allocations impacting on the practical resourcing of appropriate staff ratios to facilitate person-centred care. A seamless support model will require capacity to resource an alternative option for people when the service is no longer working for them.

2. **Inclusion of measurable indicators for better health, well-being and quality of life**

The use of valid, reliable and relevant wellbeing indicators and quality of life measures across the lifespan will assist to determine if service options are meeting their targets, or if modifications are required. There are a variety of such instruments, but no single one is mandated, and therefore each organisation is left to invest, or not, in the capturing and analysis of information using a range of instruments. This becomes a barrier to implementation and the ability to track data across the life of an individual who may change services many times. Being able to consistently measure and track quality of life and wellbeing indicators will be a critical factor in determining the quality and outcomes of services delivered across the care sectors.

A. **Adopt Annual Health Assessment & Screening across the lifespan to identify and limit chronic health conditions**

The research identified that the average PwID had approximately 4 chronic health conditions, with a range between 0 and 14 health conditions. These findings are in line with national and international studies.

Many PwID experience life-course disadvantage in relation to adequate and timely access to health practitioners and a lack of targeted preventive and promotive health strategies,
including access and adequacy of service provisions. A UK-based study assessed the role of incentives for medical practitioners to provide annual health checks of PwID and found that PwID who were part of the study had more regular health checks (Buszewicz et al., 2014).

The higher prevalence of many of the chronic health conditions is often attributed to limited health assessment and lack of regular health screening of PwID. Many of the risk factors for chronic disease are associated with lifestyle behaviours which are modifiable, such as smoking, lack of physical activity and poor nutrition.

Consistent and more regular screening, and a proactive approach to addressing modifiable risk factors, would assist with the early identification and hopeful avoidance of potential multi-morbidities.

**B. Adopt preventive/promotive strategies for reducing burden of mental health disorders**

Poor mental health and the presence of mental health conditions (psychological / psychiatric) is common in the cohorts of both PwID and PwA. Although the development of many mental health conditions may occur initially in childhood or early adulthood, these may be missed due to lack of appropriate assessment. In case of PwID, family and staff are often ill-equipped to identify the need for further assessment. However, even where an appropriate referral is made, the treating practitioner may not have suitable training around PwID and symptoms are incorrectly diagnosed as being due to the existing disability and left untreated. In the general population, people often do not seek treatment for mental health issues, due to stigma or difficulty to access appropriate services. Furthermore, mental health is inter-connected to many other issues that service providers need to be cognisant of and develop policies to ensure that individuals are able to lead fulfilling lives. **Maslow’s Hierarchy of Needs Model (1954)** and **CHIMES Model of Recovery** (Leamy et al. 2011) are useful frameworks for thinking about promotion of mental health in these two populations.
C. Use valid measures for measuring Quality of Life

The increased interest in the QoL concept is also consistent with the rise of consumer empowerment with its emphasis on person-centred planning, personal and valued outcomes, and self-determination. QOL as a concept is currently used as a sensitising notion that allows us to focus on the individual, a unifying theme that provides a framework to apply and measure QOL, and a social construct to collaborate for societal change (Schalock et al. 2002; Schalock, 2004). Verdugo et al. (2005) outline basic principles that must guide the process of measuring QOL for PwID.

These include:
- evaluating the degree to which people have life experiences they value;
- they reflect domains that indicate a meaningful life;
- attention is paid to the relevant physical, social and cultural environments; and
- there are measurable experiences that are both common to all and unique to an individual.

QoL & Older People without ID

There is considerable work on quality of life in older people without lifelong disabilities. In this study, the use of validated scales for measuring QoL in both cohorts indicated that the average QOL scores were not significantly different. This indicates that, potentially, the issues and domains for QoL for PwID who are ageing and are arguably not very different from those for PwA.

