

**Housing and Support for People with Intellectual Disability
and High, Complex or Changing Needs**

Proceedings of the

**SECOND ANNUAL ROUNDTABLE ON
INTELLECTUAL DISABILITY POLICY**

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INTRODUCTION

This collection brings together the papers and discussion from the second Annual Roundtable on Intellectual Disability Policy held at LaTrobe University in April 2007. The Roundtable 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 intellectual disability and high, complex or changing needs who are some of the community’s most vulnerable people 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 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, and will be the subject of an audit for the Auditor General later in 2007.

There was attention to ‘what is happening now’, the implications for people’s lives in 2011 if current trends and policies continue and what needs to be resolved to reach scenarios more in tune with the aspirations of the State Disability plan. The papers explored experiences of housing and support from the perspectives of people being supported, providers, policy analysis and research. Colin Hiscoe, (with Patsie Frawley and on behalf of

Reinforce self advocates) succinctly described how people with high, complex and changing needs ‘are not always able to tell people what it is like for them; have to put their lives in other people’s hands; and could be left in bed all day if they don’t get good support.’ In a similar vein, Erin Wilson’s paper (with Chris Fyffe, Estelle Fyffe and Diana Heggie) outlined case studies of the service system and posed the question ‘can best practice can be implemented in a resource vacuum?’ They concluded that ‘there is a gulf between the policy ideals and the pressures of day to day resources allocation which, without explicit recognition, cannot be directly tackled.’ The paper by Chris Bigby and Chris Fyffe, analysed current mid level policy and strategies, suggesting it appeared that people with high or complex needs who require 24 hour are being left out of the new emerging housing and support options and that practice issues for this group were not being addressed. Paul Ramcharan’s paper (with Karen Nankervis and Geraldine Abdilla) explored the findings from research about housing and support as a basis for articulating good practice and the importance of responding well to those with the highest needs. Jim Mansell’s presentation outlined his fruit less search for the available Australian data, to describe and contrast service responses here and with the USA and UK, where such figures are available. He posed the challenging question: ‘If knowledge is power- why don’t you have any?’

Also included in this collection is a draft policy outcome statement on housing and support for people with intellectual disability and high, complex or changing need developed from the Roundtable.

SUMMARY OF DISCUSSIONS

There was a strong consensus that the papers presented at the Roundtable represented well the major issues in relation to housing and support for people with intellectual disability and high, complex or changing needs. The main points arising from group discussions were:

- The need to understand the perspective of people with high and complex needs and develop staff practice accordingly
- Without policies which specify how implementation will occur, the high level aspirational policies of the State plan are being compromised
- The lack of population-based targets meaning there is no basis for planning and monitoring, nor for systemic advocacy
- The realisation that best use is not being made of available resources in a resource constrained climate
- The ever present tendency for the disability sector to isolate itself from other sectors and wider issues, in this case affordable housing.

It was noted that the focus of the papers was formal provision of housing and support and issues associated with support for continued residence with family had not been canvassed and are often not included in the same discussions. The adequacy both of volume and timeliness of services to enable families to continue to care for children and support adults with intellectual disability and high, complex or changing needs, was highlighted as well as the complexities of assuming lifelong care within a family. It is not always clear whether living at home with family continues from choice or because of system shortfalls, and therefore if it is the latter supporting families is not the main policy response required. The bulk of discussion, summarised below, explored further the nature of the major issues identified in the papers, considering which were the most pressing and potential action to resolve some of these.

Understanding needs and choices

The group discussion stressed the importance of housing as a right. Housing is fundamental for the development and maintenance of positive of well-being. One of the first decisions about quality of life was recognised as who we choose to live with. This revealed the disconnection between disability ideology and structural problems in provision of housing and support. Further, the system has invested so many resources in risk management, often contrary to the pursuit of quality of life, there is little left for emphasis on relationships and how to make a 'house a home' (see Paul Ramcharan's paper).

The debate moved to the difficult question about how it can be known what the needs and choices of people with intellectual disabilities and complex needs are; and how their views or preferences can be recognized both in individual planning but also in broader organisational and service system planning. Issues that have not been well addressed or debated in Victoria are, who can represent people with intellectual disability and high or complex needs and on what basis, and the provision of support for people who can more readily represent themselves and who participate in policy and organizational forums. The Roundtable process this year started to explore participation by funding support for a small group of self advocates to present their views about housing and support. Issues of representation and participation in policy debate by people with intellectual disability were flagged as the focus for the 2008 Roundtable.

Stronger planning frameworks and population based targets

A planning framework articulates the strategies by which policy aims will be achieved, and gives a greater sense of certainty about acceptable strategies. The absence of a planning framework and associated population-based targets for housing and support means there is no clarity about the translation of high level policies about inclusion or choice to 'on the ground' provision of housing and support for people with complex needs. High level policy is inevitably silent about the detail of what typical living arrangements look like for people with intellectual disability and high, complex or changing support needs. Mid level policy should be how such detail is outlined for implementation.

