

Reinforce Inc

The Victorian Association of Intellectually Disadvantaged
Citizens

2nd Floor Ross House 247 251 Flinders Lane Melbourne Vic 3000

> Phone 03 9650 7855 Fax 03 9639 4004 ACN A0012853U ABN 93226896012



235 Napier Street Fitzroy Vic 3065 Phone: (03) 9416 4003 Facsimile: (03) 9416 0850 Email: office@valid.org.au www.valid.org.au



Advocating for people with intellectual disability and their families 2nd floor Ross House, 247 –251 Flinders Lane

SUBMISSION TO INQUIRIES INTO SUPPORTED ACCOMMODATION FOR THOSE WITH DISABILITY AND MENTAL ILLNESS

VALID: Victorian Advocacy League for Individuals with Disability

STAR Victoria Inc. Advocating for people with an intellectual disability and their families.

REINFORCE Inc: Victorian Association of Intellectually Disadvantaged Citizens

AMIDA: Action for More Independence and Dignity in Accommodation

Prepared with the assistance of:

Christine Bigby, School of Social Work and Social Policy, La Trobe University Ilan Vizel, Faculty of Architecture, Building and Planning, University of Melbourne

1. Background

- This submission has been prepared by four advocacy organizations with a specific focus on Victorians with an intellectual disability and their families as a response to the Inquiries into Supported Accommodation for those with Disability and Mental Illness by the Committee of Family and Community Affairs in the Victorian Parliament. The submissions is based on the experiences of our organisations in supporting people with intellectual disability and their families and also draws on Australian and international research, about accommodation and support for people with intellectual disabilities We focus in particular on the extent of unmet need and the implications for people with intellectual disabilities and their families, on the one hand, and congregate-care models of service provision, on the other. We call for extensive and immediate response to unmet need, that is sensitive to the principle of community inclusion, the complexity of factors which determine quality of services and the diversity of the population of people with intellectual disabilities.
- The goals of community inclusion and individual choice are high priorities in the *Disability State Plan 2002-2012*. We strongly support these goals. However, inclusion and choice cannot be achieved in a service system bedevilled by unmet need that continues to offer institutionalisation or large scale congregate care as residential options for people with intellectual disabilities, and that continues to expect families to wait without hope for much needed support services.
- We emphasise three priority areas for action to overcome barriers to inclusion and choice: a
 comprehensive response by State Government to unmet need; closure of all state run or funded
 institutions and congregate care facilities; and, the further development and refinement of a
 range of housing and support models with particular attention to people with higher levels of
 support needs, people with challenging behaviours and older people with intellectual
 disabilities.

2. Summary of recommendations

2.1 Extensive and immediate response to unmet need

- A proactive population needs based planning approach be adopted, so that funding for current
 and future accommodation and support is planned to take account of the current and future
 projected population of people with intellectual disabilities, their location, characteristics and
 support needs.
- Allocation of services and funding packages must be based on a holistic understanding of the intensity of a person's support needs including physical, emotional, and developmental.
- A person assessed as eligible for disability services should not be denied access to housing and support services, either in the form of shared supported accommodation or an individualized package of support and access to social housing.
- Public and social housing should be significantly increased. All new units should meet
 accessibility standards for people with physical disabilities, and a significant proportion of all
 units should be allocated to people with disabilities.
- Lack of timely and adequate access to support services must not be a barrier to entry into social
 or public housing. The office of housing, housing associations and disability services should
 work in partnership to establish effective coordination of housing and support.
- More respite services are provided to support families caring for people with intellectual disabilities. New and existing respite services should not be used as long-term accommodation.
- Emergency housing should be established to provide immediate short-term accommodation for
 people with intellectual disabilities in crisis, particularly those experiencing homelessness or
 exposure to abuse. Long-term housing should not be used as crisis housing, and crisis housing
 should not be used as long-term accommodation, but as a temporary arrangement while an
 appropriate long-term placement is established.

2.2 Commitment to deinstitutionalisation

- Housing and Support models developed, including response to unmet need, must not offer congregate care, cluster housing or institutionalised options which are inherently contrary to principles of community inclusion in the Disability Act and the State Disability Plan.
- The State Government make an unequivocal commitment within a specific time frame to close the Colanda and Sandhurst Training Centres and other state-funded congregated facilities, including Plenty Residential Services.

 Residents who move out of congregated facilities must be given a choice of community-based options that include housing as well as support appropriate to their needs.

2.3 Development and refinement of a range of housing and support models with attention to diversity among people with intellectual disabilities, and commitment to the principles of the Disability Act and the Disability State Plan.

- Individualized funding packages should be attached to a person-centred plan and systematically audited to ensure quality outcomes consistent with the Disability Service Standards.
- Independent advocacy must be strengthened to support people with intellectual disabilities when applying, planning and implementing plans for support and accommodation.
- People with more complex support needs should not be excluded from individualised funding.
- Intensive specialized housing and support options, delivered by experienced provider
 organisations should be put in place to enable people with challenging behaviours to move out
 of group homes, where such a placement is clearly detrimental to their quality of life and
 inappropriate for them.
- Housing and support options, particularly shared supported accommodation, must be funded in
 a way that support can be adapted to the changing needs of people with intellectual disabilities
 as they age, to enable ageing in place.
- The disability sector should take a leading role in the provision of housing and supports for
 older people with intellectual disabilities, to avoid premature and inappropriate admission to
 residential aged care and to develop the capacity of the geriatric and community aged care
 services to provide services to people with an intellectual disability who are aging.
- People with higher levels of support needs, people with challenging behaviours and older people
 with intellectual disabilities should not be excluded from new models of housing and support
 that are developed. Specialist innovative programs should be developed for these particular
 groups.
- Development of new models of housing and support should occur alongside strategies to
 improve the quality of support provided by shared supported accommodation. It should be
 acknowledged that shared supported accommodation is not a defunct model, but one that holds
 significantly more potential than is currently realised in Victoria.
- People must be able to exercise choice about residents with whom they share a home, including possibilities for sharing accommodation with a partner.

- Continuous staff development through ongoing training programs. House-supervisors should be supported to play a more significant role as mentors working closely with all other staff members.
- Systematic and independent monitoring of the quality of service across the shared supported accommodation system to ensure all services meet standards, without increasing the administrative burden on staff.
- Significant resources immediately allocated to refurbishment of CRUs in a way that improves
 their design to allow more private space and less shared space, including breaking up of larger
 houses into smaller units, where possible, to deliver better quality outcomes and address issues
 of tenant incompatibility.
- People living in shared supported accommodation wishing to move out should be provided with sufficient supports to be able to do so.
- People with intellectual disabilities living in all forms of housing should enjoy full tenancy rights comparable to the rest of the population.
- Tenancy rights should include a right for immediate and proper response by proprietors to maintenance issues.
- All people with intellectual disabilities should have opportunities to develop their independent living skills and be able to access the supports necessary to lead an active life in their community.

3. Comprehensive response to unmet need

Indisputable evidence exists about the volume of unmet need among people with intellectual disabilities in Victoria. The implications of unmet need are immense: thousands of people are in desperate need of support and accommodation, often in a state of crisis that in the worst – though not rare – cases, involves exposure to homelessness and abuse. Such evidence alone should be enough to trigger immediate action by the state government to respond to unmet need. However, unmet need has significant implications, beyond that of the individual, and affects the entire disability services sector, turning it into a reactive crisis driven system, which compromises policy principles of rights and inclusion.

