

Exploring the efficacy of housing alternatives for adults with an acquired brain or spinal injury: A systematic review

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Objective

Supported by The Hopkins Centre and The Motor Accident Insurance Commission (Queensland), this systematic review examined the current research evidence regarding the efficacy of housing alternatives for adults with acquired brain injury (ABI) or spinal cord injury (SCI) in relation to four principal outcomes of interest: the person's (1) community integration/participation, (2) independence (including physical/cognitive functional recovery), (3) psychosocial well-being (including satisfaction, choice and control in decision-making, adjustment) and (4) quality of life. The review also sought to identify how the reported efficacy of the housing alternatives might be impacted by individual factors.

Overview

In Australia there is an estimated unmet need for suitable, affordable housing for between 83,000 and 122,000 people with significant and lifelong disabilities (National Disability Services, 2018; Wiesel & Habibis, 2015). People with ABI or SCI feature in these estimates (Wright, Colley, Knudsen & Kendall, 2019; Wright, Muenchberger & Whitty, 2015) and individuals with these conditions, require not only high levels of health care, rehabilitation and support, but also modifications to their home and/or living environment.

Adults with ABI or SCI aspire to live as independently as possible within the community, and it is widely acknowledged that living environments, housing design, location and the way people are supported, play a central role in well-being, mindset and the regaining of independence and autonomy.

There are a number of accommodation options in Australia for people with disability, including ABI and SCI, however, for many people with disability, where they reside often becomes a forced choice out of necessity.

This study reviewed the current research evidence surrounding the effectiveness of housing alternatives for individuals with SCI and ABI and grouped the accommodation options into the following categories: 'Home-like' settings (living at home alone or with partner, family, friends, relatives) and 'Non-home' settings, which can be broken down into 'Disability-specific' settings (group homes, foster care), or 'Structured' settings (residential aged care (RAC), nursing homes, slow-stream rehabilitation or long-term care facilities).

Returning to life in 'home-like' settings following an acquired brain or spinal injury, whilst preferred, requires careful planning and consideration, particularly during the initial recovery and rehabilitation period. Continued care and ongoing support is often required long-term, and more often than not, the original home requires significant modifications, which can put financial strain on families.

Whilst staying at home in privately owned/rented housing is often the preferred option, in many cases it is not possible, nor financially viable – depending on the level of acquired

disability (low, moderate or severe), aspects of recovery and outpatient rehabilitation, support services and care required, and home-modifications required to meet specific needs.

Where staying in the family (or pre-injury) home is not an option, the move into more adequately equipped 'disability-specific' settings, with higher care living arrangements may be necessitated. These accommodation settings are dependent on availability and suitability, including;

- Physically accessible social housing or public housing managed by Government departments,
- Accredited Specialist Disability Accommodation (SDA) funded through the National Disability Insurance Scheme (NDIS), typically owned by individuals or non-government organisations,
- Disability Specific (SSA) settings, including shared supported housing, apartments, cluster units and foster care homes, or
- Residential Aged Care (RAC), including high, nursing and long-term care facilities.





“ There is currently a strong focus in Australia on the provision of suitable, affordable housing for this population and on maintaining people’s right to choose where they live, and with whom. ”

Results

The research identified lower levels of community integration/participation, independence, psychosocial well-being and quality of life for adults (particularly younger adults) with ABI living in 'structured settings' (i.e., residential care) compared to those living in 'home-like' environments (i.e., private homes) and 'disability-specific' settings (i.e., shared supported accommodation, group homes, foster care homes, cluster units).

The findings also suggest that the SSA model is more suitable for young adults with ABI than RAC. It highlights that home-like and disability-specific settings may better support the independence and social participation of adults with traumatic brain injury (TBI).

The evidence indicated that 'home-like' settings (i.e., private homes) were associated with greater community integration/participation, independence, psychosocial well-being and quality of life, compared to 'structured settings' (i.e., RAC, residential care facilities, nursing homes).

'Disability-specific' settings (i.e., SSA, group homes, foster care homes, cluster units) were also associated with greater community integration/participation, independence (in relation to performing activities of daily living without difficulty) than 'structured' settings. Further, 'disability-specific' environments appeared to make independence and participation easier for people living in them, despite many people still experiencing social isolation.

Community integration/participation, psychosocial well-being (specifically, choice and control in decision-making), quality of life and the ability to live in 'home-like' accommodation with good quality and accessible design, in addition to having necessary supports and care, were areas that rated highly amongst participants of the studies included in the review.

Aspects that rated poorly, included RAC-style living arrangements and having limited opportunities to make everyday choices (i.e.: meal, bathing and bed times), feelings of isolation due to lack of, or restricted indoor and outdoor leisure time and social activities, lack of privacy and control over simple things often taken for granted, such as personal grooming, clothing and furnishing choices).

Conclusion

The findings of this review support international policies and practices that are focused on moving people with complex disabilities (particularly younger adults) out of RAC or preventing them from entering such settings in the first place, with 'home-like' and 'disability-specific' settings preferred as the more suitable alternative.

Overall, the study successfully uncovered many areas for future consideration and collaboration between key stakeholders, including policy makers, architects, designers, builders, developers, funding agencies, international researchers, as well as people with ABI or SCI and their families, who will no doubt benefit from the findings of this review.

Why this work is important?

Dr Grace Bitner, Research Fellow

This work draws much needed attention to the important role that the built environment plays in facilitating improved outcomes for individuals with disability in a number of important domains such as independence, community participation, psychosocial wellbeing and quality of life. Equally importantly, it highlights the need for more consistency in evaluating the impact of different housing typologies in which individuals live. As the authors highlight, "Uniform evaluation frameworks, methods and measures are urgently needed to consistently and rigorously evaluate the efficacy of housing alternatives for adults with ABI and SCI" (p.24).

This review provides an excellent springboard, from which we are able to launch much needed further research into the person-environment relationship for individuals with acquired brain or spinal injury, particularly those living in 'home-like' and 'disability-specific' settings in the community. While there has been a good deal of work on how structured settings like institutions impact on the daily lives, health and wellbeing of individuals, there has been considerably less work into 'home-like' and 'disability specific settings' within the community.

This work is even more critical at the moment, as the current COVID-19 pandemic highlights a range of existing and new challenges that individuals with disability (and their families) living in community settings face, such as the increased risks associated with private residences being both a 'home' and 'workplace' for paid caregivers. Several projects currently underway at The Hopkins Centre are delving deeper into the range of accessible housing options available for individuals with disability in Queensland, as well as looking at the complex interrelationship that individuals with disability and their families have with their home environments.

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