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Suggested citation:

Wright C, Muenchberger H, Whitty JA. The choice agenda in the Australian supported housing context: A timely reflection. [Accepted *Disability & Society* 2 Apr 2015] doi: 10.1080/09687599.2015.1038336 [Epub ahead of print]

The choice agenda in the Australian supported housing context: A timely reflection

Abstract

The last thirty years has seen significant developments in the Australian housing sector for people with disabilities. Despite much change in the sector, and advancements in disability services, the range of current supported housing options for younger Australian adults with a neurological disability remains vastly under-developed. This is despite a widely accepted and endorsed recognition that, as is the general population, people with *all* forms of disability have a right to housing of their choice. This paper presents a timely critique of the key actions made by the Australian disability and housing sectors and subsequently proposes a more informed approach to supported housing design and development: one that is based on a comprehensive understanding of consumer housing priorities and preferences, and is conducive to a person's biopsychosocial health.

Keywords: Housing policy; housing design; housing choice; physical disability; cognitive disability

The choice agenda in the Australian supported housing context: A timely reflection

Introduction

It is widely acknowledged that adults with acquired brain or spinal injury or progressive neurological illness (e.g., Multiple Sclerosis; Cerebral Palsy) incur significant housing challenges post diagnosis (Cameron, Pirozzo, and Tooth 2001; Foster, Fleming, and Tilse 2007; Nalder et al. 2012). Due to the complex physical and/or cognitive nature of their condition, individuals living with a neurological disability often require assistance with activities of daily living (ADL) and personal care. This has direct implications on the type of housing they require in the long-term, and differentiates their housing need from other disability types. The housing challenges experienced are reflective of a broader and persistent issue relating to housing availability as well as the problem with housing suitability. In the case of acquired neurological injury, once the person is deemed medically stable by a physician or able to function semi-independently, arrangements are made to refer the person back to: (a) their family home, where the infrastructure often requires modifications; or (b) some form of supported accommodation or residential care facility (in instances where the family home is not an option) to continue their care and support as needed during this initial recovery period (Beer and Faulkner 2008; Cameron, Pirozzo, and Tooth 2001; Foster, Fleming, and Tilse 2007; Nalder et al. 2012). Similarly, adults living with a neurological disability or progressive illness since birth or childhood often reside in the family home much longer than a person of similar age without a disability (Australian Bureau of Statistics 2009). This is, in part, due to the lack of suitable housing alternatives currently available to support the person in living away from family.

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Whether the person's neurological disability is acquired or developmental in nature, individuals are usually faced with two scenarios relating to their long-term housing situation: (1) stay at home with family indefinitely, though this often increases pressure on families and may not be the person's preferred option (Beer and Faulkner 2009; Buhse 2008; Carnes and Quinn 2005; Harrell, Kassner, and Figueiredo 2011); or (2) move out of the family home into physically accessible social housing that is typically managed by government housing departments and housing services (Beer and Faulkner 2009; Saugeres 2011). Group homes are the dominant housing model under this scenario, due to cost efficiencies and the lack of physically accessible housing stock. Sadly, private housing is often not an option for those with a physical disability, due to its physically inaccessible or unaffordable nature (Australian Housing and Urban Research Institute 2007; Australian Network for Universal Housing Design and RI Australia 2014; Robst, Deitz, and McGoldrick 1999; Saugeres 2011). For younger adults aged under 65 years (i.e., pre-retirement age and therefore considered 'too young' to occupy residential aged care), a prolonged stay or relocation back to the family home, or placement in a group home or care facility – where these settings are not their preferred living environment – is a depressing, and isolated experience that represents a loss of independence, autonomy, control and choice (Bostock and Gleeson 2004; Cameron, Pirozzo, and Tooth 2001).

While more contemporary, individualised, supported living options may be more appropriate for the person and their family, supported living dwellings are often not readily available or physically accessible for younger adults with a neurological disability. Further, there is little evidence currently available to support their use. This is due to much of the existing literature: (a) focussing on traditional group home models or cluster settings at the expense of other design alternatives; and (b) failing to provide 'strong' evidence regarding the

impact different housing models have on resident outcomes (Callaway et al. 2013; Winkler, Farnworth, Sloan, and Brown 2011). This lack of information has, in part, supported (by not challenging) the ‘one-size-fits-most’ near-monopoly market currently occurring in parts of Australia. The near-monopoly market describes an over-reliance on the traditional group home model (outside of the family home) by the State, non-government organisations (NGOs) and not-for-profit housing agencies, which has resulted in limited housing design alternatives (see Figure 1). Although it has been reported that there is no single or ‘one size fits all’ housing solution (Sloan et al. 2012; Taleporos et al. 2013), consumers and disability advocates have strongly championed the need for greater choice when it comes to their housing options.