- The shortage in support and housing is most evident in the waiting lists for shared supported accommodation and in-home and community support the Disability Supports Register (DSR) that in June 2008 reached 1,358 people waiting for shared supported accommodation, and 1,282 waiting for in-home supports (Department of Human Services 2008c). Only people in immediate need are registered, which means that these figures are far from representing the real mid-term and long-term demand for services. In 2007, one in six people waiting for supported accommodation in Victoria were cared for by family members aged 75 years and over (Standing Committee on Community Affairs, 2007: 90).
- The main causes of unmet need are the lack in resources available to respond to changing family demographics and increased life expectancy among people with intellectual disabilities, and the absence of medium and long term planning for the service system. As argued by the Victorian Auditor-General, demand for services 'is increasing by around 4 to 5 per cent annually and DHS has not accurately quantified future support needs or the associated need for resources. The reactive nature of DHS's response to accommodation needs, combined with the stringent prioritisation criteria, is likely to continue, and therefore perpetuate a crisis-driven system' (Victorian Auditor-General 2008: 2).

Emma, an 'Intake and Response' officer at DHS: "I had a client a while ago who has been in the community her whole life but previously she spent her day at her mum's, and her mum used to cook for her ... But her mum has entered a nursing home. She is not coping in the way that she can't open a can. She has been sexually abused and she lets people in the house because she does not have the ability to say no. So she really needs to be living in a CRU (Community Residential Unit) setting, but there are no vacancies ... And I don't know when that will happen. So it can be quite heart breaking." (Vizel, Forthcoming)

3.1 The crisis-driven nature of the service system resulting from unmet need

- Unmet need means that the service system is driven by crisis response which affects all people
 with intellectual disabilities in the state those already experiencing crisis and those who are
 not.
- Access to government funded accommodation and long-term support services is only available
 to people with an urgent need or who are already in a state of crisis.
- The most basic forms of individual choice are undermined by the crisis-driven management of resources. Allocation of services becomes a 'take it or leave it' practice. Applicants who reject an offer may be penalised, labelled as not being of urgent priority and in effect removed from the register even where an offer is clearly unsuitable for their needs (Vizel, forthcoming)
- Locational preferences of applicants for shared support accommodation and their compatibility with other residents are commonly overlooked when vacancies in shared accommodation are allocated as crisis-housing. As a result, people with intellectual disabilities move to places which are distant from their families and support networks, and to houses with residents with whom they are likely to experience ongoing conflict or detachment. Young people are often placed in homes with people much older than them. (Vizel, forthcoming)
- Because a significant portion of people in crisis also have challenging behaviours, there is a
 high likelihood that incompatibilities between residents will disrupt the existing fragile sense of
 home. For the four or five residents already living in that house this can turn their home into
 crisis housing, even though they were not in a state of crisis in the first place.
- Significant levels of unmet need and a crisis driven approach is also evident in respite services.

 Respite is "fundamental to enabling people with disabilities to continue to be cared for within

families (and yet) many families are unable to access adequate respite unless they face a crisis situation" (Standing committee on Community Affairs 2007: 64). A 1998 ABS survey has found that 3,200 primary carers reported a need for respite services but had never received them, and although a further 2,100 had received respite services the provision fell below that required to meet their needs (AIHW 2002b: 168)

3.2 Lack of access to affordable housing

- The extent of unmet need is reinforced by the exclusion of people with intellectual disabilities from the private housing market, and the lack of social housing and disability housing to provide an alternative.
- A severe shortage in affordable housing in Victoria means that people living on a disability pension can hardly access private rental. While in March 2007 16.8% of new lettings in Victoria were considered by the State Government's Office of Housing as affordable (rent price within 30% of household's income), in March 2008 this rate has fallen to 8.9%. Median rent prices for a one-bedroom unit in Melbourne was estimated in March 2008 at \$235 per week and at \$120 per week in regional Victoria (Department of Human Services 2008b). The disability pension basic rate is a fortnightly payment of \$546.80. In addition, a person with a disability may apply for rent assistance up to \$107.20 per fortnight (Centrelink 2008:23). These figures suggest that a person with an intellectual disability living in a one-bedroom unit in Melbourne is likely to pay 72% of their very limited income on rent, providing that they have found one, which is becoming increasingly difficult in almost any suburb of metropolitan Melbourne (Berry and Hall 2001). Research conducted in Australia has shown that even the very limited stock of affordable housing available, is occupied by higher income households (Yates & Wulff, 2005)
- People with complex disabilities are often excluded from private rental because of the physical inaccessibility of the housing stock. In Australia there is no legislation to ensure that residential housing is built according to accessibility standards.
- Discrimination by landlords and real-estate agents often effectively excludes people with
 intellectual disabilities from the private rental market. The reluctance of homeowners to rent
 property to a person without a proven history in the private rental market, also creates a
 significant barrier for many people with intellectual disabilities. Landlords are not required to
 account for their choice of rental applicants.
- Public and social housing is also extremely difficult to access for people with intellectual disabilities due to enormous waiting lists, and competition with other low-income households.

People with intellectual disabilities do not have priority access to public and social housing in Victoria, and in some cases are even disadvantaged compared to other applicants because social housing agencies are often reluctant to take people with disabilities who do not have sufficient supports available and are thus at risk of being poor tenants. The table below provides data on the waiting lists for public housing in Victoria (Department of Human Services, 2008b):

	Eastern Metro Region	Southern Metro Region	North & West Metro Region	Gippsland	Barwon South West	Grampians	Hume	Loddon Mallee
Public housing units in region	6339	27,619	15,942	4206	5770	3483	4805	5330
People on the waiting list for public housing	4,485	9,706	14,548	920	2,458	874	1,271	1,077

3.3 Inappropriate placements in nursing homes and SRSs as a result of unmet need

- Due to lack of access to affordable private rental, public housing or shared supported
 accommodation, people with intellectual disabilities are often forced to turn to highly
 inappropriate forms of accommodation such as respite facilities, nursing homes and Supported
 Residential Services (SRSs).
- The 2003 SRS Census (Department of Human Services 2003) has found that 13% of residents in pension-level SRSs have an intellectual disability, 8% have an acquired brain injury, 45% have a psychiatric illness and 2% have serious medical issues. Only 3% were reported to have no disability.
- SRSs, particularly pension-based SRSs in which people with intellectual disabilities are more likely to be accommodated, are privately owned, sub-standard congregated forms of accommodation. The 2006 Disability Act does not apply in SRSs. For example the Act requires 60 days notice of rent increases, and restricts the amount of rent that can be charged in advance. These protections, which cover residents of Community Residential Units, do not apply for residents of SRSs and there are currently no restrictions on the amount payable upon entry into a SRS. SRS residents also do not have the legal protections that rooming house residents have under the Residential Tenancies Act 1997.
- Pension-level SRSs are becoming unviable, and many of them are closing down. In 2005-2006 five SRSs closed, resulting in the loss of 83 pension-level beds (Community Visitors 2007: 20).

