

***EXPLORATION OF THE POPULATION OF
PEOPLE WITH DISABILITIES WHO ARE AGEING,
THEIR CHANGING NEEDS AND
THE CAPACITY OF
THE DISABILITY AND AGED CARE SECTORS
TO SUPPORT THEM TO AGE POSITIVELY***

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Short report: Key Findings

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The views and recommendations contained in this report do not reflect the views of the Australian Government. The report contains factual errors in its description of Australian Government policies and programs.

Abbreviations

ACAT: Aged Care Assessment Team

ACSA: Aged and Community Services Australia

AIHW: Australian Institute of Health and Welfare

ATE: Alternatives to Employment

ATSI: Aboriginal and Torres Strait Islander

CACP: Community Aged Care Package

COTA: Council on the Ageing

CSTDA: Commonwealth State and Territory Disability Agreement

DADHC: (NSW) Department of Ageing, Disability and Home Care

DFACSA: (Commonwealth) Department of Family and Community Services and Indigenous Affairs. (Previously called DFACS)

DHA: (Commonwealth) Department of Health and Ageing

EACH: Extended Aged Care at Home

HACC: Home and Community Care

IDSC: Intellectual Disability Services Council

NMDS: National minimum data set

NDA: National Disability Administrators

WHO: World Health Organisation

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1. Introduction to the project

The purpose of the research was to explore the population of people with lifelong disabilities who are ageing within Commonwealth, State / Territory Disability Agreement (CSTDA) supported accommodation, and to better understand their changing needs and the roles of the Disability and Aged Care Sectors in supporting people to age positively.

The project team undertook this research based around the following four research questions:

- What are the features of shared accommodation arrangements that are able to support people to age-in-place in shared supported accommodation?
- What are the pathways to aged care from disability services?
- What are the perspectives of the aged care system about assessing and providing services for this group?
- When is the aged care system, particularly its nursing homes, appropriate for people with lifelong disabilities?

1.1 Target population and definitions of terms

For the purpose of this research, the target population was defined as people with lifelong disabilities; whose needs are changing as a result of ageing; and who are in receipt of CSTDA accommodation support services, namely, shared supported accommodation and various in-home support initiatives, referred to in this report as 'in-home' support.

The term 'lifelong disability' has been adopted to refer to people who have lived most of their lives with a developmental or acquired disability before reaching older age.

'Ageing' and 'older age' has been understood as older than 65 years.

'Third age' refers to people in the general population who are between 65 and 80 years. 'Fourth age' is the term used to refer to people older than 80 years who are more likely to be frail, in poor health, less independent and less involved in social and community activities.

The term 'increasing or changing support needs' has been used to denote any situation in which a person with a disability has services and supports provided that no longer match their current support requirements.

There were three broad groups of stakeholders, who have been denoted as follows:

- people with disabilities and their carers;
- service delivery agencies or staff who could be government or non-government employees but are involved primarily in providing services and supports; and
- staff with policy-level responsibilities; that is, staff with roles that define the parameters of service delivery programs, including the funding, and rely on service delivery agencies and staff to implement or deliver what the policy describes. Such policy roles exist in the Disability and Aged Care Sectors.

1.2 Method

The project involved four components, namely, policy analysis and literature review; development of a profile of the population of older people with CSTDA accommodation support; a national survey of shared supported accommodation providers; and national consultations sampling people with disabilities receiving CSTDA in-home support and their carers, service providers, peak bodies and policy officers in Aged Care and Disability Sectors.

1.3 Structure of this report

The report is in two forms: this short report which summarises and discusses the main findings, and a separate full report.

2. Summary of findings

This section summarises the findings arising from the four research questions.

The study reports a range of findings from across Australia. It is not a report about each state and territory. Findings from one or other data source (particularly consultations and the national survey) are attributed as appropriate.