[PLEASE INSERT FIGURE 1 APPROXIMATELY HERE]

In response to the increasingly recognised importance of consumer housing choice in Australian political and legislative narratives for all people with disabilities¹, two sectors have been key drivers of movements to translate choice policy into practice: (1) The Disability sector, and (2) the Housing and Construction sector. Indeed, the Disability sector has reframed and redefined the nature, provision and financing of social services provided to individuals with a disability (Foster et al. 2012) with movements such as decentralisation of the disability service system and an increased focus on person-centred service delivery. With similar intent, the Housing and Construction sector has responded to the choice agenda by focussing on housing

¹ E.g., Australia’s ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; United Nations 2006), the National Disability Agreement (Council of Australian Governments, 2012) [Commonwealth], the Disability Discrimination Act 1992 [Commonwealth]; the Disability Services Act 1986 [Commonwealth], the National Disability Insurance Scheme Act 2013 [Commonwealth], and the Guardianship and Administration Act 2000 [State of Queensland]

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design for people with physical accessibility needs: the introduction of international Universal Housing Design guidelines (Australian Institute of Health and Welfare [AIHW] 2011; Commonwealth of Australia 2009; Livable Housing Australia 2012; NSW Department of Ageing, Disability and Home Care 2009; PricewaterhouseCoopers [PwC] 2011). Although these initiatives align with the aspirations and desires of individuals with disabilities to increase their choice and control over their own residential arrangements, a disconnection between housing choice policy and practice has remained.

The current article presents an informed insight into the Australian housing choice agenda, and identifies the implications of this agenda for younger adults with a neurological disability. As will be shown, a number of factors have determined individuals' living situation, including challenges regarding policy implementation, failure to penetrate market mechanisms to stimulate greater accessible housing, and the absence of a comprehensive approach to housing provision that systematically involves consumers in early design processes. With the lack of suitable, long-term residential options remaining a significant issue in Australia (Commonwealth of Australia 2009), this timely contribution to the field highlights the need to develop innovative housing design alternatives that are: (a) based on user housing priorities and preferences; and (b) conducive to a person's biological (physical), psychological and social (often termed 'biopsychosocial') health. To place the housing choice agenda into context, the systemic and community factors contributing to supported housing outcomes in Australia will first be discussed.

Systemic and community factors contributing to housing outcomes

As the group home model has emerged (post-deinstitutionalisation²) as the blueprint underpinning Australian social and disability housing, group home placement is particularly likely for younger adults with a neurological disability wishing to live in the community. Indeed, there is evidence to suggest the group home model can lead to good social participation and quality of life (QOL) outcomes for residents with a severe or profound disability (see Clement and Bigby 2010; Felce 1989; Kozma, Mansell, and Beadle-Brown 2009; Lamontagne et al. 2013; Mansell et al. 1987; Sloan et al. 2012). However, research also suggests outcomes are variable and dependent primarily on the person's adaptive skills and degree of disability, the staff practices implemented, and the culture developed both within the dwelling and service organisation as a whole (Author's Own 2013; Bigby 2012; Bigby et al. 2012; Clement and Bigby 2010, 2012; Kozma et al. 2009; Mansell et al. 2008). For example, poor staff and organisational practices that employ a custodial approach to service delivery rather than an approach that places the person in the centre (and in control) of their living arrangements has been described as creating 'a smaller-scale version of the large residential institutions of the past' (Mansell 2009, p. 12). In addition, the group home model is viewed by some younger adults with a neurological disability as an 'only option' or a stepping-stone to independent (supported) living. Thus, the group home model is not preferred by everyone (Bergmark, Winograd, and Koopman 2008; Ownsworth et al. 2004). What remains is a dominant housing model that when managed well, has the potential to deliver positive outcomes for younger adults with a neurological disability.

² Deinstitutionalisation refers to the active removal of people with disabilities from large institutional facilities into the community since the 1980s. Although not discussed here, deinstitutionalisation led to major reforms in Australian community residential services and supports.

However, given its current dominance in the market, the consumer is unable to choose an alternative housing model if desired because few (validated) options exist (Author's Own 2013).