- No planning is in place to find alternative accommodation and support for people with intellectual disabilities living in SRSs that are in threat of closure.
- Community Visitors reports raise serious concerns about the adequateness of SRS facilities for people with intellectual disabilities: "During this year, Community Visitors witnessed a young man cutting himself, apparently attempting to commit suicide... In another SRS the incident book noted three recent serious incidents: an attempted suicide; a man armed with a knife threatening to cut himself; and a resident threatening to cut out his eye with a coat hanger. In yet another SRS, staff found a resident sitting on her bed with a lamp cord around her neck, holding to an end of the cord with each hand. She told staff she was going to kill herself. These are very disturbing events, and it is a serious question whether SRS staff are trained or equipped to handle them." (Community Visitors 2007: 5)

Jim is a 21 years old person with an intellectual disability. His family applied in DHS for him to access supported accommodation, but they have been advised he is not "really suited to a CRU". Over the last three years he has been placed in a series of inappropriate accommodation settings, including SRS's and aged care facilities, none of which have met his particular needs for support. As a consequence of successive "failures", his mental health has deteriorated to the extent that he became suicidal, and he has been hospitalised twice for treatment of psychosis. Despite the urgency, he still hasn't been offered supported accommodation and is once again back in an SRS. (Reported by VALID)

- Several SRSs rent out beds for respite. This means people moving in and out on a regular basis, disturbing the sense of continuity which is essential for a feeling of home. (Community Visitors 2007: 5-6)
- Level of maintenance in SRSs is often very poor, particularly in pension-level facilities which are often located in older run down buildings: "strong urine smells, carpets requiring cleaning and/or replacing, soiled and smelly bathrooms and broken or missing lights...damaged and soiled window coverings, painting upgrade needed, overflowing gutters on roofing, broken steps and ramps, poor heating and cooling, cigarette butts lying around internally and externally and unkempt gardens." (Community Visitors 2007: 18)
- Many pension-level SRSs do not provide activities and programs, often because of a lack of funds or low staffing ratios.

• Very little, if any, consideration is given to compatibility between residents in SRSs and limited support from staff is in place to ensure such incompatibilities do not lead to incidences.

Box 3

A recent publication in *The Age* newspaper (Reilly 2008) reports allegations raised by former workers in an SRS operating in Victoria. These workers have filed complaints in DHS about neglect and physical and verbal abuse of residents by the proprietor. The complaints include reports of physical abuse which in some cases resulted in injury. The proprietor is also the only carer on site overnight, and is allegedly ignoring emergency calls from residents requiring assistance between 8pm and 7.30am. The findings of DHS's investigation into the case have not been made public, although the Department consequently imposed new conditions on the license to run the facility. While this is an extreme case of neglect and abuse in an SRS, which does not necessarily represent what is happening in all other places, it highlights the lack of regulation and control to which residents of SRSs are extremely vulnerable, particularly if they have intellectual disabilities.

• People in crisis are often accommodated for long periods in respite facilities which were originally designed to provide temporary relief for families supporting relatives with a disability. In March 2006, 40 people continued to live in respite facilities for long periods, in some cases years (Community Visitors, 2007: 17). The current figures are probably much higher. When respite beds are occupied for longer-terms - in some cases years - by individuals in crisis, they can no longer serve their purpose, and families have no respite services available for them. The ongoing demands of care-giving with no respite sometimes results in relationship breakdowns, and consequently more people with intellectual disabilities in crisis.

Box 4

Lea has been living in a respite facility in the North-West region for two years. Her pension and her family funds the costs of approximately \$175 per week. She has a high level of support needs, and presents challenging behaviours, including incessant screaming. Living in a respite facility means that different people are moving in and out on a daily basis, she has very limited privacy and no sense of permanency and home. Individualised packages, as allocated by DHS, are too small to provide sufficient supports for Lea to live in the

community. She is on the register for shared supported accommodation, and is classified as urgent priority, but no vacancies are available and it is not clear how issues of compatibility between her and the other residents will be addressed, given the lack of resources. (VALID 2007: 6)

3.4 Approach to address unmet need

- Following an understanding that unmet need is the result of inadequate planning and lack of resources, and the cause of unnecessary suffering for people with intellectual disabilities and their families and the chronic crisis-driven nature of the disability service system in Victoria, we call for immediate and extensive action by the Government to provide the essential supports and services required for those in need:
 - A proactive population needs based planning approach be adopted so that funding for current and future accommodation and support is planned with account of the current and future projected population of people with intellectual disabilities, their location, characteristics and support needs.
 - Allocation of funding packages must be based on a holistic understanding of the intensity of a person's support needs including physical, emotional, and developmental.
 - Resources allocation should be proportional to the support needs of individuals applying. (Annual Roundtable on Intellectual Disability Policy in Victoria 2007: 46).
 - A person assessed as eligible for disability services should not be denied access to
 housing and support services, either in the form of shared supported accommodation or
 an individualized package of support and access to social housing.
 - If a person is 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 (Annual Roundtable on Intellectual Disability Policy in Victoria 2007: 46).
 - Public and social housing should be dramatically increased and a proportion of all units should be allocated to people with disabilities (Annual Roundtable on Intellectual Disability Policy in Victoria 2007: 46).
 - Lack of timely and adequate access to support services must not be a barrier to entry into social or public housing. The office of housing, housing associations and disability

- services should work in partnership to establish effective coordination of housing and support.
- Emergency housing should be put in place to provide immediate short-term accommodation for people with intellectual disabilities in crisis, mainly for those experiencing homelessness or exposure to abuse. Long-term housing should not be used as crisis housing, and crisis housing should not be used as long-term accommodation, just as a temporary arrangement while an appropriate long-term placement is set-up.

4. Unequivocal commitment within a specific time frame for deinstitutionalization

- It is crucial that the State Government consistently follow its policy of deinstitutionalization, complete the closure of existing state run and state funded congregate care facilities, and curtail the creation of new forms of congregate care and institutionalization of people with intellectual disabilities by non-government agencies.
- Deinstitutionalization in Victoria has made some important achievements but is not yet complete. Some state-run institutions are still operating, and other forms of congregate care facilities providing substandard housing for people with intellectual disabilities are abundant. These facilities include Colanda Residential Services in the Barwon-South Western region, Sandhurst Centre in the Loddon Mallee region and Plenty Residential Services in Bundoora. There are still more than 220 people living in undesirable and deteriorating institutionalised environments that are in need of urgent decisions for redevelopment. (Community Visitors 2007: 16). AIHW data from 2006 states 167 other people living in hostels.
- The understanding that people with intellectual disabilities should not be congregated is based on the principles of improving their quality of life and their community inclusion. Three decades of research have unequivocally demonstrated the improved inclusion and quality of life outcomes for people with intellectual disabilities who move out of institutional environments and live in small scale group homes in terms of :
 - more choice and self-determination
 - more frequent contact with people in their social networks

- more participation in community-based activities (Emerson & Hatton's (1996) review of 71 publications on the effects of deinstitutionalisation between 1980-1994 in the UK and Ireland and Noonan Walsh et al (2008) review of literature between 1994-2007.)
- The inherent characteristics of institutions create conditions that are the very antithesis of those necessary for social inclusion and individual efficacy of people with intellectual disability.
- Institutions 'have become humanly and socially and culturally unacceptable ...and cannot be substantially changed by reorganising work or increasing resource supply (Tossebro, 1996). "Institutions became both the symbol and the instrument of separation and consequent stigmatisation of people with an intellectual disability." (Bradley, 1996).
- Institutionalizing people with intellectual disabilities in congregated, often isolated, facilities is a form of exclusion. It undermines their ability to take part in mainstream society and further marginalises them as an invisible population. Exclusion is not just the wellbeing of one individual in a particular time and place. It is about deeply embedded social norms and material realities in which certain social groups are *systematically* rejected from participating in social life. Exclusion is a vicious cycle in which people's poverty and vulnerability only get worse over time, because it further reduces their ability to improve their own lives.