2.1 The features of shared accommodation arrangements able to support people to age-in-place

a. Summary of findings from the national survey

The respondents to the national survey reported that they were supporting 3912 people in total in their shared supported accommodation services. This is 34.6 per cent of the total shared supported accommodation residents (AIHW, 2005b). This included 1647 people aged 50 years and older and 2265 people younger than 50 years. That is 42.1 per cent of the people in the sample were aged 50 years and over.

Of the people 50 years and over, 285 were people older than 65 years. This represented 56 per cent of the 506 people over 65 years in supported accommodation as estimated by the AIHW (2005b). (See section 3.1, Table 2.) There were few people living in shared supported accommodation older than 65 years in real terms or as a percentage of the age group with most in the third age (65 – 79 years) and very few in the fourth age, older than 80 years. The largest group of people older than 65 years were those with an intellectual disability between the ages of 65 to 79 years.

There were 603 people in the national survey sample with increasing support needs reported in the younger age groups (less than 50 years), that is, 603 of 2265 aged less than 50 years (or 26.6 per cent of this age group). When all of the residents described from the survey across all ages are considered, there were 1682 people (603 less than 50 years of age and 1079 people more than 50 years) with increasing support needs which is 43 per cent of the total residential population described through the survey (3912 people). While increasing support needs are more common

for people over 50 years, and for those in the older age groups (over 65 years), they are also associated with younger age groups.

In the last two years it was reported that 27 of the total client group (all ages) moved to residential aged care, and that five of these people were older than 65 years. That is, according to these respondents, few people move to residential aged care, and the minority of these are in the age group considered older for the general population, that is, above 65 years.

b. Arrangements to support ageing-in-place

The results from the national survey indicate that, from the perspective of disability shared supported accommodation organisations, most people with increasing support needs, including those who are ageing, are being supported to age-in-place. This is a change from earlier studies in Australia which suggested a steady transition of residents from shared supported accommodation to residential aged care (Bigby, 1999).

The most commonly mentioned strategies supporting ageing-in-place involve various aspects of staffing, although the combination of several approaches seemed important to providers, suggesting one strategy alone was not sufficient. The range of strategies described includes:

- increasing the number and skills of staff, particularly in relation to more staff to respond to day support when day/ employment programs were no longer available and different staff to provide nursing, health and aged care;
- staffing and recruitment initiatives, ranging from roster reviews to staffing bonuses;
- modifications to the physical living environment and alterations to house design;
- additions to aids and equipment;
- variations to service design, such as how residents are grouped together and where; and
- changes to internal planning and the organisational 'mind set', such as the agency's understanding and readiness for a role in supporting people to age-in-place.

The inability to provide these variations was recognised by providers as a barrier to ageing-in-place.

The national survey of shared supported accommodation providers also suggested that interplay of contextual factors is important for ageing-in-place. These are:

- the willingness of the staff and the organisation to adapt (which includes the possibility and perception of any alternatives);
- the capacity of the staff and the organisation to adapt (staff skills, resources for staff and the modified physical environment);
- the desires and preferences of the people with disabilities and their family members; and
- people having higher support needs from a younger age (and therefore more likely to have lifting equipment, adapted devices, appropriately trained and willing staff).

Organisations reported being more likely to develop responses to support ageing-in-place if staff, the person's family and the person with the disability wanted that to happen. The absence of these supporters, particularly the organisational and staff endorsement, meant adaptations and individual responses were more difficult to initiate. The decision that a person should move (or stay) in shared supported accommodation was determined by the combination of these complex factors together with the willingness of an Aged Care Assessment Team (ACAT) to be involved.

In addition, from the consultations, the trend for people to age-in-place in shared supported accommodation may be explained by the interaction of:

- the increased capacity of shared supported accommodation to adapt to age-related needs as a result of the issue being on the agenda for the past 10–15 years;
- the changed ACAT practice arising from the young people in nursing homes issue and aged care reforms generally that means an ACAT will not typically assess or refer to residential aged care anyone younger than 65 years;
- the belief from ACATs that shared supported accommodation must provide more than residential aged care, because of the greater per capita funding; and
- the view from residential aged care providers that compatibility among residents in their facilities is critical and depends among other things on residents all being around the same older, fourth age, age group.