A combination of systemic circumstances has resulted in an overreliance on the group home model in Australian social and disability housing at the expense of other design alternatives. First, a shortage in the supply of physically accessible dwellings in both the private and public housing sectors (Australian Network for Universal Housing Design and RI Australia 2014; Saugeres 2011) combined with cost-efficiencies (i.e., economies of scale) has fostered collective living arrangements. It is not uncommon for people with a similar degree of physical and/or cognitive disability, and therefore similar level of care needs, to have been grouped together to share their housing support packages and staff (Bostock et al. 2001; Taleporos et al. 2013). The combination of these circumstances has resulted in a crisis-driven, needs-based, vacancy allocation system that seems more service determined than consumer-driven. As Wiesel and Fincher (2009) highlight, the rhetoric of housing choice appears to have transpired as a principal concept after community-based models had already become standard in Australian disability services (post-deinstitutionalisation).

Societal factors have also contributed to residents' housing outcome. For instance, the prejudicial attitudes of some local community members regarding the nature of disability facilities and the people who use them have resulted in some neighbourhoods opposing housing for people with disabilities in their area (Bostock and Gleeson 2004; Wiesel and Fincher 2009). While this intolerance has not prevented the State, NGOs, or not-for-profit housing agencies building some physically accessible dwellings in central locations, it is possible these prejudicial attitudes of some (not all) local residents has made community integration for younger adults with a neurological disability difficult. As Winkler, Farnworth, Sloan, and Brown (2011)

suggest, being physically located within a community does not necessarily result in community participation: 'Assisting people with high care and complex needs to be included in the mainstream of society is a challenging area of work that requires tenacity because relationships are not always spontaneously formed' (p. 161). This situation suggests considerations for suitable, long-term housing options must extend beyond the dwelling itself, and consider residents' location and neighbourhood context.

The Australian disability sector: Response to choice policy

Decentralisation movement

Historically, Australia has attempted to enact greater consumer choice and control (and less centralised responsibility) for people with disabilities through: (a) outsourcing housing and support services to the not-for-profit sector, and (b) separating housing and support services to safeguard vulnerable individuals. According to Wiesel and Fincher (2009), these initiatives aimed to increase the range and quality of services available to consumers by challenging the monopoly of service provision held by the State. The initiatives also aimed to enhance consumer choice by promoting competition amongst service providers rather than Governments being responsible for and facilitating a 'one-stop-shop' for housing and support (Wiesel and Fincher 2009). However, implementation of both decentralisation initiatives have had little impact in increasing consumer housing choice, especially for younger adults with a neurological disability (Bigby and Ozanne 2001; Bostock and Gleeson 2004; MacKinnon and Coleborne 2003; Wiesel and Fincher 2009).

Although it is likely that there are a number of individual agencies providing quality accommodation for adults with complex disabilities, 'new' housing models developed through

outsourcing are at risk of maintaining institutional practices and structures (Author's Own 2013; Bigby 2012; Bostock and Gleeson 2004; Mansell et al. 2008). Most importantly, consumers have had limited *systematic and early* input in developing innovative housing design that goes beyond meeting their physical accessibility needs (Commonwealth of Australia 2009; Heywood 2004; Imrie 2004; King 1996).

Further, disability agencies have tended to focus on the nature of social, financial and therapeutic supports required by individuals living in the community rather than the built environment residents will call 'home' (Author's Own 2012; Bostock and Gleeson 2004; Wiesel 2011). This service approach reflects a lack of collaboration and communication between different providers and highlights the silos under which the Australian disability and housing sectors have continued to operate (Bostock and Gleeson 2004; Foster et al. 2012; Parker and Fisher 2010; State of Victoria, Department of Human Services 2003).

Person-centred practice and its impact on housing

Widely accepted as best practice (Sanderson, Thompson, and Kilbane 2006), a person-centred approach places the person with disability at the centre of decision-making when it comes to the supports and services they use. Rather than regarding independence as physical capacity to carry out particular tasks or intellectual capacity to understand existing options (or to express a preference), person-centred service delivery views independence more broadly in terms of having choice and control (Morris 2004; Wiesel and Fincher 2009). While shifting the balance of power from professionals and agencies to the person (see Table 1), people with disabilities are provided individualised assistance and support to make an informed choice (National Insurance Disability Scheme Act 2013, NSW Department of Ageing, Disability and Home Care 2009; Wiesel and Fincher 2009). The translation of person-centred policy into practice is evidenced by

the current emphasis on individualised support plans and funding packages (also referred to as ‘direct payments’) in the National Disability Insurance Scheme (NDIS) to be rolled out in full across Australia by 2019.