For service providers, the following simple schematic figure may be of value to ensure that all domains of QoL are considered for people using their services.
**D. Develop, Enhance and Monitor Strategies for Social Inclusion and Connectedness**

People who are ageing, with or without a lifelong intellectual disability, want to be engaged and remain active, and to be supported to achieve this. Passive service delivery modalities should only be a last resort option, exemplified by situations such as when an individual is receiving end-of-life care or has end-stage dementia. The text in the following box captures the essence of social inclusion and connectedness. However, for such concepts to be meaningful, development of indicators as outlined in the figure below are required.

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**Purpose and meaning were key findings from the research. People as they age are seeking options to continue their opportunities for economic, civic, social and physical engagement. These again are indicators of wellbeing. Social, physical and mental health promotion, prevention and early intervention across the lifespan are critical.**
Note: Column 1 outlines the set of activities required by service providers to ensure social inclusion of older people. Column 3 outlines the potential positive outcomes and impact of undertaking activities outlined in column 1.

Source: Simplican et al., 2015.
3. Service improvements are required to achieve change and better outcomes to facilitate successful ageing

A. Nationally consistent policies and standards across an integrated aged and disability care sector are needed to improve equity of service access

- A seamless, easy to navigate and integrated care system should include nationally consistent policies and standards. This is required to ensure equitable access to existing service provision, particularly in rural areas.

The research identified challenges in accessing services, for example, the availability of allied and specialist health professionals such as dentists, optometrists, geriatricians and, in some cases, general practitioners.

The practice of fly in, fly out services and assistance for people and their carers/family members to travel to services is one strategy to facilitate service access in areas without the necessary local resources. The success of this approach, moving forward, will need to be based on a sound understanding of need in each different local population.

Another strategy supported by the research is the use of technological and digital solutions to facilitate responsive, appropriate cost-effective adjunct supports. However, this should not be used as a cost-cutting measure, and should not occur at the expense of local capacity building.

- The sharing of ideas and successful solutions will be critical for service providers to implement good options to enhance quality, personalisation and in the context of existing and predicted critical future workforce challenges across all jurisdictions.

- Nationally consistent policies are also required to align funding parameters and criteria to reduce anomalies across the existing service systems. As already noted, this can significantly impact waiting lists for community care packages and guidelines that may impede the timely delivery of individual supports to people with high or complex support needs.
B. Targeted services for people with complex needs, and emerging significant health needs, are required to prevent the breakdown in the ability to live within the community

Of course, it is worth acknowledging that not all people will be able to remain within their preferred community home until the end of their life. However, the current care system requires diversification and resourcing to adequately respond to ageing within community when an individual person experiences a major health crisis. The current model of transferring people to acute care hospitals, and then to congregate residential facilities, due to lack of alternative community-based care arrangements, is highly problematic. For disability and aged care workers, having the skills to initially identify and then refer to the appropriate health-care support to address emerging health issues, may assist people to continue to age in their chosen place and prevent premature admission into residential aged care.

Some of the participants and their carers who engaged in this research felt that “they had no options”, because the easiest decision was to transition to large congregate aged-care facilities. A key concern, particularly in rural areas, was the potential disruption of long-standing social connections.

- It was identified that disability expertise is required within the mainstream health and community services to address best care practice. Particularly in rural areas, there is a need for strategies to improve service access, options, specialisation and equity.
- With the move to the NDIS, there is a transition away from services being provided by disability services, and more informal or family care is occurring. Any training should therefore also consider the needs of this new group.
- A human rights framework necessitates exploration of different ways to navigate complexities around multi-morbidities, emerging ageing issues, societal and demographic change.
- In a person-centric model, the focus needs to be on feasible and achievable outcomes within the concept of community-based living. However, there is currently a policy vacuum in this space on a local, state and national level.

A care system is required that can be incrementally tailored to meet needs at a given point in time. This system needs to be one that responds to individual need, complexity and diversity. Fundamental resourcing issues need to be addressed to ensure the capacity of services to deliver person-centred care, in the community (having access to support at the appropriate level) and in congregate settings (have appropriate staffing levels, or other means of innovation to respond to key needs). In the absence of this, people are at risk of
ending up in higher care at a much earlier age or living with reduced quality of life, and at risk of neglect, abuse and a breach of their human rights.

