

POSITION STATEMENT ON HOUSING AND SUPPORT FOR PEOPLE WITH INTELLECTUAL DISABILITY AND HIGH, COMPLEX OR CHANGING NEEDS.

Christine Bigby & Chris Fyffe on behalf of the Annual Roundtable on Intellectual Disability Policy in Victoria.

Preamble

The Annual Roundtable on Intellectual Disability Policy in Victoria, aims, "To provide a space for fearless debate, among interested groups, about policy within both the disability and the broader human service sectors for people with intellectual disabilities, with the intention of naming issues, clarifying concepts and ideas, exploring challenges, articulating solutions and informing practice".

The theme of the 2007 Roundtable was housing and support for people with intellectual disability and high, complex or changing needs. These people are some of the community's most vulnerable members in terms of the likelihood of them being supported to experience ordinary life. The topic was chosen to draw attention to the potential exclusion of this group in the implementation of visionary disability policy unless specific attention is focussed on them, and because housing and support continues to be the greatest, and most fundamental area of unmet need for people with intellectual disability. The rights of people with disabilities, in common with other citizens, are legislated through various State and Commonwealth acts pertaining to equal opportunity, anti discrimination and disability-specific legislation. There are also various state and national service standards. However, history has shown that legislation and service standards will not guarantee enactment of these rights or the quality of services.

This position statement was developed collaboratively by members of the Roundtable. It attempts to set out what people with intellectual disability and high, complex or changing support needs might expect in terms of housing and support if the principles embedded in the current disability legislation and the Victorian State Disability Plan are implemented. It highlights the issues that require particular attention for this group, as well as the majority of issues that they have in common with people with lower support needs. These issues are expressed primarily in

terms of the individual rather than the shape or nature of the service system which is the means to achieve these outcomes. The components of housing and support described are in many ways common for all people with disabilities, however, without specific representation, people with the highest housing and support needs are relegated to inappropriate living arrangements. Without somewhere to live with sufficient support, aspirations about empowerment, community inclusion and participation are meaningless.

Who are we talking about?

This paper emphasises issues for people with an intellectual disability who cannot easily or safely make life's major, and sometimes daily, decisions without significant assistance or representation by another person. In terms of measures such as the Supports Intensity Scale (Thompson et al., 2004) and Inventory for Client and Agency Planning (Bruininks et al., 1986); people in this group require a frequent and high volume of support across a number of life areas including personal or attendant care, assistance with daily living tasks, assistance with decision making and close monitoring of health and wellbeing. This group of people has severe or profound intellectual impairment, typically including difficulty with cognition, communication, comprehension, problem solving, memory, as well as often physical and sensory impairments or behaviour or health support requirements. Their exercise of choice or participation in activities is dependant on the presence of opportunities to be involved and the availability of appropriate assistance to engage in these activities. They also require frequent contributions from a substitute decision maker who knows them well and/or proxy representation in daily and major life decisions. Such representation is needed systemically as well as individually.

While acknowledging people's strengths, people with high and complex needs will always require housing and support and will be reliant on the specialist disability service system in some way for that support. These individuals are unlikely to be left out of the service system as they are dependant and vulnerable, and have no other options apart from family, who will usually find it difficult alone to provide support. These people aren't able to use mainstream services in the same way as people without disabilities and frequently mainstream services will not, or cannot, make suitable adaptations to ensure physical, cognitive and sensory access. There is a tendency for family, community members, managers and support staff alike to struggle with what inclusion and participation mean for these individuals. As a consequence these goals are viewed as less feasible or irrelevant, which further disadvantages this group of people.

Research shows that people with intellectual disabilities and complex support needs receive inferior support in terms of enabling demonstration of strengths, maximizing choice and for inclusion and participation compared with those who are more able. Small scale shared housing, and at times larger congregate arrangements, have continued to be the only housing options offered to this group. Due to their high cost support needs or

requirements for modified housing designs that include safety features such as sprinklers, they are excluded from the range of innovative community-based housing and support options being developed. Such innovations use a combination of affordable social housing developments, through the Disability Housing Trust or other community housing organizations, and funding for individualized support from disability services.

Research Findings: Deinstitutionalisation, congregate care and community living.

There is no evidence supporting congregate living arrangements for people with intellectual disabilities, in contrast with community-based housing and support.