The central feature of total institutions can be described as a breakdown of the barriers ordinarily separating the three spheres of life. First, all aspects of life are conducted in the same place and under the same single authority. Second, each phase of a member's daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same things together. Third, all phases of the day's activity are tightly scheduled, with one activity leading at a prearranged time into the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials. Finally, the various enforced activities are brought together into a single rational plan purportedly designed to fulfil the official aims of institutions. (Goffman 1961/1978)

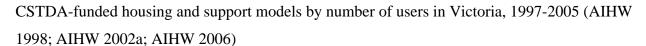
• The notion of social exclusion means that even if cluster housing 'might reflect the choice of a few now...(it) will live behind a legacy of bricks and mortar that will restrict choice and segregate people with intellectual disability for decades to come' (Bigby 2004b: 204)

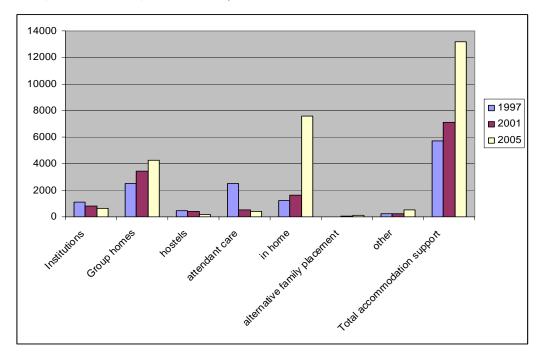
- Debate continues about the potential benefits of living in cluster housing particularly for groups labelled as having challenging behaviour or with severe or profound impairments. The driving force behind much of the debate is not so much the advantages of larger scale living, but rather the failure of small group homes to match expectations and deliver community inclusion (Bigby, 2004b). Research, for example, reflects similar views to those often put by families in media campaigns, demonstrating that the physical presence of people with intellectual disabilities in small group community homes does not always equate with social connectedness and community inclusion (Kim et al. 2001; Noonan Walsh, 2008; Hatton & Emerson, 1996; Young et al. 1998). Shared supported accommodation has been the dominant model to replace institutions and congregate care, but as Hatton suggests, outcomes are 'are far from optimal when judged against normative standards, notions of decency and acceptability or the aspirations associated with the model itself' (2001, p. 6).
- The closure of institutions creates the conditions necessary for social inclusion, small scale community living models but these are not sufficient in themselves to attain it. A mediating factor is the weak implementation of such models, illustrated by the significant variability found in the outcomes for people with intellectual disability in shared supported accommodation. The worst programs deliver outcomes that resemble institutional life whilst the best can foster engagement and community participation for people with severe as well as mild intellectual disability (Mansell 2006).

4.1 Approach to address continuing institutionalization of people with intellectual disabilities Following the principles of social inclusion and improved quality of life for people with intellectual disabilities, we call for the following actions to be taken:

- The State Government make an unequivocal commitment within a specific time frame to close Colanda, Sandhurst, Plenty Residential Services and other state-funded congregated facilities
- Residents who move out of congregated facilities must be given a choice of community-based options that include housing as well as support appropriate to their needs.
- Implementation of alternative models of housing and support, including shared supported accommodation, should be attentive to the variety of factors which determine quality of life and inclusion outcomes for residents, as elaborated in the following section.
- 5. Strategies to improve outcomes in shared supported accommodation and other housing and support models

• Much of the debate about the future directions of the disability services sector is about the model of housing and support that would be most appropriate for people with intellectual disabilities. It is important to understand that factors which determine the effectiveness of each model are complex. There is no one housing and support model that can work as a blanket solution for all people with intellectual disabilities. A careful and detailed policy response should be taken to improve existing models and to introduce new ones in a way that is inclusive and effective.





- The graph above illustrates trends in the models of housing and support in Victoria. A significant increase occurred in the number of individualized 'in home' services provided. Around 6,000 people have received new in home services based on individualised funding. However, 77% of individualised funding packages are valued less then \$10,000 and only 1% exceeds 55,000 (Victorian Auditor-General 2008:1).
- In terms of funding, shared supported accommodation is still the dominant model of housing and support in Victoria, with 49.5% of the overall disability services budget allocated annually to "Residential Accommodation Support" which comprises shared supported accommodation and congregate care (Department of Human Services 2006: 32)
- Shared supported accommodation is still highly sought after by families caring for a person with an intellectual disability as evident from figures of 1,358 people in June 2008 on the Disability

- Support Register. However, no new CRUs have been built in recent years to meet the increased demand apart from those built under the KRS redevelopment.
- The main problems associated with shared supported accommodation are their inflexibility to allow individual lifestyle and choice for residents, as well as problems of incompatibility between residents (see Box 6 below).

A survey conducted by Reinforce Inc (Efstratiou 2003) among residents in CRUs has found that most participants did not choose to live there, and have not chosen who lives with them and who would support them. Most participants stated that they were not even asked. Most participants were dissatisfied with their co-residents. Most participants had to ask staff before using the phone or inviting guests. Only half of them had a key to the house. Most participants stated they have to eat at the same time as the other residents and go together on the same outings, as one of the participants tells: "When we go out, all residents have to be able to, or no-one goes. Like Luna Park for instance, one resident can't move easily, one gets agitated, so we can't go" (p. 9) Colin Hiscoe, President of Reinforce concludes: "Members of the community have the right to live where they want and do what they want. Why can't people with intellectual disabilities have the same right within the law?"

- People with low levels of support needs may often lead a less restrictive life in supported
 independent living rather than group homes if provided with sufficient training and sufficient
 ongoing supports. However, for people with middle to high levels of support needs, group
 homes are still a highly important housing option.
- A large body of research now suggests such variation in group homes is due to staff practices and the organisational elements that mediate these (Noonan Walsh 2008). Once a threshold of resources is passed, it is their effective use rather than more resources that makes the difference. The situation is summed up by Felce and Grant (1998) who suggest 'the devil is in the detail'. Attention to the details of program implementation and management is fundamental in determining outcomes for residents. Shared supported accommodation is not a defunct model but one that holds significantly more potential than is currently realised in Victoria.

Clement and Bigby (2008) found that some residents who moved to CRUs after the closure of Kew Residential Services, have experienced greater *community presence* in their new homes. However, the level of their *community participation* has remained low. Many activities outside the CRU take the form of a group-outing, and most decisions and interactions with other community members in such outings are made by staff and not by residents. This results from various factors such as the roster of staffing in the house, the use of big vans which orient towards group-activities, staff's understanding of their role in facilitating community participation and the attitudes of people in the community towards people with disabilities.

- Not all group homes are the same. Variation in quality between different group homes is significant. The factors that affect quality of a group home are complex:
 - Quality and training of staff
 - 'The way staff provide support to the people they serve has been singled out as a key determinant of outcome' (Mansell 2005: 25).
 - Particularly important is the role of the house supervisor, as a manager and leader of
 the other staff. Their work, however, is often hindered by excessive paperwork.

 Also, they have few opportunities to supervise some of the other staff in the house
 due to the way rosters are organized. (Clement & Bigby 2007)
 - Workforce instability is caused by frequent use of casual staff in many CRUs, high
 levels of staff turn-over and other practices whereby permanent staff are taken from
 one house to fill temporary roles in others. The instability of the workforce makes it
 hard to develop significant relationships between staff and clients and to provide ongoing training and supervision (Clement et al. 79-80).
 - o Mix of residents and their compatibility
 - Physical design of the house:
 - Group homes may be designed in a more flexible way to allow residents more
 privacy in separate sections of the house, while still maintaining their access to
 support staff.
 - A DHS survey from 2004 has found that 200 CRUs do not meet accessibility requirements and occupational health and safety standards. Since then only 51

