

Improving housing and care for adults with disabilities

This Bulletin reports on one of several AHURI projects examining the linkages between housing and support programmes and how they might best operate in order to deliver better service to their clients. In this case, the clients are adults with disabilities, ranging in age from 20 to 60-plus. This study, by Catherine Bridge, Hal Kendig, Susan Quine and Amanda Parsons of the AHURI Sydney Research Centre is one of the few Australian projects to have looked at the policy linkages across housing, disability and care - and the first to explore the differences between the needs and experiences of younger and older people.

KEY POINTS

- There is currently no national framework for the co-ordinated and flexible delivery of housing and support services to adults with disabilities, and this hinders efficient and fair service provision.
- Linkages between programs are mainly informal co-operative efforts that vary in their effectiveness.
- Given that people with high dependency needs often require services from a range of providers, a whole-of-sector approach to support is critical.
- Two-thirds of adults with disabilities live in some form of cared accommodation setting, mainly aged care nursing homes.
- Younger adults (20-59 years) with disabilities are much more likely to reside in the community than are older persons.
- The trends towards deinstitutionalisation and 'ageing in place' for adults with disabilities have increased the demand for community care, whilst the resources to meet that demand are inadequate.

BACKGROUND

Over the last decade, policy shifts in the area of housing, disability and care at Commonwealth, State and regional levels have aimed to maximise independence and improve client satisfaction and service flexibility. At the same time, spending has been constrained in a climate of increasing market competition, privatisation and outsourcing.

A review of research and literature on the subject shows that disability, housing and care are interdependent and complex:

- Linkages between access, safety and dependency are not well understood in the Australian context;
- Community care services can augment in-home support, but a piecemeal approach and financial restraint means demand has not been met;
- The needs of adults with disabilities have been largely ignored in designing and building private dwellings and cared accommodation, resulting in more dependency and social exclusion; and
- To 'age in place' depends on the availability of informal care, but carers can face financial hardship and increased risk of acquiring a disability themselves.

Reform has been impeded by a lack of research knowledge about the best way to package services, the complexity and piecemeal nature of the current system and the plethora of bureaucracies funding housing and support. The current policy emphasis on "user pays" care packages, along with decreasing support for public housing, limits options for community integration and flexible responses to care needs.

Against this background, the study attempts to deepen understanding of the connections between housing, disability and care, while exploring the combined impact of these policies in meeting needs.

The research aimed to answer three main questions:

- What are the housing circumstances and service use of older and younger adults with disabilities?
- How do policymakers and service providers view the key issues?
- Within the past decade, what housing and care packages have been explored in the Australian context?

Statistical information used to answer the first research question is based on the 1998 Disability, Ageing and Carers Survey (DACs) conducted by the Australian Bureau of Statistics. However, most of the findings are based on interviews with leading 'players' drawn from peak advocacy organisations such as National Shelter and Physical Disability Council of Australia (PDCA) and from a range of Commonwealth and State policy areas including housing, ageing, disability, family and community services. These 'key player' interviews aimed to answer the final two questions above by identifying policy factors and themes that help or hinder whole-of-government approaches to the accommodation and care of younger and older people with disabilities.

FINDINGS

A. HOUSING CIRCUMSTANCES AND SERVICE USE

Analysis of the 1998 DACs data included the findings that for adults with disabilities:

- Two-thirds of those with a significant disability reside in some form of cared accommodation setting, mainly aged care nursing homes;
- Younger adults (20-59 years) with disabilities are much more likely to live in the community than are older persons;
- Public tenancies provide accommodation for approximately 10% of both older and younger adults with disabilities residing in the community;
- Older adults (60+ years) with disabilities are much more likely than their younger counterparts to live alone (30% versus 15%); have a profound level of disability (30% versus 13%); and are somewhat more likely to own their own homes (76% versus 62%);
- Over four-fifths (85%) of adults with disabilities reported some need for assistance, including property maintenance (60%), housework (46%), mobility and health care (44%), transport (42%), self-care (29%) and meal preparation (18%);
- Three-quarters of adults with disabilities residing in the community rely on informal care whilst only 6% are entirely reliant on formal care services alone;
- Being a public or a private tenant does not appear to be a significant predictor of need for care.

The housing tenure of adults living with disabilities in the community is summarised in the table on the next page.

- Overall, nearly 70% of them – virtually the same proportion as for the general population – have the financial and other benefits of owner occupied housing.
- Ten per cent, much more than the general population, have the reduced costs and relative security of public housing.
- More than 20% are private tenants or are living in other forms of less secure accommodation.

B. 'KEY PLAYERS' VIEWS

In-depth interviews with 24 'key players' identified medium to long-term policy trends, including:

- *Deinstitutionalisation*, resulting in community care being the preferred care context;
- *Ageing in place*, which has massively increased the demands for community care, highlighting the unsuitability of existing housing and transport infrastructure;
- *Increasing expectations of carers* arising from both 'ageing in place' and 'deinstitutionalisation' trends;
- *Consumer rights*, reflecting the rising expectations of people with disabilities;
- *User pays*, at a time when reductions in government contributions and cost shifting are expected to continue.

Housing Tenure	AGE BY LIVING ARRANGEMENT								
	Younger Adults			Older Adults			Total Adults		
	Alone	With Others	Total	Alone	With Others	Total	Alone	With Others	Total
Owner	24	30	29	68	66	66	53	45	46
Outright Purchasers	17	35	32	4	13	10	9	26	22
Public Tenant	27	9	12	18	6	10	21	8	11
Private Tenant	25	14	15	5	4	4	12	9	10
Other ²	7	12	11	5	12	10	5	12	11
Total % (number)	100 (229)	100 (1249)	100 (1479)	100 (437)	100 (915)	100 (1352)	100 (666)	100 (2164)	100 (2831)

Table 0-1: Percentage of Adults with Disabilities¹ by Housing Tenure, Age and Living Arrangement, Australia, 1998.