Emerson & Hatton (1996 & 1996b) reviewed effects of deinstitutionalisation between 1980-1994 in UK and Ireland based on 71 publications. Findings were that smaller, community-based residential services were generally, though not inevitably, associated with:

- increased user engagement in ongoing activities
- increased contact from care staff
- increased use of community facilities
- increased adaptive behaviours
- reductions in observed challenging behaviour
- increased opportunities for choice
- increased contact with family and friends
- a better material standard of living
- increased acceptance from the community.

All of these outcomes had been found to be deficient in institutional settings.

"While the reasons for deinstitutionalisation are complex and vary across political contexts, one common factor is the embrace of the concept of normalisation and the rejection of segregation of people with intellectual disabilities from the rest of society. Institutions became both the symbol and the instrument of separation and consequent stigmatisation of people with an intellectual disability." (Bradley, 1996).

There can be no doubt, in general, that people with an intellectual disability benefited from deinstitutionalisation (Mansell & Ericsson, 1996). The appalling conditions in USA, UK and Australia are almost gone - "institutions are in terminal decline."

It has become apparent that physically closing institutions does not guarantee against the re-emergence of so called "institutional" practices or ensure improved client outcomes (Felce, 1996; Mansell & Ericsson, 1996). Low engagement of clients in meaningful activities has persisted in community houses (Mansell, 1996) and increasing staffing has not automatically increased levels of staff-client engagement (Felce, 1996). The amount of time available to consumers has been shown to be unrelated to the number of carers, unless consumers were supported in very small groups of 1-4 clients. People with higher support needs have been found to have typically received less staff time (Felce, 1996). The best of community living requires careful and sustained implementation and monitoring strategies.

Position statement on housing and support

A person with intellectual disability and high, complex or changing support needs should be able to expect standards and outcomes for housing and support that are equal to that of people with less severe disabilities and wider community members.

Arrangements for structuring housing and support, and allocating funding should achieve:

- A partnership between formal and informal supporters, without placing an undue burden on family before access to formal support can be gained.
- People being able to live alone or share a small household with others with whom they have a common interest, life pattern or friendship.
- Forms of housing that are people's homes and are the same as those available in the general community.
- Decisions about housing and support that are interdependent and ensure coordination of support around the individual.
- Opportunity for changes to daily life patterns.

- Opportunity to use local services, public spaces and be included in the social, economic and spiritual life of the local community.
- Sustained involvement in their life of at least one person from outside the service system who can help raise issues of concern and give voice to their interests and involvement in the everyday running of their household.
- Resources allocation that is proportional to support needs.

Arrangements for structuring housing and support, and allocating funding should NOT mean that:

- People with the highest support needs experience the worst, most restrictive, most outdated or most unstable housing and support arrangements
- People live in congregate living arrangements or facilities.
- People are required to move as their support needs change.
- Residential aged care is the default solution for people with increasing support needs.
- People live with others with whom they have nothing in common.

Components of housing and support

<p>1. Planning and decision making <i>Timely and coordinated</i></p>	<ul style="list-style-type: none"> • Timing of support decisions should assist, and not put at risk, access to housing. • Support is not tied to a particular place of residence. • Individuals are not forced to move as their needs change.
<p><i>Planning over a life time</i></p>	<ul style="list-style-type: none"> • Long term plans are developed with regular reviews. • Allocation of resources takes into account long term costs and benefits not just 'snap shot' costs. • The impact of decisions on others are explicitly considered and taken into account.
<p><i>Rationale for resources allocation</i></p>	<ul style="list-style-type: none"> • Transparent and inclusive of family and advocates, and all providers. • Resources allocation is proportional to support needs. • Not tied in to access to services. • Cost is not a basis for refusal of housing or support.
<p>2. Decisions & advocacy</p>	<ul style="list-style-type: none"> • Individuals have a relationship with at least one person outside the service system who can help raise issues of concern and be involved in decision making. • All decisions, including selection of support staff, are made in consultation with the person with a disability, their family or advocate. • Decisions about support are reviewed and monitored regularly by the person, their family member or advocate. • People with complex support needs are a high priority in the service system.

