Creating Sustainable Futures for Queenslanders with Intellectual Disability

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Summary:
Our current research is investigating, which types of neighbourhood best support independent living for adults with intellectual disability. These adults have the very real prospect of outliving their parents, and this is causing significant stress for families when considering accommodation and housing options. Adults with an intellectual disability should not be forced into inappropriate housing options, such as aged care or group housing if they do not wish. Everyone has a right to housing choice. Indeed a United Nation’s Convention establishes that “Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living” (United Nations, 2006 p 13). Not all neighbourhoods are equal, and our research is exploring which neighbourhoods and the characteristics of them that may best suit ongoing independent living. Through collaboration involving adults with intellectual disability, their families, government and the industry we are delivering a practical framework which will support decision-making for the design, redesign and choices options of neighbourhoods and housing when it comes to better supporting the future lives of everyone in our community.

The following dot points provide an overview of the findings of our research to date.

- It is critically important to understand where the housing is rather than just the type of housing to be provided.
- Adults with intellectual disability and their families would prefer housing located within a familiar location within 5-10km of the family home.
- Housing is best located in a street that provides a sense of community where neighbours can interact safely and look out for each other.
- Housing is best located in a neighbourhood that has access to or public transport providing access to employment, recreation and basic services.
- Our model for the assessment of neighbourhood suitability for housing is under development and cooperation with the Queensland Government would be welcomed.

Neighbourhoods and Housing for Adults with Intellectual Disability

In Queensland adults with intellectual disabilities, their parents and housing providers are struggling to find housing solutions that will enable independent living opportunities for intellectually disabled adults who wish to, or need to, live away from the family home. Looking to the future this problem will be intensified in the knowledge that advances in medicine indicate that these adults will often outlive their parents and carers (Wiesel and Habibis, 2015, Wiesel and Fincher, 2009, Grey et al., 2015, Bibby, 2013).

In 2016, an estimated 27,000 Queenslanders aged 18-40 years old who have an intellectual disability may be seeking to live independently and safely outside of the family home. International best practice scenarios suggest dispersed housing in neighbourhoods that provide a range of affordable housing, in safe, accessible neighbourhoods that enable connectedness to community will provide ultimate opportunities for this group of people.
At present there is a lack of theoretically grounded analyses to inform all stakeholders with regard to the most appropriate locations for the delivery of housing developments that foster independent living opportunities for adults with intellectual disability. Housing providers and financiers require empirical frameworks in order to develop and understand the ideal housing locations for this client group.

Our current research and ongoing research agenda is seeking to determine those neighbourhoods most suitable for independent living. The investigation will determine the significance and role planning policy has in the provision of these neighbourhoods and provide a framework for their assessment and any required adaptation to establish them as safe and equitable housing locations.

Following is a summary of the empirical information that should influence the Queensland Housing Strategy so that people with intellectual disability might live independently in the community.

**Housing needs of adults with intellectual disability**

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities states that persons with disabilities should have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others, and not be obliged to live in a particular living arrangement (United Nations, 2006). As such, Queensland adults with intellectual disability and their carers are seeking housing provisions that are more aligned with the general population. They do not want to end up in aged care homes (Dunlevy, 2015).

*Inclusion is the key*

Without the presence of the adult with intellectual disability in the macro level decisions of policy and procedure and at the micro level of housing placement, tenancy options and individualised support, community inclusion will not be achieved (Bigby, 2004). Bostock and Gleeson (2004) recognise the great efforts that Queensland policy makers have gone to consult with local communities about future plans to site community care homes in their neighbourhoods. However the consultation has not necessarily included the voice of persons with intellectual disabilities.

**Tenancy options**

Tenancy and tenure options present as a barrier to independent living for adults with disabilities in Australia. Persons with a disability are likely to be under-represented in the owner-occupied sector, over-represented as social renters and not have a large share of private tenancies (Hemmingway, 2014). Berry et al. (2006) believe that Australian State governments have three major roles in addressing the tenancy issue for persons with disabilities:

They must first separate rent determination from individual incomes within the social housing system. Secondly, they must restructure their own assets (possibly through transfer or internal reorganisation) to allow existing assets (including land and infrastructure as well as housing) to be recycled in such a way that asset values rise. This will enable private funding to be levered in and asset management skills to be developed. Thirdly, they must put in place land use planning arrangements which make it easier to ‘tax’ development gains by requiring land and finance for affordable housing (Berry et al., 2006).

These elements of change will not alone deliver successful housing options and community connectedness. Client outcomes, administrative systems, service viability and coordination of support providers are also listed as areas where adults with intellectual disability need to be consulted and included in policy decisions (Fisher et al., 2009).
The place’s physical setting

Whilst a home means different things to different people it often means more than a shelter or a physical space, especially for those with an intellectual disability (Hemmingway, 2014). “A person’s home is a sanctuary, a place for rest, for socialising with friends and sharing life with significant others. It is an important platform for life in the community” (Taleporos et al., 2013 p 8). Childhood experiences underpin much of the wants of young adults seeking to leave the family home (Leiter and Waugh, 2009). It is a challenge for us all to temper wants with needs, however in order to change a person’s life their space should be first considered (Lefebvre, 1991).