- A seamless service system requires a care model with the capacity to respond to the needs of people as they age, including those with specialised ongoing and emerging needs.

The current service system, with an arbitrary delineation based on a chronological age or disability type, does not accommodate those with complex care needs that do not necessarily fit well into the government’s defined boxes. As an example, aged care providers identified that they do not feel equipped to manage the needs of people with intellectual disability. Likewise, access to aged care services by adults with intellectual disability in some cases has been discouraged by service providers due to non-acceptance/discrimination by other residents or service participants.

A level of cross-disciplinary training is essential to deliver integrated service options to meet the specific and general needs of people as they age. A level of service specialisation is also required to cater for the specific needs of people as they age, in both community-based services and in specialised service delivery models.

C. Need for a National Workforce Planning and Training Strategy

A relevant national work force and training strategy is urgently required to address the projected workforce required to meet the needs of our ageing population. Training and upskilling is required across the existing aged, disability and health sectors, and also for family and unpaid carers.

This strategy will need to identify the:

- Projected population care requirements in each local area, and strategies to address
- Workforce gaps and demands/issues
- Training needs and requirements
- Retention strategies
- Cost assumptions and financial modelling

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4 Examples could include people with dementia; intellectual disability and dementia; younger onset dementia; younger onset dementia and intellectual disability; intellectual disability and challenging behaviours; intellectual disability and mental health issues; intellectual disability and physical disabilities etc.
• Consideration of the industrial mechanisms
• How training costs will be factored into pricing of services

The industrial awards governing the caring sector requires review to **address wage inequities and to incentivise the current and future workforce**. This must occur in conjunction with training and skills development to **support career pathways and retention of skills** within the sector. An appropriate wage is required to reflect the value of the work undertaken.

This research identified a **need to review the skill base of professional care staff** in relation to the additional needs of people with intellectual disability as they age and in particular around multi-morbidity.

- The existing aged care sector requires additional training to manage the complexity of health and behavioural issues of people as they age, and to effectively support adults with intellectual disability who may enter residential aged care towards the end of the life.
- The introduction of the NDIS has seen a movement towards increased casualisation of the workforce, dramatically reducing the financial capacity for organisations to train their staff. These factors have further contributed to a decline in the skill base of existing staff, and particularly for newer workers entering the sector.

The three most important areas identified for **interprofessional learning (IPL)**, and where there is considerable commonality of issues faced by health professionals and support staff across both the **ageing and disability sector**, were:
1. Health & associated issues
2. Community & Social support
3. Navigating the Health System.

The winding up of workforce planning agency – Health Workforce Australia – may have led to administrative efficiencies. However, the incorporation of its mission and tasks back to the Department of Health has led to fragmentation of workforce planning both at the level of Commonwealth and States. Interim strategies tend to dilute the long-term planning of resources and requisite policies for future health and community sector workforce.

- Policy makers need to ensure that there is **appropriate modelling of the health workforce for both the short- and the longer-term**.
- **Part of good workforce planning is a strong focus on retention of skilled workforce.**
The current ad hoc planning and, more importantly, repeated changes based on political expediency, need to be replaced with an effective and well-resourced workforce planning strategy need to cover health, aged and disability, to deliver a seamless system.

**D. Encourage Place-based Collaboration**

Place-based collaboration based on the needs of the ageing population is one strategy to improve and deliver quality individualised supports. The findings of this project emphasise the fact that older persons’ needs straddle across the health, aged and disability care sectors. Yet, there is little evidence of effective and ongoing collaboration between these three sectors. While collaboration is nominally supported and indeed encouraged by policy makers, the lack of a seamless system means that bureaucratic barriers effectively stymie the majority of attempts to establish proactive or innovative models of care.

**Communities of Practice**

The establishment, resourcing and support of communities of practice across health, aged and disability is an investment required to enhance place-based opportunities and solutions.