The views of 'key players' on policy and programs included the following:

- *No national framework* exists to ensure the co-ordinated and flexible delivery of housing and support services for adults with disabilities. Divided responsibility and lack of harmonisation between Commonwealth and State programs hinders efficient and fair service provision.
- *Linkages are still primarily informal co-operative efforts* that vary in their effectiveness. The lack of policy integration undermines linkages within health, housing and cared accommodation services, causing inefficiency and cost shifting.
- *Income support* was seen as underpinning the ability to buy housing and care services.
- *The Commonwealth/State Housing Agreement (CSHA)* was viewed as essential, particularly given increasing numbers of older tenants with disabilities living alone.
- *The Commonwealth/State Disability Agreement (CSDA)* was viewed positively for its rights focus, but was criticised for overspending on group homes, perceived inflexibility and gaps relating to children's and mental health services.
- *The Home and Community Care* program was seen as flexible and locally responsive, but concerns were expressed about bias towards older people, rural and regional disparities, and funding formulas that severely limit capacity building.
- *Community transport* is viewed as fundamental to housing and care for both younger and older adults with disabilities.
- *Residential Cared Accommodation Services* for older persons, funded by the Federal Government, were generally viewed as a last resort for those who were unable to obtain the level of care and housing support they required in their communities.

C. HOUSING AND CARE PACKAGES IN AUSTRALIA

Four main models of housing and care packages are currently in use in Australia.

- Those with a focus on **formal care** include:

- *Group homes*, which suit younger adults with disabilities who are unable to be cared for in the family home. These six-bed homes are designed to cater for four to five residents with a live-in carer;
- *Cluster housing* in which group homes are clustered together to achieve economies in care, and accommodating 30 to 40 adults. This model works best for those with similar age and/or disability needs;
- *Secure Accommodation Units* that are specially designed and staffed for those at risk of harming themselves or others.
- Those with a focus on **privatisation** include:
 - *Rooming houses, boarding houses and private hotels*, which cater for large numbers of people with disabilities, particularly mental health and intellectual disabilities and alcoholics;
 - *Singletons accommodation units*, which are clustered single apartments that allow sharing of communal facilities and care;
 - *Aged Care Units*, which are usually built to provide older people with a particular lifestyle, and include some level of support or care.
- Those with a focus on **informal care** include:
 - *The Supported Living Model*, where families form a company to receive money directly to provide care for their children;
 - *The Community Disability Housing Program*, which involves partnerships between local community groups along with disability and housing support;
 - *Local Area Co-ordination* programs, which help families to 'age in place' by co-ordinating support and information services at a grassroots level.
- Finally, *Adaptable Homes* are a form of private dwelling for rent or purchase that can be built as a house, unit, flat, townhouse or villa. They are intended to grow or change as the occupants need change. Key principles of adaptable design include level entry and accessible toilets and showers.

1. Excludes people with mild disabilities and those in cared accommodation. 2. Includes renter other (31), boarder (123), rent free (122), other non specified (24).

POLICY IMPLICATIONS

- A whole-of-government approach is critical, given that people with high dependency needs often require the involvement of more than one health and aged care service provider. The research revealed that a fragmented approach to delivering housing and support services for adults with disabilities makes for unwieldy, costly and sometimes unfair service provision. Further work is needed to develop a common approach both within Commonwealth/State agreements and within State-based policy and programmes involving urban planning, housing, social welfare, health and disability support.
- As the 'key player' interviews attest, meeting the surging demand for community care is hard because of the lack of suitable community housing. There is a need to create supportive and enabling residential environments. One option worth exploring is to introduce adaptable and accessible housing, which would increase housing choices in the mainstream market for people with disabilities.
- Better zoning, land use provisions and building regulations would help people with disabilities to 'age in place' in future. Despite their potential importance, building and land use controls take little account of the needs of people with disabilities.
- Equally, public housing for adults with disabilities needs to be maintained and diversified. Implicit throughout the study was the fact that adults can 'age in place' within their local community only if they have a secure home base into which support can be brought.
- To meet the greater expectations of carers identified in the research, several options warrant further investigation. These include better training for carers so that they can manage behavioural problems and prevent health and safety problems; providing carers, as well as people with disabilities, with aids and helping devices; and finding ways to reduce the cost of caring, both directly and in lost earnings.
- Given the importance of income support in allowing people to buy housing and care services, maintaining nationwide caps on public housing rental at 25 % of income would allow more people with disabilities to buy these services.
- Ways also need to be found for government departments like housing, disability and welfare to have joint responsibility for meeting needs, rather than shifting costs onto each other. More formalised agreements and linkages between housing and care providers could improve service.
- The study revealed increasing numbers of older tenants with disabilities living alone. What does this mean for property profiles, stock upgrading, housing allocation, staff training and linkages with support agencies? More work is needed on these issues.
- More research is needed on the problems of younger people with disabilities entering inappropriate aged care accommodation due to a lack of alternatives. Converting a greater number of residential care places into community care packages would potentially benefit younger people with disabilities.
- The growing community housing sector was viewed as more flexible and locally responsive but more research is needed into how to improve its viability, accountability and standards.

FURTHER INFORMATION

For more information about this research project, the following papers are available:

- Positioning Paper
- Work in Progress Paper
- Final Report

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Acknowledgments

This material was produced with funding from the Commonwealth of Australia and the Australian States and Territories. AHURI Ltd gratefully acknowledges the financial and other support it has received from the Commonwealth, State and Territory governments, without which this work would not have been possible.

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