[PLEASE INSERT TABLE 1 APPROXIMATELY HERE]

Individualised support plans and funding packages

Individualised support plans and funding is advocated as a means for service users to determine their own housing and support packages. In this way, funding is attached to the individual instead of a service agency, allowing the person to ‘choose for themselves the type of housing that they want (and can afford) and the types of supports they wish to use within the range of available options, just as any other member of the community’ (Sach and Associates 1991, 8, cited in Bostock and Gleeson 2004). While the promotion of individualised support plans and funding does embody a shift in control from the professionals to the person, cost ceilings have previously prevented some individuals from receiving the level of funding they require to be supported in the home of their choice (Lord and Hutchison 2003; Morris 2004).

Specifically, the direct payment initiative in Victoria, Australia (prior to the commencement of the national NDIS scheme) was seen to be more successful in increasing housing choice for people with lower support needs over those with more complex support needs. An example from Victoria highlighted the larger funding packages offered to those with lower levels of support need to assist them in moving out of groups homes, to allow more people with high support needs to move in (Wiesel and Fincher 2009). Younger adults with a complex disability were therefore at risk of continued categorisation into specific housing models – the

group home – even with individualised funding policies in place. Given that the NDIS is currently being trialled in sites across Australia, further research is needed to evaluate the impact individualised support plans and funding packages (under the NDIS scheme) have had on increasing consumer housing choice, especially for younger adults with a neurological disability.

The Australian housing and construction sector: Response to choice policy

Promotion of universal housing design principles and guidelines

With the number of individuals living with a disability viewed as a ‘minority’ population in Australia, the physical design of most dwellings does not cater to the needs of individuals who sit ‘outside the norm’ According to Imrie (2004, 685),

The physical design of dwellings is not well suited to [the] needs [of people with physical disabilities] for access into, and ease of movement about and use of, domestic spaces.

Rather, most domestic design is premised on the production of dwelling spaces to facilitate use by people without bodily impairments.

Existing mainstream housing stock (i.e., villas, apartments, private rental, purchase housing) therefore prevents many younger adults with a physical disability from physically accessing more individualised accommodation. This situation directly contributes to the shortage of suitable housing stock in Australia, impacting consumer housing choice by limiting the number and variety of potential dwellings that may accommodate individuals. This housing shortfall has significant repercussions for the ‘minority’ population, given that roughly 4 million Australians, or 20% of the population have a disability and nearly 1.3 million people have a profound or severe disability (PwC 2011, 11; AIHW 2013).

In joining with international trends, Australian governments began producing and implementing design guides, codes of practice and/or statutes based on the seven Principles of Universal Design (applied to housing; see Appendix A) to guide the production of more physically accessible dwellings. In the absence of a national focus however, Australian State, Territory, and Local governments and councils had established inconsistent Universal Housing Design guidelines (Office of the Public Advocate – Queensland 2005; Saugeres 2011). Subsequently, the Australian Government committed \$1 million seed funding over three years (2011-12 to 2013-14) to support the Livable Housing Design Initiative. This national framework aims for all new residential dwellings across Australia to be of an agreed Livable Housing Design standard by 2020 (Australian Government Department of Families, Housing, Community Services and Indigenous Affairs 2010; Livable Housing Australia 2012).

Due to a perceived lack of consumer demand however, the voluntary nature of the Livable Housing Design guidelines has been met with resistance to implement by the Housing and Construction sector (Australian Network for Universal Housing Design and RI Australia 2014). In May 2014, approximately 294 new dwellings were registered as having been built to Universal Housing Design specifications. This is in stark contrast to the agreed target: 25% of all new residential dwellings (approximately 35,000 dwellings) by 2013 (Australian Network for Universal Housing Design and RI Australia 2014). This slow uptake by the Housing sector has meant a greater number (and variety) of physically accessible dwellings remain unavailable to younger adults with a physical disability. This situation therefore perpetuates the reliance of younger adults with a neurological disability on the State, NGOs and not-for-profit housing agencies for housing and support.