The conclusion from this study is that most older residents (older than 65 years) living in shared supported accommodation are ageing-in-place within their long-term home or by moving within the disability organisation. The low frequency of moves from shared supported accommodation is a shift, which is likely to have resulted from increased knowledge and will within the disability system of issues about ageing and from drivers such as tightened access to aged care as a result of the 'younger people in nursing homes' issue. Ageing-in-place is occurring primarily within the existing resources of disability organisations, without systematic additional funds from CSTDA or support from the aged care or other sectors. Shared supported accommodation providers are reporting implementing disability-related practices consistent with supporting ageing-in-place in shared supported accommodation.

It not clear, however, how 'successful' ageing-in-place is and whether older residents in shared supported accommodation are receiving optimal health care or whether the current situation is sustainable as numbers increase. Successful ageing-in-place must be conceptualised as more than not moving, as this alone does not guarantee an appropriate service response. Whether ageing-in-place is successful is hard to judge as there is no agreement about its nature, components, the service providers and family partnerships that should be involved, or about its cost.

2.2 The pathways to aged care from disability services

From the national survey, in the last two years, very few people of any age moved to residential aged care from shared supported accommodation. Based on the responses from the national survey and the consultations the pathway into residential aged care is more common for people not in receipt of CSTDA accommodation support or for those in receipt of in-home support from the Disability or Aged Care Sectors. In these situations moves are triggered by increased support needs of the individual, reduced capacity of informal carers and unavailability of increased support from either or both sectors to compensate for these changes. The limits of support available in-home vary and are determined by differing service providers' interpretations of duty of care or occupational health and safety when available support hours are deemed inadequate.

From the case studies and the consultations, in those instances where people do move to residential aged care from shared supported accommodation, this occurs more commonly via acute health or subacute (rehabilitation) following an accident or illness when it is judged — usually by the shared supported accommodation or

general practitioner/hospital staff — that the person cannot be supported at the new level in their previous home.

2.3 Perspectives of the aged care system

All jurisdictions reported examples of difficulties for people with disabilities of any age accessing Home and Community Care (HACC) and other community aged care programs if they were in receipt of disability funding. However, few difficulties in accessing residential aged care were reported for older people (over 65 years) receiving CSTDA funds, although CSTDA funds typically ceased if this occurred — but not always. These exceptions involved funds being made available for community or social activities.

a. Aged Care Assessment Teams (ACATs)

ACATs are the gatekeepers to residential aged care, community-based aged care and other health and ageing specialists. The vast majority of the ACAT clientele are aged over 70 years. Aged care legislation emphasises functional rather than chronological ageing. In practice, consultations and the national survey indicated that ACATs prefer not to assess people younger than 65–70 years, and certainly not to refer these younger people to residential aged care.

ACATs reported difficulties in assessing people with disabilities referred because of issues of ageing. They referred to the unsuitability of standard assessment tools; the lack of sufficient consultation with people who know the history of the person with a lifelong disability; and the absence of previous records of functioning and assessments, which make it hard to differentiate ageing-related issues from disability-related issues.

b. Residential aged care providers

The residential aged care system is judged as appropriate for people with disabilities who are older and require the additional services of that system, for example, daily or 24-hour availability of nursing care. Aged care providers stress the importance of resident compatibility within their settings, but such compatibility is not readily achieved when people with lifelong disabilities are decades younger than the majority of residents, who are in their eighties. However, there are some examples of people with lifelong disabilities living harmoniously in residential aged care.

Typically it was suggested that people with disabilities should be able to remain in shared supported accommodation, perhaps in specialist houses, and get support from the Aged Care Sector.