The evidence from health care suggests a positive impact on quality of care, improvement in practice, and innovation. The opportunity to share expertise, learning, skills and resources has enormous potential to meet local population needs.

Industry leaders have clearly demonstrated via this research their willingness to be change agents and to shape, improve and inform service systems to meet the needs of people as they age. Given the significant and ongoing reforms of the last five years to both the aged and disability care sectors, resourcing is required to facilitate a Communities of Practice to break away from current sectoral silos.

- The concept of Communities of Practice would need to operate to include state and federal public servants, sector leaders and moving to geographical CoPs to inform face-to-face services and how these are delivered.

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5 Communities of Practice (CoP) are groups of participants that have an ongoing interaction around a shared concern. CoPs can be used to share knowledge, as a tool to improve clinical and health practices and to facilitate the implementation of evidence-based practice. “In the healthcare field, CoPs have been promoted as a tool to: Cross knowledge boundaries; Generate and manage a body of knowledge for members to draw on; Promote standardisation of practice; Innovate and create new ideas, knowledge and practices”. [www.med.monash.edu.au/assets/images/scs/nutrition-dietetics/s01-what-is-a-cop.pdf](http://www.med.monash.edu.au/assets/images/scs/nutrition-dietetics/s01-what-is-a-cop.pdf)
• There is clear value in the sharing of information and evidence-based examples of good practice in supporting people as they age.

• The funding of demonstrations models by government would also provide an opportunity for intersectoral collaboration and innovations in service delivery.

• It may also facilitate the trialling of new person-centred approaches and foster a seamless life journey approach, rather than the current model that conceptualises ageing as a distinct phase.

• Additional evidenced-based research and evaluation of nationally significant models to identify their critical success factors, unique characteristics or innovative and creative responses would be critical.

A key initiative would be the establishment of a nation-wide research project focused on services that achieve quality outcomes and customer satisfaction through evidence-based practice.

4. Is it different in the country?

One of the key foci of the project was consideration of the similarities and differences experienced by people living in either urban or rural locations. Perhaps not unexpectedly, there were limited differences identified in terms of the participants’ thoughts on what is a good life, what it means to age in place, changes in health, and aspirations for the future. However, there were some major divergence in identifying specific factors that were recognised as potential barriers to a good life.

Some of the main differentiating features between urban and rural participants included:

• Access to medical services, particularly specialist medical services. The actual process of ‘getting there’ in terms of accessing services was much harder for people in the rural sites compared to large regional and urban study sites. While access to services was not necessarily ‘easy’ in urban areas, there was generally specialist support available within a reasonable distance. This was not the case in rural areas, with access to specialist, and sometimes even general health care, often requiring overnight travel.

• Limited service provision in regional and rural areas. There were concerns relating to the availability and choice of service providers in rural locations. This issue manifests particularly if there is only one service provider or a major operator in the town, with any choice and control limited not only to what is available but also to what is the best fit for all clientele of the organisation (which might not be best for the individuals).
For people continuing to live at home with family, some age-associated needs could be met with some simple and low-cost home modifications using tele-health and e-technologies. The rollout of the NBN across both rural and metropolitan Australia provides an opportunity to connect individuals with support staff, as well as help PwID who are ageing to maintain social connections through social media. These issues are particularly relevant for rural residents, as they are at great risk of both premature and inappropriate admission to residential aged care that is often located at considerable distance from their familiar community.

However, it is worth reiterating the concern of some rural communities that tele-health is seen as a ‘cost-saver’ for government, who can either not replace or even remove local health-care staff and instead use a cheaper remote delivery option. Any move to tele-health should only occur to supplement non-existent services, and not be used instead of supporting local capacity building.

CONCLUSIONS

One of the main drivers of this research project was the desire to support community-based ageing of both PwID and non-ID ageing groups to avoid premature and inappropriate institutionalisation.