- houses have been replaced, and nine have gone through major refurbishments. (Victorian Auditor-General 2008: 3)
- The staff's office is often the most 'lived-in' room in the CRU, staff's toilets most clean and homelike. The separation between staff and residents creates an institutional environment rather than one that is homelike (Clement et al. 2007).
- Location: some CRUs have no easy access to public transportation and other community resources.
- Despite the variation between houses, most of these issues are systematic and can be attributed to limited resources, poor protection of residents' rights and weak implementation.
 - o Residents in CRUs are not protected by tenancy rights as all other renters in the general community. People with disabilities who live in "a home for the aged or disabled or like institution" are not covered under the *Victorian Residential Tenancies Act* (1980) (AMIDA 1997). While the new *Disability Act* 2006 now covers residents of CRUs, it remains unclear about tenancy issues. With maintenance, for example, the Act vaguely states that the service provider is required to "ensure that the premises in which the residential services are provided and any fixtures, furniture and equipment provided are maintained in good repair". There are no explicit requirements for a specific time length within which providers should fix the problems, as in the *Victorian Residential Tenancies Act* (1980).
- Many of the problems in accommodation and support are not related to one specific model but are evident across the whole sector and across all housing and support models. Community Visitors, for example, have identified "a large number of unsuitable and often bleak and depressing facilities where many residents, sometimes with deteriorating health, are forced to reside. This is a widespread problem irrespective of who is the landlord DHS, a community service organisation, Singleton Equity Housing, the Office of Housing or a private landlord... nearly one quarter (24 per cent) of all issues raised by Community Visitors during the reporting year relate to fabric and maintenance concerns, with 712 (or 20 per cent) specifically referring to upkeep of building and fittings." (Community Visitors 2007: 18)
- New models of accommodation and support are currently developed through partnerships of
 Government and non-government agencies, under the *Accommodation Innovations Grant*scheme, the *Disability Housing Trust* and other initiatives. Such innovations are an important
 step towards a more creative service system, and may open up new ways to overcome some of
 the challenges, and to increase the variety of options available. Several of these initiatives aim –

- and are in some cases successful in fostering long-term informal support networks for people with intellectual disabilities.
- However, the last injection of funds for new Innovations in Accommodation was in 2004 and not all innovative projects have received ongoing funding.
- Moreover, most new models which are developed predominantly cater for people with low levels of support needs.
- Shared equity or private/ public initiatives such as those pursued by the Disability Housing Trust require significant time and resources for development, and extraordinary coordination to ensure funding for both housing and supports and to develop a long-term informal support network. The number of new housing units that have been placed on the ground under such initiatives is very limited, and is far from meeting the increase in demand estimated at about 4-5 percent annually.

5.1. Principles for development and refinement of housing and support models

- Housing and Support models developed, including response to unmet need, must not offer
 congregate care, cluster housing or institutionalised options which are inherently contrary to
 principles of community inclusion in the Disability Act and the State Disability Plan. Housing
 should meet standards which include a clear limit to number of residents on a single site
- People with higher levels of support needs, people with challenging behaviours and older people
 with intellectual disabilities should not be excluded from new models that are developed.
 Specialist innovative programs should be developed for these particular groups.
- There is a need for direct investment in projects and infrastructure to promote innovative programs; they cannot be totally reliant on existing individualised funding schemes. For example, in the KeyRing model (described in Box 8 below) group-based funding ensures that even if some of the members of the network leave, it does not collapse.
- Development of new models of housing and support should occur alongside strategies to improve the quality of support provided by shared supported accommodation.
- Continuous staff development through ongoing training programs. House-supervisors should be supported to play a more significant role as mentors working closely with all other staff members.
- Systematic and independent monitoring of the quality of service across the shared supported accommodation system to ensure all services meet standards, without increasing the administrative burden on staff.

- Significant resources immediately allocated to refurbishment of CRUs in a way that improves
 their design to allow more private space and less shared space, including breaking up of larger
 houses into smaller units, where possible, to deliver better quality outcomes and address issues
 of tenant incompatibility.
- People living in shared supported accommodation wishing to move out should be provided with sufficient supports to be able to do so.
- People must be able to exercise choice about residents with whom they share a home, including the possibility of forming relationships with others that may lead to live in partnering.

KeyRing is a support model developed in the UK in which refers to a local network of people with mild intellectual disabilities living independently in the community. Members of the network provide each other with mutual support to strengthen community links Members of such rings increase their own resourcefulness as individuals and as a group and increase their involvement in the local community. People with higher support needs are not the KeyRing target group (Simons 1998).

6. Acknowledgement of diversity among people with intellectual disabilities in the planning and provision of services

People with intellectual disabilities are a diverse group of people with different needs and desires. Any policy response to unmet need must address these differences, in order to avoid blanket solutions which may be appropriate for few, but have negative exclusionary implications for many others. Particular consideration should be made for people with complex disabilities and higher levels of support needs and for people with behaviours that are considered as challenging. Moreover, attention should be given to the changing nature of support needs.

6.1 Individualised funding without exclusion of people with high levels of support needs

• The Disability State Plan highlights the importance of individualizing services for people with intellectual disabilities. Growth funding in disability accommodation and support has been redirected towards individualised funding schemes which provide recipients with a limited number of support hours each week, wherever they live. This policy enables more people to live independently in the private housing market, rather than in government funded group homes.

- However, people with higher levels of support needs are currently excluded from access to individualised funding, as explained below.
- The vast majority of individual packages allocated in Victoria are smaller than \$10,000 per year for one individual and only 1% of all individualised support packages provided by DHS exceed \$55,000 (Victorian Auditor-General 2008:1). In comparison, supporting an individual living in a group home costs DHS and support agencies over \$70,000 per year. Hence, the current allocation practices mean that individualised packages are really only beneficial to people who require very limited supports to live independently, and excludes people with high levels of support needs.
- Smaller packages of individualised funding enable people with low levels of support needs to
 move out of shared-supported accommodation, thus allowing them to lead a less restrictive life,
 while freeing up vacancies for other people with high levels of support needs to move in to
 shared supported accommodation.
- However, almost half of the people moving out of CRUs are not moving into more independent living arrangements, and some move to SRSs which are even more congregated than CRUs and provide a lower living standard. In 2004-5 only 55% of the people moving out of CRUs have moved into independent living arrangements (in private rental or public or social housing), 31% have moved back to live with their family carers and 14% have moved into SRSs (Kihl Larssen 2006).
- Moving people with low support needs out of CRUs implies a redefinition of the shared supported accommodation model, orienting it towards clients with higher levels of support needs. This process calls for reforms in the shared supported accommodation model in terms of funding, management, organizational skills and transitional arrangements. The need for such reforms has not yet been addressed in policy (Bigby and Fyffe 2007).
- Most people with medium or higher levels of support needs have no access to individualised funding, because packages are too small, nor to group homes, because the few vacancies that arise are allocated only to people classified as having an urgent need.
- Allocation of packages which are too small to meet the actual needs of their recipients in the absence of accommodation standards, has led to the creation of new congregated facilities by non-government organisations. Several organisations in Victoria have initiated housing developments to cater for clients receiving individualised funding packages. However, because these packages are often too small to provide the actual level of support a person requires, some support agencies chose to develop a clustered or congregated facility where residents can share

their supports. Such facilities are in some cases more than three times larger than CRUs in terms of the number of residents congregated on a single site. This is the very opposite outcome to that which is implied by the notion of 'individualization'. Therefore, an individualized funding package allocated should be attached to a person-centred plan which is audited systematically, to ensure outcomes meet the principles of community inclusion and individual choice.