2.4 The appropriateness of the aged care system, particularly, nursing homes

Both sectors express concern about the applicability of residential aged care for (older) people with disabilities primarily due to compatibility with other residents and the narrowness of nursing homes' focus on nursing care, at the expense of broader quality-of-life issues argued to be relevant for people with lifelong disabilities. A question remains about the role for residential aged care in respect of people with lifelong disabilities who are older or identified as ageing prematurely.

The national survey identified few people who have moved from shared supported accommodation to residential aged care in the last two years. This is a change from earlier Australian studies, which suggested a steady transition from shared supported accommodation to residential aged care. The interface between disability and residential aged care is not, therefore, the main response to people ageing with a disability in receipt of CSTDA shared accommodation support. Conversely, there may be sufficient argument, as followed by the Young People in Nursing Homes Alliance, for a different response from residential aged care, such as specialist nursing homes for younger people.

People with a lifelong disability and their families can be influential in the decisions about choosing or not choosing residential aged care. Conversely, CSTDA or HACC in-home providers may make the final decision about the level of care (amount and nature) that can be provided to someone, particularly in their own home, which may not coincide with the person's wishes and which results in a move to residential aged care. There may be no other possibilities available for high levels of support apart from residential aged care for people from bush communities or in rural home settings.

3. Discussion of findings

In this study, people with increasing and changing support needs have been identified across all age groups in shared supported accommodation. The majority of people with increasing support needs are younger than 65 years.

People older than 65 years represent a small proportion of people living in CSTDA accommodation support and this is not likely to change in the near future, although the small number of people who are older will continue to grow. There will be more people who are older, and an unknown number of these older people will experience increasing support needs due to ageing. There are important differences in the ageing process across different disabilities, including the likelihood of additional disabilities, that need to be recognised and understood, at least at the individual level.

The conclusion from this study is that most older residents (older than 65 years) living in shared supported accommodation are ageing-in-place within their long-term home or by moving within the disability organisation. This is a change from earlier years where moving from shared supported accommodation to residential aged care was more typical and expected. The low frequency of moves from shared supported accommodation is a shift, which is likely to have resulted from increased knowledge and will within the disability system of issues about ageing and from drivers such as tightened access to aged care as a result of the 'younger people in nursing homes' issue. Ageing-in-place is occurring primarily within the existing resources of disability organisations, without systematic additional funds from CSTDA or support from the Aged Care or other Sectors. Shared supported accommodation providers are reporting implementing disability-related practices consistent with supporting ageing-in-place in shared supported accommodation.

Decisions about the viability of ageing-in-place reflect the interplay of organisational and staff willingness, organisational capacity and individual or family preference. Disability service organisations are most challenged by reduced mobility, acute ill health and any wide disparity between one person and other residents occurring as a result of changed support needs.

It is not clear how 'successful' ageing-in-place is and whether older residents in shared supported accommodation are receiving optimal health care or whether the current situation is sustainable as numbers increase.

There is an absence of specific policy about provision of support for older people with lifelong disabilities. As a result informal policy exists at service provider level, which means the situation regarding access to support is inconsistent, unpredictable, unfair and possibly untenable. Among service providers in given localities a lot has happened, but not in a reliable or predictable way across the country. At a policy level across sectors few jurisdictions have a concerted commitment to this issue, but rather a preoccupation with who pays and debate about what is the equitable rationing of scarce resources. This contrasts with the service provider level where joint commitment to the issues is much more evident. Different rationales underpin the quite different approaches of these two groups to the interface between the Aged Care and Disability Sectors, with service providers regarding it as an opportunity for partnerships and combined funding, while policy makers tend to see the sectors as mutually exclusive and the interface as creating the risk of double dipping that should be avoided by exclusion from concurrent access to both sectors. Therefore, rigid sector boundaries are more likely to dominate in relation to shared supported accommodation, which is equated with residential aged care by the Aged Care Sector.