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<p>3. About support</p> <p><i>Support is individualised</i></p>	<ul style="list-style-type: none"> • Support is organised around a person’s needs and preferences and not dominated by organisational needs. • All regular support is coordinated and based on a person centered plan which is reviewed regularly. • Individuals are known well by their support staff and managers of support services. • Support and housing may be shared with others in the same house or with people who live nearby. • If an individual shares a house, support is coordinated for the household or group as well as each member. • Confusion and inconsistency are minimized when support staff change.
<p><i>Support is flexible, reliable and coordinated</i></p>	<ul style="list-style-type: none"> • Support is available where each individual lives. • A choice of support provision is available through different providers, staff and/or approaches. • Where support is shared, benefits, compromises and changes are explicitly discussed and agreed on by all individuals affected or their advocates.
<p><i>Support enables choice of activities and participation in a range of daily life activities</i></p>	<ul style="list-style-type: none"> • Support changes in response to the type of lifestyle pursued by people over time. • Support allows meaningful participation in the home and in the community. • Support enables individuals to go regularly to places in the community where they can become known.
<p>4. About housing</p> <p><i>There is a range of housing and living situations available</i></p>	<ul style="list-style-type: none"> • Individuals can choose where they live and with whom. • Individuals can choose their form of housing i.e. house, unit, and apartment; from the same range of housing options available to the rest of the community of comparable age in their geographical location. • Individuals can choose their mode of living i.e. to live alone, or share with others, who are family, or friends, paid or voluntary helpers or chosen house/flat-mates. • Individuals can choose to live in housing that has other people with disabilities nearby. • An individual is not expected to live in a large scale congregate facility unless they are of similar age and circumstances as the typical resident population and it is the most appropriate option for the person. • Housing costs and choice of housing takes into account people’s incomes and financial plans.
<p><i>Housing in context of the local area</i></p>	<ul style="list-style-type: none"> • Houses fit in with streetscapes and are not enclaves isolated from the general community. • Houses are in close proximity to the street and neighborhoods so people can see activity in their neighborhoods and participate in it by easily going out, walking, shopping and using immediate neighborhood transport and public facilities. • Any provisions for staffing are secondary and do not interfere with the impression of the house being a home (e.g. staff or bus car park is not the main external feature; any separate staff facilities in the house are separated from the residents’ living space.)
<p><i>Shared housing and support is by choice</i></p>	<ul style="list-style-type: none"> • Individuals are not expected to live with others unless they chose to do so. • If people do choose to share with others, they have a choice about who they are. • Individuals are supported to think about the disadvantages and benefits of various living situations (e.g. costs, socialization, security, isolation, privacy, how they like to live).

<i>Housing design</i>	<ul style="list-style-type: none"> • Housing design should help to create a home, not a facility. • Housing is adapted to be fully accessible and take into account a person's capacities and physical, sensory and cognitive impairments. • Housing is subject to the same requirements as any other private home. • Individual needs are the primary reason for specific housing design features. Design is not dominated by staff needs or perceived future needs of possible future residents. • The interior of houses is homely and may have shared spaces for social and household activities as well as private spaces.
5. Housing supply	<ul style="list-style-type: none"> • If individuals are unable to afford to purchase their own housing or rent in the private market, responsibility for the provision of housing rests with government departments and community based organizations with responsibility and funding for housing. • People with disabilities can expect that a proportion of all public and social housing should be allocated to them without any conditions attached.
6. About systems <i>Population based targets</i>	<ul style="list-style-type: none"> • There are population-based targets for the provision of housing and support for all people with disabilities and for the sub group of people with intellectual disability and high and complex needs. In the absence of Victorian/ Australian population-based data, the targets are at least comparable to those devised overseas.
<i>Monitoring and organisational accountability</i>	<ul style="list-style-type: none"> • The services and support provided by organizations is in accordance with the disability standards and is regularly monitored and reviewed. • Residents, and those who know them well outside the service system, are regularly consulted in a meaningful way about the quality of support provided.
<i>Planning for systems and person-centered planning</i>	<ul style="list-style-type: none"> • Aggregate information arising from person-centered planning is used to guide system-level planning and review.

For further details contact:

Associate Professor Christine Bigby
C.Bigby@latrobe.edu.au
School of Social Work and Social Policy
LaTrobe University
Bundoora, Victoria, 3086

And see:

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