As confirmed by the Social Determinants of Health and Environmental Health Promotion Framework (Schulz & Northridge 2004), multiple factors within the broader built environment influence residents' biopsychosocial health and wellbeing. Despite the intuitive benefits of a nationally recognised accessibility design standard, the use of Livable Housing Design guidelines is limited because of the narrow focus on the functional (i.e., physical accessibility) aspects of the dwelling and lack of attention to broader behavioural and psychological impacts of place, which is now well reported in research (see Author 2012; Carr et al. 2011; Clark and Kearns 2012; Curtis et al. 2007; Dyck et al. 2005; Kyle and Dunn 2008; Shultz and Northridge 2004; Wister 2005). The following examples highlight the important contextual factors that research suggests should also be considered in a more comprehensive approach to housing: (1) information regarding additional housing design features (beyond physical accessibility) that might improve residents' 'social, psychological, spiritual ... and behavioural components of health ... [necessary for the] stimulation of healing and the achievement of wholeness' (Jonas and Chez 2004, S1; Imrie 2006); (2) the social and care environment (i.e., appropriate tenancy arrangements; non-family paid carer characteristics; nature of support packages; care design features that promote efficiency of care; Parker et al. 2004; Ulrich 2000, 2006; Young People in Nursing Homes National Alliance and Monash University 2014) for individual residents; (3) housing affordability and tenure (Johnson, Parkinson, and Parsell 2012; Tsemberis, Gulcur, and Nakae 2004; Victorian Coalition of ABI Service Providers Inc 2014; Wiesel and Fincher 2009); and (4) community participation and access (Dyck et al. 2005; Schulz and Northridge 2004; Wagemakers et al. 2010; Young People in Nursing Homes National Alliance and Monash University 2014).

A new way forward: A consumer-driven, environmental approach to innovative supportive housing design and development

Despite a commitment to the internationally renowned United Nations Convention on the Rights of Persons with Disabilities (United Nations 2006), widely endorsed legislation, a significant restructure of the social and disability service system, as well as a push for national Universal Housing Design guidelines, Australian adults with complex disabilities have been inadvertently disadvantaged by the housing agenda (Wiesel and Fincher 2009).

Although Australian authorities recognise the importance of providing alternative housing models (choice) to consumers with a disability, a combination of circumstances has prevented authorities from implementing innovative housing design and alternative housing models for this population. These circumstances include:

1. A continued shortage of physically accessible housing stock;
2. Cost efficiencies related to communal living;
3. Limited evidence regarding the impact of different housing models on resident outcomes;
and
4. The absence of a comprehensive approach to housing that conceptualises consumer priorities and preferences in relation to broader contextual determinants of health and wellbeing (e.g., psychological, physical, emotional and social health). Such a framework would guide the development of innovative housing design alternatives that are not only based on consumer needs and wishes, but that are also conducive to a person's wellbeing.

To address the shortage of physically accessible housing stock, a number of advisory authorities have called for universal housing design guidelines to be mandated and regulated to ensure implementation (Australian Network for Universal Housing Design and RI Australia

2014; Disability Investment Group 2009; Queensland Action for Universal Housing Design n.d.). While increasing the number of physically accessible dwellings is needed in Australia, addressing physical access issues forms only part of, rather than the whole, of the improved housing picture. According to Heywood (2004), a 'full understanding' of the needs and experiences of consumers is imperative in any residential design and development process. Consistent with person-centred planning, the user must be at the centre of the approaches to innovative housing design and be driving that process.

A contemporary approach to new housing development therefore requires a change to the current model so that the voices of consumers are no longer incorporated superficially into design processes. Thus, person-centred approaches recognize that developing innovative housing design to address the residential needs of people with disability is best met by the consumers themselves (Williamson 2006). One way to meaningfully engage consumers in developing innovative housing design is to systematically investigate their housing priorities and preferences. Demonstrating the goods or services consumers prioritize is better able to inform market decisions around viability and consumer value than an approach broadly asking individuals what they 'want'.

In addition, new housing initiatives in disability ought to consider a person's biopsychosocial needs, indeed as an integration of components rather than separate entities (Antonovsky 1996; Eriksson and Lindström 2008). As an environmental lens to residential development recognises that there are physical, psychological and social components of environments and that these elements interact to affect the biopsychosocial health of individuals (Wister 2005), consumer priorities and preferences ought to be guided by an environmental approach to housing development to ensure innovation does not compromise residential quality.

An environmental approach to housing for people with disabilities would integrate considerations regarding the design of the dwelling, its location, and neighbourhood context across the person's built, social, and care environment. Investigating consumer priorities and preferences underpinned by such an approach would redefine the minimum standard of housing for people with disabilities. Indeed, this improved standard would likely ensure the future development or re-development of housing alternatives are meaningful to users, market-relevant and be of a standard conducive to biopsychosocial health and wellness.

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