- One of the major roles of the welfare state is to support those who are most vulnerable (Rawls 1971) in this case people with higher and more complex needs. In many ways, this principle offers a safety net for *all* citizens. This principle means that people with higher levels of support needs should not be excluded from individualised funding, but rather prioritised.
- Allocation of larger individualised funding packages would enable people with challenging behaviours to move out of group homes. Group settings such as shared supported accommodation are inappropriate for people who have very serious difficulties living with others, but in Victoria such options have become the default option for people with challenging behaviours in the absence of other alternatives. Supporting people with challenging behaviours to move out of group homes to more individualised settings, with sufficient specialised supports, may solve many of the compatibility problems which undermine quality of life for most residents in shared supported accommodation in Victoria. Group-homes may thus become more liveable homes.
- Many people with intellectual disability, particularly those with more severe and profound impairment will find it difficult to express their own preferences and aspirations, and rely on others to identify needs and organise support to meet these. Research on individualised funding suggests the importance of peer or professional support in the planning process for all service users (Askheim, 2003). It also highlights the potential need for independent advocacy for adults with intellectual disability to avoid conflicting interests and ensure as far as possible decisions reflect those the person would have made rather than what parents or others may regard as being in their best interests. Independent advocacy is rarely available in Victoria, and should be strengthened to support people with intellectual disabilities in the process of applying, planning and implementing plans for support and accommodation.

6.2 Individualised living arrangements for people with challenging behaviours

People with challenging behaviours are often placed in shared supported accommodation because of their intensive support needs. However, group housing is often the least appropriate model for them. A person with challenging behaviours has serious difficulties to share a home with other people.

That person as well as their co-residents will all suffer from such an unsuitable placement, as evident in the account in Box 9 below. Challenging behaviours may be reduced if people are allowed and supported to lead a lifestyle based on their individual needs and desires, in more individualised accommodation settings.

Box 9

VALID reports constant complaints coming from people with intellectual disabilities and families about clashes between residents in group homes, particularly sharing in group homes with one or more people with challenging behaviours or autism. In one case, for example, five people with challenging behaviours were housed together in a CRU. The result was daily incidents, friction between the residents as well as their families and extreme pressure on all concerned, including the staff. Over this time, DHS spent vast resources to try and ease the pressure through training programs and workshops, consultancies, meetings, appeals, investigations and assessments – the 'hidden costs' (Mansell 2007) of inappropriate placements. Eventually, the housed closed down and all residents were transferred to other CRUs. Nevertheless, the problem of incompatibility has not been fixed – just transferred. It should be acknowledged that group living is inappropriate for many people with challenging behaviours, and that a more individualised and specialised approach should be taken to accommodate and support them.

Evidence shows (see Box 10 below for example) that vacancies in shared supported
accommodation in Victoria are often not filled because of the behaviours of some residents. It
means that the efficiency of the whole service system is undermined by inappropriate
placements of people with challenging behaviours in group settings.

Box 10

Michael, manager in a non-government support agency providing CRUs: "We have 3 residents in one of the houses ... who have challenging behaviours, and can be quite aggressive... That's why we have three residents in a six- bedroom house. And we're supposed to have a fourth person in there, but we are not prepared to move another person with a challenging behaviour into the house, because we don't believe it will

serve anyone's needs. And we'll be willing to talk about taking two people into the house ... who didn't have challenging behaviours. But we're concerned about people being subjected to abuse, and so that has to be the right two people who will be strong enough".

Michael's account raises the impossible dilemmas which are inevitable when people with challenging behaviours are placed in group homes. On the one hand, it is not fair to house two people – even if they are 'strong enough' - in a house with three people who may be abusive; on the other hand, it is also not fair not to fill up vacancies with so many people on the waiting list in urgent need; and, it is not fair nor wise to cluster people with challenging behaviours together. Since each of these solutions is extremely unfair, it appears that the only way forward is to individualise supports for people with challenging behaviours (Vizel, Forthcoming)

- An understanding that group housing is an inappropriate housing model for people with challenging behaviours, and placement in group homes has detrimental outcomes to them as well as for other other residents, leads to the conclusion that people with challenging behaviours should be supported to move into more individualised settings with intensive supports.
- Despite the perceived additional costs of providing one-on-one supports for people living on their own, this is unlikely to be so in the long run as savings are made on the costly ad-hoc responses to problems created by incompatible residents in group homes and unfilled vacancies in group homes (see Box 9 for example).
- Once supported in a more compatible model, it is likely that some of the challenging behaviours will disappear and over time support requirements will decrease. Several organizations in Victoria have put in place individualised accommodation and support arrangements for people with challenging behaviours (See Box 11 for example), but such programs continue to operate as isolated 'best practice' cases and have not yet been adapted on a wider basis within the service sector despite the pressing need and placement in a CRU is still the default and only option considered in planning for people with challenging behaviours.
- Challenging behaviours should not be used as an excuse to institutionalise people. In the 1997 closure of Janefield and Kingsbury Training Centres, while 250 people were moved to group homes, 100 other people were moved into a new institution that was built for them, Plenty Residential Services, with an explicit explanation that this is because they require additional

supports due to 'physical and behavioural needs' (Coalition Against Segregated Living 2000: 2). Such practices exclude people with challenging behaviours from the principles enshrined in the Disability State Plan, by condemning them to continuing institutionalisation. For example, the annual report of the community visitors program drew attention to the 'institutional nature' of this service, suggesting that significant cultural and attitudinal change needs to occur to address the "sense of staff bringing the world into residents' lives at PRS, rather than looking to provide opportunities to take residents out into the world" (Community Visitors, 2003: 7).

Box 11

Naomi is a 51 years old woman with an intellectual disability. She had first been institutionalised as a child and an attempt to move back to live with her mother failed as their relationship broke-down shortly after. After many years of wandering between different types of inappropriate accommodation in group settings, Naomi has only recently moved to live on her own under a new person-centred program led by the non-government organization that has been supporting her in her previous CRU. After so many years, she finally lives in a place she can call home and where she would like to stay. Also, there are no other co-residents who suffer from her behaviour. Naomi was able to access individualised housing thanks to the availability of individualised funding and individualised planning mechanisms, as well as her relatively low level of support needs (which was not as low when she lived with other people as it is now when she is living independently). She finally has a real home where her obvious difficulty to live with other people is not constantly tested.

• Individualising supports for people with challenging behaviours should not be used as a way to socially isolate them. As Mansell (2007) argues, it is not 'simply a matter of switching the service model and expecting the problem to disappear' (p. 8). A specialised and intensive support program should be provided to avoid this and other risks.

6.3 Changing needs

As people age, their supports needs change and often increase. Community Visitors, for
example, noticed in their visits to CRUs in 2006 an increasing number of people displaying the
onset of dementia. (Community Visitors 2007: 17). Neither the disability sector nor the aged-

- care sector in Victoria adequately addresses the needs of older people with intellectual disabilities. (Bigby 2002)
- Most dominantly, people with intellectual disabilities in the age group of 50-60 have poorly serviced accommodation needs (Standing Committee on Community Affairs 2007). 1,364 people with disabilities in Victoria aged 50-65 and another 220 aged less than 50, live in aged care facilities. 15% of them have intellectual disabilities (Department of Health and Ageing 2006; Winkler et al. 2006).
- Nursing homes are highly restrictive forms of accommodation, inappropriate for most people
 with intellectual disabilities. Numbers of young people in nursing homes in Victoria appears are
 increasingly particularly for people in the age groups of 30-39 and 60-64 as evident in the table
 below (data obtained from the Department of Health and Ageing, cited in Young people in
 Nursing homes National Alliance, 2008, and is not specific for people with intellectual
 disabilities):

Year/Age group	0-9	10-19	20-29	30-39	40-49	50-59	60-64	Total under 65
March 2005	X	X	14	34	163	655	663	1,529
March 2006	0	X	14	40	169	661	681	1,565
September 2007	0	X	15	43	154	649	752	1,615

- Significant too is the inappropriate placement in residential aged care of 'younger older 'people with intellectual disability, who in their 60s and 70s are much younger than other residents, and remain for much longer periods of time. They have difficulty forming relationships with other residents and participating in activity programs community, and staff often lack the expertise of supporting people with intellectual disabilities. (Bigby et al. 2008).
- Moving to another service often means relocation from the local community, and thus a loss of
 the natural support network. There is no policy in Victoria to support aging in place and adapt
 funding to take account of changing needs as residents in shared supported accommodation age.
 In fact policy documents explicitly maintain that clients are expected to move to another service
 (Bigby and Fyffe 2007: 24). This is discriminatory and contrary to the policy intent applicable
 to the general population that supports aging in place (Bigby, 2008)
- The disability sector should take a leading role in the provision of housing and supports for
 older people with intellectual disabilities, to avoid premature and inappropriate admission to
 residential aged care and develop the capacity of the geriatric and community aged care services

to provide services to people with an intellectual disability who are aging. (see Box 10 below) (Bigby 2002: 240).