The data indicates additional complexity and richness to the existing ageing-in-place concept, which now should not be conceptually limited to just remaining in the same home or place. Rather, this needs to be seen as having autonomy over both where and how to live life as an older person; it was about ensuring a quality of lifestyle and making one’s own choices about that lifestyle. The term ‘ageing-in-my-chosen-place’ is recommended instead of ageing-in-place, as it more appropriately encompasses the variety of experiences desired by participants.

Key to this concept includes autonomy in choosing where and with whom people live and hence meaningful consultation and engagement around decision-making. In addition, this should be a key strategy around safeguarding, quality and supporting individual outcomes.

Decisions about where one lives also include access to social networks – family, friends, peers and community networks – and existing formal supports, and the capacity to maintain regular contact as desired through visits and phone calls. Many participants talked about wishing they could see their family more often than they do; being able to sustain relationships was of critical importance. The maintenance or facilitation of valued social roles was also very important, with many referring to this as having ‘something to do that was their job’, such as continue in work, helping out others, playing a key role in their home or community. For many people, a change in health circumstances triggered retirement and the maintenance of connections and a valued role, as identified by themselves and others, was of critical importance for their mental well-being.
Maintaining a focus on **health, mobility and wellbeing** was also identified as important to enable engagement in a range of social and recreational options and reduce isolation. Access to specialist health services to support the diverse needs of older people was a concern across both rural and urban areas.

**AREAS FOR FUTURE WORK**

The current project has also identified a number of key areas that require additional follow-up research.

1. It is worth acknowledging that the focus of this project was on issues relating to aged and disability care. However, underpinning both of these sectors are the mainstream health services. It was beyond the scope of this project to comprehensively review the interactions across the aged, disability and health sectors, particularly when considering the duality of health service provision that occurs at both a state and also national level. It is therefore recommended that additional work be undertaken to evaluate this important issue in light of the findings of this project.

2. Due to the nature of the research, which required consent by individuals participating in the in-depth interviews and the survey, the study was limited to PwID with mild-to-moderate levels of ID. Thus, the issues faced by people with severe and profound impairments is largely missing. An attempt was made to obtain information from this group (n=15) through face to face interview, but there were huge gaps in the requisite information making the findings unusable. We recommend that a specific collaborative study is designed to facilitate the participation of group, who are largely still living in community-based settings, in order to better assess the health and social support needs of this cohort.

3. The perspectives of carers were limited in the present research, particularly in relation to a better understanding of the impact of caregiving on their own health and well-being. This was not a focus of the study, but it became apparent that carer-health is clearly an area of concern for many people. Without family carers, many individuals who are ageing, either with or without lifelong disability, will be forced prematurely into residential aged care. Therefore, more research into how carers can be better supported is considered to be vital.

4. Following on from carer health, it is also clear that the provision of services under the NDIS may start to see more use of staff from non-traditional sources (i.e. not from established disability support agencies). As such, analysis of the training needs of this group, including parent and family carers, needs to be undertaken.

5. There is a need for a gaps-analysis in relation to available health, community and social support services and accessibility of services for PwID who are ageing, as well those who are ageing without lifelong disabilities, across both rural and
metropolitan areas. There appears to be a consensus amongst service providers, which is supported by statistics available from national agencies, that community-based services for older people have many gaps for both groups.

6. The changing demographic profile of older Australians also requires a focus on the needs and issues of older people from culturally and linguistically diverse (CALD) communities. For many of these people, ageing in Australia is akin to ageing in a foreign land, and therefore requires attention in how to realign policies, structures and practices that are more culturally appropriate.

7. The needs of people with Aboriginal or Torres Strait Islander origins need to be carefully examined. The impact of the ‘stolen generation’ is starting to become evident, with many individuals who were forcibly removed from their families and institutionalised at a young age now facing re-institutionalisation in their old age. This is potentially re-traumatising a highly vulnerable group of our community, and care needs to be taken to ensure that models of care are providing that are culturally appropriate and sensitive to historical injustices.
References