The small but increasing numbers of older people with lifelong disability and the differential development of supported accommodation services across the States and Territories suggest that the starting point for the development of services for each State and region may be quite different. Within the context of broad policy directions different avenues of service development and design may need to be pursued that reflect and build on existing local and regional service systems. Services may have little exposure to or understanding of this group. This may also partially explain the apparent concern in CSTDA services about supporting older people, despite the comparatively low numbers. In those States with a higher proportion of potential older service users the issue will be ageing within existing services rather than new people at an older age being on waiting lists or seeking entry to services in later life.

3.1 Potential directions

The research found that, although the support needs of older, younger (aged less than 50 years) and middle-aged people in CSTDA services are likely to increase,

there is an absence of any systematic mechanisms to respond to such changes. The type of disability is a predictor of the nature of support changes. The contrast with the aged care system in this respect is stark, and development of funding sensitivity and systems' response to changing needs should be a policy priority.

Work should be undertaken that accurately describes adulthood for people with lifelong disabilities so that the needs that arise in middle life may be conceptualised and understood as distinct from those of old age.

Current disability policy is adopting a whole-of-government approach to access and support for people with disabilities, suggesting that all sectors have a role to play in ensuring access by people with disabilities to their services. This direction is not well reflected in respect of ageing and people with a disability where, at a policy level, the overlap of the populations in the different sectors is not readily acknowledged. The particular and sometimes unique needs of people with disabilities are not recognised in health and allied health care initiatives for the general population nor are the difficulties of their access to such services. In addition, the value of cross-sector partnerships to enable the Disability Sector to share expertise within the Aged Care Sector when adapting to age-related health and functional changes is not widely accepted at a policy level.

Aged care policy reflects a vision of world-class care, and emphasises the contribution of the Health Sector. This sector must take account of the specialist needs of people ageing with a disability to achieve this vision for them. The interface of the Disability and Health Care Sectors requires more prominence. Policies are needed that acknowledge and address the difficulties experienced by people with lifelong disabilities in accessing primary and acute health care and long-term rehabilitation. These policies would compensate for the lack of informal support available to people with disabilities to negotiate access, receive post-acute care and undergo the routine health monitoring necessary for some conditions as well as compensating for the failure of the Health Sector to include the needs of this group in preventative and health promotion. The isolated examples of policy and practice that address these issues provide an indication of the type of responses that should be systematically adopted in all jurisdictions. For example, in one jurisdiction protocols have been developed between the Disability and Health Sectors for hospital admissions and transitional care support that includes agreements about funding of support staff; use of hospital substitution schemes to provide additional short-term

support to residents in shared supported accommodation or in-home settings; and the widening of a telephone service for 'over the phone' health support for residential staff aimed at reducing presentations in emergency departments. Capacity must also be created for the development of specialist health knowledge and services for people ageing with a lifelong disability who have health- or age-related needs that are quite different from those of the general population.

There is strong evidence to support the aged care system giving formal recognition to sub-groups of people with a lifelong disability who age prematurely in regard to access to ACATs and residential and other forms of aged care, and the need for its narrow response in residential care to be supplemented by broader support from the disability and wider health systems.

The impact of aged-related eligibility for specific disability programs such as continence aids, equipment and mobility allowance currently disrupts support arrangements for people with lifelong disabilities when they reach 65 years. The need for the response to older people to accommodate and recognise the circumstances of people with lifelong disabilities is again apparent.

The situation for people with disabilities either not in receipt of CSTDA accommodation support or receiving very low levels of disability and/or aged care accommodation support in their own home requires further investigation.

The importance of resolving such issues is palpable in light of the burden reflected in disability service providers' comments, which seem out of proportion to the small numbers of older people with disabilities (that is, older than 65 years). There are much larger numbers of people older than 50 years reported to be difficult to support. Increasing support needs — for a range of reasons and at all ages — are being responded to by service providers, without a policy and funding framework. The reduction of adult years to only issues of ageing or of disability appears to be an oversimplification of what is happening, which ignores or masks progression of disability, health and illness. It also limits investigation of what should be the appropriate service responses and reinforces the imposed or chosen tendency to self sufficiency or isolation of the Disability Sector.

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