Box 12

Cooperation between the disability sector and the aged-care sector has been successful in the US, where joint planning is mandatory and takes place in research and teaching consortiums in key Universities, in regional joint planning forums, conferences and joint initiatives to produce innovative programs. (Janicki 1994; Bigby 2002) In Australia, a "significant cross-sector pilot program was established in 2003/2004 by the Department of Health and Ageing as part of their Aged Care Innovative Pool Pilots (AIHW, 2006). Nine projects across Australia were established to explore the provision of community-based aged care services for ageing residents in group homes. Objectives were to identify age-related needs and to test whether the addition of aged care services would reduce inappropriate entry to residential aged care. The programs were targeted at residents assessed as eligible for residential aged care. State governments, in partnership with disability provider organisations, maintained existing disability supports while project funds purchased additional services through partner aged care providers. The projects demonstrated improved quality of life for older residents and the feasibility of supporting them to age in place largely through additional health planning, access to allied health care, and day-time community support. Furthermore, the projects demonstrated the potential of cross-sector partnerships when resources are made available to support them. Highlighted also was the complexity of distinguishing age-related from disability-related needs, and the importance of joint assessment processes by ACAS and disability services (AIHW, 2006). Despite advocacy from the disability sector in support of these pilot programs, they were not continued" (Bigby 2008: 80)

- People with mild intellectual disabilities which are just slightly outside the eligibility criteria for state funded disability services are also at risk of homelessness, as their needs change over time.
- As with the rest of the population, personal relationships among people with intellectual
 disabilities change over time. However, support and accommodation services are often too
 inflexible to adapt to such changes in relationships, particularly for couples moving into a
 relationship or out of one (see Box 13).

Adam has an intellectual disability and lives in a group home with four other men. He is the only resident who has had a girlfriend and he found that he had little privacy in the group home to spend time with her. Even when he was in his room with his girlfriend the other residents would often come and stand outside the door or knock to come in. Staff tried to discourage this but with limited success. Adam had even paid for the use of a motel room so that he could have time with his girlfriend away from the group home but he could only afford this rarely. The stress on his relationship resulting from the lack of private space had a negative affect and the couple broke up. (Reported by AMIDA)

7. Principles to address housing and support for people with intellectual disabilities

The following principles have been devised collaboratively by members of the 2007 Annual Roundtable on Intellectual Disability Policy which included representatives from DHS, support agencies, advocacy organizations and researchers. We call upon the State Government to endorse these as guiding principles to the provision of housing and support for people with intellectual disabilities in Victoria (Copied in full from the Annual Roundtable on Intellectual Disability Policy in Victoria 2007: 45-47):

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

1. Planning and decision making Timely and	access to housing.Support is not tied to a particular place of residence.
Coordinated	Individuals are not forced to move as their needs change.
Planning over a life time	 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.
Rationale for resources allocation	 Transparent and inclusive of family and advocates, and all providers.

	T
	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.
2. Decisions & Advocacy	 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
2 414	service system.
3. About support Support is	Support is organised around a person's needs and preferences and not deminated by organisational needs.
Individualised	and not dominated by organisational needs.
mairianansea	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.
Support is flexible,	Support is available where each individual lives.
reliable and	A choice of support provision is available through different
coordinated	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.
Support enables	• Support changes in response to the type of lifestyle pursued by
choice of activities and participation in	people over time.
a range of daily life	• Support allows meaningful participation in the home and in the community.
activities	 Support enables individuals to go regularly to places in the
	community where they can become known.
4. About housing	Individuals can choose where they live and with whom.
There is a range of	• Individuals can choose their form of housing i.e. house, unit, and
housing and living	apartment; from the same range of housing options available to
situations available	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.
Housing in context	Houses fit in with streetscapes and are not enclaves isolated
of the local area	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
C11.1	space.)
Shared housing and support is by choice	• Individuals are not expected to live with others unless they chose to do so.
support is by choice	 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).
Housing design	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	 If individuals are unable to afford to purchase their own housing
5 ~ FF-J	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.
	There are population-based targets for the provision of housing
6. About systems	There are population-based targets for the provision of housing and support for all people with disabilities and for the sub group
Population based	of people with intellectual disability and high and complex
targets	needs. In the absence of Victorian/ Australian population-based
	data, the targets are at least comparable to those devised
	overseas.
Monitoring and	The services and support provided by organizations is in

organisational accountability	 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.
Planning for systems and person-centered planning	

References

- ABS Australian Bureau of Statistics (2004). Disability Ageing and Carers Australia. http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02003?OpenDocument
- AMIDA (1997). Respecting renters rights: exploring a model of tenancy rights for people with disabilities who live in supported housing. Melbourne: AMIDA. http://www.amida.infoxchange.net.au/REP/RENTERS.htm
- Australian Housing and Urban Research Institute (2002). Improving Housing and Support Service Coordination for People Living With Mental Illness, *AHURI Research & Policy Bulletin* (pp. 1-4). Melbourne: AHURI Australian Housing and Urban Research Institute.
- AIHW (1998). Disability Support Services Provided Under the Commonwealth/State Disability Agreement: National Data 1997. Canberra.
- (2002a). Disability Support Services 2001: National data on services provided under the Commonwealth State/Territory Disability Agreement. Canberra.
- (2002b). Unmet need for disability services: effectiveness of funding and remaining shortfalls. Canberra.
- (2005). Disability Support Services 2003-04: National data on services provided under the Commonwealth State/Territory Disability Agreement. Canberra.
- (2006). Disability Support Services 2004-05: National data on services provided under the Commonwealth State/Territory Disability Agreement. Canberra.
- Annual Roundtable on Intellectual Disability Policy in Victoria (2007). Position statement on housing and support for people with intellectual disability and high, complex or changing needs, *Proceedings of the Second Annual Roundtable on Intellectual Disability Policy* (Eds. C. Bigby & C. Fyffe), Melbourne: La Trobe University.
- Askheim, O. (2003). Personal assistance for people with intellectual impairments: experiences and dilemmas. *Disability and Society*, *18*(3), 325-339.
- Beadle-Brown, J. & Forrester-Jones, R. (2003). Social impairment in the care in the community cohort: the effect of deinstitutionalization and changes over time in the community, Research in Developmental Disabilities, 24(1), 33-43.
- Berry, M. & Hall, J. (2001). *Policy options for stimulating private sector investment in affordable housing across Australia: stage 1 report, outlining the need for action.* Affordable Housing National Research Consortium, Sydney (www.consortium.asn.au).
- Bigby, C. (1997). When parents relinquish care: Informal support networks of older people with intellectual disability. Journal for Applied Research in Intellectual Disabilities, 10, 333-344.
- (2002). Ageing people with a lifelong disability: challenges for the aged care and disability sectors. *Journal of Intellectual Disability*, 27 (4), 231-241.
- (2004a). Ageing with a lifelong disability: a guide to practice, program, and policy issues for human services professionals. London, New York: Jessica Kingsley.
- (2004b). But why are these questions being asked? a commentary on Emerson (2004). *Journal of Intellectual & Developmental Disability*, 29, 202-205.
- (2008). Beset by obstacles: a review of Australian policy development to support ageing in place for people with intellectual disability, *Journal of Intellectual & Developmental Disability* 33(1), 76-86.
- Bigby, C., Webber, R., Bowers, B. & McKenzie-Green, B. (2008). A survey of people with intellectual disabilities living in residential aged care facilities in Victoria, Journal of Intellectual Disability Research, 52(5), 404-414.