Access is a major issue for everyone in deciding where to live. Accessibility is more than the dwelling itself as it can include access to the local environment, public services and amenities and good transport links (Hemmingway, 2014). Being able to maintain connections with family, friends and community activity are access considerations linked to the physical setting. It is in the street and neighbourhood in which social inclusion occurs (Bigby et al., 2015). Places and spaces that exclude disabled people are rarely natural, rather are a result of state policy, building regulations and architectural and planning practices (Imrie, 2001).

Activities, situations and events

Places where community members gather to associate, share stories and meet a diverse range of people is also an important consideration when a person is choosing where to live. The same is true for adults with intellectual disabilities and such place destinations should include, for example, cafes, coffee shops, beauty parlours, bars, community centres, and many family-owned shops or enterprises where “regulars” hang out, gossip, and socialise (Amado, 2014, Milner and Kelly, 2009).

Places that promote a sense of membership and belonging, besides formal and informal groups, are community places that are welcoming, where an interest can be shared and a place where people with disability can assist, volunteer or have a meaningful role (Amado, 2014). However, these places also need to avoid creating an area of concentration of people with disability (Bigby et al., 2015, Tually et al., 2011). When determining locations for suitable housing to provide independent living opportunities organisations, housing providers and ‘gatekeepers’ attitudes, assumptions and practices may just be as disabling as the physical and financial environment (Hemmingway, 2014).

Supportive communities for people with intellectual disability

In general, research indicates that dispersed housing in the community provides a better quality of life and is at least as cost-effective as institutional and larger group care (Bigby et al., 2015, Taleporos et al., 2013). Overwhelmingly, “the evidence points to community settings being preferable to institutional ones for most individuals with an intellectual disability” (Taleporos et al., 2013 p 11). The importance of community inclusion is acknowledged as essential for self-worth and social wellbeing (Bigby et al., 2015, Bigby and Fyffe, 2009).

In comparing dispersed, clustered and institutionalised accommodation the housing needs for adults with intellectual disability is much the same for all young adults leaving the family home for the first time (Mansell and Beadle-Brown, 2009a, Mansell and Beadle-Brown, 2009b). Parents and the adults with intellectual disability both identify as significant factors the: desire for quality housing, a range of housing, location of the housing to allow for easy access to shops, services, employment, further education and the ability to maintain social networks within the general community (Cooper-Stanbury, 2012, Hutch et al., 2011, Shaw et al., 2011, Taleporos et al., 2013).

The community placement of housing is crucial. Bullying and high incidents of crime against people with disabilities are cited as some outcomes of disability housing in social housing estates that lack mixture of tenure overall (Aspis, 2005). Facilitating education within a community, and identifying
appropriate supportive communities to help residents understand and value the social capital an adult with intellectual disability brings to a community, is an important factor to achieving inclusion and connectedness opportunities (Bostock and Gleeson, 2004, Onyx and Bullen, 2000).

Wiesel and Fincher (2009) warn against the fostering of community members to have the right to choose not to accept tenants with a disability. “A focus on choice in the context of an excluding community may actually undermine real individual choice for people with intellectual disabilities, as the community has more power to execute its choices than a person with a disability” (Wiesel and Fincher, 2009 p 11). The NIMBY syndrome should not be allowed to interfere with the best placement of dispersed housing, especially if it is due to communities being poorly educated about what people with disabilities can bring to a neighbourhood (Bostock and Gleeson, 2004).

**Key points for the Queensland Government Housing Strategy**

The research to date indicates that the location of housing, after adequate funding, is the major factor in the success of independent living for adults with intellectual disabilities. As long as the dwelling was appropriately designed and amenable the type of housing was less important.

Interview recipients cite suburbs within a 5-10km radius proximity to the family home in safe streets that afford interactions with neighbours and other residents as ideal locations. Access to public transport, employment opportunities, commerce, retail, medical and recreational facilities are identified as enhancing the independent living experience. Parents were determined that the independent living opportunity still allow for the adults to engage in the education and recreational activities that they need to continue to learn and be active members within society.

Those families interviewed who have established successful independent living identified many of the characteristics of a cul-de-sac as preferable neighbourhood criteria. The perceived amount of traffic and traffic movements in a dead-end street were nominated as key points. The high visibility of the houses from the street which allowed neighbours to see people arriving and leaving and the chance to interact as people walked past provided an added safety for the adults with intellectual disability and their parents/carers.

Sense of community was a high priority for those interviewed. The advantages of seeing people in their front yards was important for the parents of adults with intellectual disability. The convivial interactions provided within a neighbourhood have been identified as extremely important factors in the independence of this group of people (Wiesel and Bigby, 2016).

The walkability of a neighbourhood then becomes an important factor in the success for independent living opportunities. The positive encounters a person has with their neighbours has been recognised by those interviewed as extremely important for the success of the away from home experience.

References:


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