- Bigby, C., & Fyffe, C. (2007). An analysis of the current policies on housing and support for people with intellectual disability and complex or challenging support needs in Victoria. In C. Bigby & C. Fyffe (Eds.), Second Annual Roundtable on Intellectual Disability Policy (pp. 18-26). Melbourne: La Trobe University.
- Bradley, V. (1996). Foreword. In J. Mansell & K. Ericsson (Eds.), Deinstitutionalisation and Community Living. London: Chapman and Hall.
- Centrelink (2008). A guide to Australian Government Payments. Canberra: Australian Government.
- Clement, T., Bigby C. & Johnson, K. (2007). *Making life good in the community: the story so far. Interim Report.* Melbourne: Department of Human Services.
- Clement, T. & Bigby C. (2007). Making life good in the community: the importance of practice leadership and the role of the house supervisor. Melbourne: Department of Human Services.
- (2008). Making life good in the community: Building inclusive communities: facilitating community participation for people with severe intellectual disabilities. Melbourne: Department of Human Services.
- Coalition Against Segregated Living (2000). Challenging institutions: community living for people with ongoing needs. Melbourne: AMIDA.
- Community Visitors (2003). Community Visitors Annual report, Melbourne: Office of the Public Advocate.
 - (2007). Community Visitors Annual Report 2006, Health Services Act 1988, Melbourne: Office of the Public Advocate.
- Department of Health and Ageing (2006). Reducing the Number of Younger People with Disabilities Living in Nursing Homes. Canberra: Australian Government.
- Department of Human Services (2003). 2003 Supported Residential Services (SRS) Census. Victorian State Government.
 - (2005). Evaluation of Support & Choice: How did the first year work? Melbourne: Victorian State Government.
 - (2006). Disability services: policy and funding plan 2006-2009.
 - (2008a). Rental Report, March Quarter 2008. Melbourne: Victorian State Government.
 - (2008b). Total number of applicants on the public housing waiting list as at June 2008, Office of Housing. Melbourne: Victorian State Government.
 - (2008c). People on the Disability Support Register. Accessed on 25 August 2008, http://hnb.dhs.vic.gov.au/ds/disabilitysite.nsf/sectionone/supports_people#dsr.
- Efstratiou, N. (2003). Ownership of our own lives. A research and education project on the rights of people with intellectual disabilities living in Community Residential Units. Melbourne: REINFORCE INC (Victorian Association of Intellectually Disadvantaged Citizens).
- Felce, D., Grant. G. (1998). *Towards a full life: researching policy innovation for people with learning disabilities*, Oxford: Butterworth Heinemann.
- Goffman, E. (1961/1978). Asylums: Essays on the social situation of mental patients and other inmates. London: Pelican Books
- Golding, L., Emerson, E. & Thornton, A. (2005). An evaluation of specialized community-based residential supports for people with challenging behaviour, Journal of Intellectual Disability, 92(2), 145-154.
- Hatton, C., (2001). Strategies for change: implementing Valuing People at the local level. Developing housing and support options: lessons from research. Lancaster University: http://www.lancs.ac.uk/fass/ihr/publications/housing_support.pdf
- Hatton, C. & Emerson, E. (1996). Residential Provision for People with Learning Disabilities: a Research Review. Manchester: Hester Adrian Research Centre, University of Manchester.
- Janicki, M. (1994). Policies and supports for older persons with mental retardation. In M. Seltzer, M. Krauss & M. Janicki (Eds), *Life course perspectives on adulthood and old age.* Washington DC: American Association on Mental Retardation.
- Berry, M. & Hall, J. (2001). *Policy options for stimulating private sector investment in affordable housing across Australia: stage 1 report, outlining the need for action.* Affordable Housing National Research Consortium, Sydney (www.consortium.asn.au).
- Kihl-Larssen, K. (2006). NACS Conference 2006 presentation: www.nds.org.au/vic/NACS/NACS2006/presentations/Kihl-Larssen.ppt
- Kim, S., Larson, S. A. & Lakin, K. C. (2001). Behavioural outcomes of deinstitutionalization for people with intellectual disability: a review of studies conducted between 1980 and 1999, Journal of Intellectual and Developmental Disability, 26, 35-50.
- Mansell, J. (2005). Deinstitutionalisation and community living: an international perspective, *Tizard Learning Disability Review*, 10(1), 22-29.
- (2006). Deinstitutionalisation and community living: Progress, problems and priorities. In: *Journal of Intellectual and Development Disability* 31(2), 65-76.

- (2007). Services for people with learning disabilities and challenging behaviours or mental health needs. London: Department of Health.
- Noonan Walsh, P., Emerson, E., Lobb, C., Hatton, C., Bradley, V., Schalock, R., Moseley, C. (2008). Supported accommodation services for people with intellectual disabilities: A review of models and instruments used to measure quality of life in various settings. Dublin: National Disability Authority
- Poll, C. (2007). KeyRing Living Support Networks and Neighbourhood Networks, In S. Hunter and P. Ritchie, *Co-production and personalisation in social care*, London: Jessica Kingsley.
- Rawls, J. (1971). A theory of Justice. Cambridge MA, Belknap Press.
- Reilly, T. (2008). Bullying claim at elderly home, The Age, 7/9/2008.
- Simons, K. (1998) Living support networks. An evaluation of the services provided by KeyRing. Bristol: Joseph Rowntree Foundation.
- Stancliffe R. J., McVilly, K. R., & Radler, G. (2008). Research into client outcomes where staff have been trained in Active Support methodology. *Reflections on the Kew Residential Services Redevelopment Forum*, 22/9/2008, Melbourne: Department of Human Services.
- Standing Committee on Community Affairs (2007). Funding and Operation of the Commonwealth State/Territory Disability Agreement. Canberra: The Senate.
- Tossebro, J. (1996). Deinstitutionalisation in the Norwegian welfare state. In: Deinstitutionalisation and Community Living (Eds: J. Mansell and K. Ericsson). London: Chapman and Hall, 65-78.
- VALID (2007). Crisis in the North & West: VALID demands answers, VALID News, September, 6-7.
- Victorian Auditor-General (2008). Accommodation for People with a Disability. Melbourne: Victorian Government.
- Victorian Auditor-General (2008). Accommodation for People with a Disability. Melbourne: Victorian Government.
- Vizel, I. (Forthcoming). The choice agenda and shifts in the geography of housing for people with intellectual disabilities, PhD dissertation, Melbourne: University of Melbourne.
- Winkler, D., Farnworth, L., & Sloan, S. (2006). People under 60 living in aged care facilities in Victoria. Australian Health Review, 30, 100-108.
- Yates, J. & Wulff, M. (2005). Market provision of affordable rental housing: lessons from recent trends in Australia. *Urban Policy and Research*, 23, 1, 5-19.
- Young, L. et al. (1998). Deinstitutionalisation of persons with intellectual disabilities: a review of Australian studies, Journal of Intellectual and Developmental Disability, 23, 155-170.