If mid level policy is also silent on detail, if strategies and targets are not articulated, there is a danger that 'anything goes', that 'something is better than nothing', as 'there will never be enough money'. Examples of this are found in the recent building of 'larger' shared supported accommodation houses for older people with intellectual disability and those with complex needs moving out of residential aged care, despite the lack of evidence to support living arrangements of this density contributing to quality of life. In the absence of planning and sub-population targets, utilitarian principles tend to dominate, i.e. with the same resources more outcomes for more people with mild disabilities can be achieved and these outcomes may also be more apparent, than the more subtle and higher cost outcomes accomplished to the quality of life of people with higher support needs. It is important that tensions such as this, between meeting the needs of different sub groups of people are recognized

as resource allocation using utilitarian principles has the potential to steadily undermine broader policy intent. That is, to create a gap between the State Plan and what actually happens.

A planning approach based on population, rather than who happens to request (or 'demand') services, allows for an articulation of what is needed, what governments can be expected to provide, and for whom, i.e. what is the capacity for provision of housing and support that is being aimed for, what can families and people with disabilities expect from the government system, what are families or community agencies expected to provide. The underlying assumption in the discussions was that people with intellectual disabilities would have adequate housing and support arrangements, and that it was government's responsibility to plan for this to occur. This is clearly the message conveyed in policies such as the State Plan. Therefore the critical importance of systemic and population based planning for housing and support for all people with disabilities and particular sub-groups such as people with high, complex or changing needs was identified. Planning means needs are mapped and strategies identified to meet these within a time frame. Planning allows policy to be translated into concrete measures consistent with available resources, and the development of population based benchmarks for housing, support and related services. Planning makes a clear link between policy and the use of resources to achieve its aims, and is a key way to ensure resources are allocated and prioritised to sub – groups such as people with high, complex or changing needs. These arguments assumed those with higher needs are a higher priority for resources.

Planning that stipulates particular sub-groups avoids undifferentiated or simplistic outcome measures, such as the number of housing places or support packages, and thus a slide towards the provision of resources which is not directed towards nominated high priority groups. Whilst population planning places a greater onus on governments and systems for accountability, the translation of policy goals into identifiable targets also provides more leverage for the lead Department to argue for resources from Treasury and other government departments. It also makes more likely a cross government response as several departments and programs have responsibility for aspects of the housing and support responses for people with disabilities. For example, planning targets can be directed to broader housing developments, such as 15% of all affordable housing must be allocated specifically for people with disabilities. A coherent planning framework provides the ammunition for greater political influence by disability advocacy groups on politicians and the community. A concerted focus on planning

enables more transparent processes for the use of available resources, and greater opportunities for involvement by all stakeholders in the determining priorities for the allocation of resources. Long term planning would enable cost modeling over a longer time period, such as the lifespan of a person with high and complex needs, which doesn't happen currently. Such planning enables the cost benefits of expenditure on preventative or non-crisis services to be demonstrated, and highlights the financial disincentives associated with crisis management. Population based planning and financial modeling over time gives a stronger sense that the needs of people with high or complex needs are not short term but lifelong and in many ways predictable. In an era of resources limitations, and demonstrated in the case studies paper (Wilson & Fyffe), the current approaches to planning do not make best use of available resources.

Planning is critical to ensure that the disparate and cross departmental parts of the disability system response are considered together, for example, respite, family support and housing and support. This is consistent with person-centered planning but at a system level. It means that the broader context, socio-demographic or service system changes in other sectors that impact on the disability sector are foreshadowed and factored into developments. For example, declining number of beds in the SRS's, changing role of residential aged care for people aged less than 65 years, changes to priority access in HACC, caps on Linkages funds, the decline in respite beds as they are filled with long term residents, and increased life expectancy of people with disabilities and thus as people live longer more will develop/experience disability, will all impact on the demand for services.

In Victoria, the absence of planning means that the scale of the problem to be tackled remain largely unknown, there are no targets for achieving high level policy goals, and no clear sense of when and how goals will be achieved in the future. Even what has been achieved is not well articulated, a situation that does serve government well.

In contrast discussion also focused on the amount of time spent on aspirational planning for individual people with intellectual disability in the absence of any certainty about the availability of resources for implementation (see for example the case studies in the paper by Wilson and Fyffe). It was suggested there be less focus on individual planning prior to possibilities for implementation, such as the allocation of funds for specialist resources and mustering of informal supports. The bulk of planning should occur once the quantum of resources available has been identified. There is a need for attention

to resource allocation mechanisms based on level of support needs, and once resources are allocated for more individualised planning to occur with the individual and their networks. The importance of mechanisms for linking data from individual planning to system-wide planning was seen as fundamental to the development of an infrastructure of services that can be relied on to realize individuals' plans. There is a danger of over-attention to each individual in the absence of system-wide responses.

Planning data

A concurrent thread to the discussion about planning was the importance of data on the population of people with intellectual disability and high, severe or changing needs, their needs and existing service provision. Such data would enable comparison between this and other groups. Good data allows the size and nature of the problems in the disability sector to be clearly laid out and used to support claims for resources to address them. There was unanimous agreement that data on service use, unmet and under met needs are exceptionally difficult to piece together, and little data are available on the population of people with disabilities who use support services. For example, no common assessment is made of the nature or severity of a person's disability, often basic diagnostic information is no longer collected. Data are also fragmented and different sources are not comparable. Changing definitions and data collection methods have also meant that it is difficult to track trends over time.

Translation of broad policy principals for people with high, complex or changing needs

Closely related to discussion about the absence of a strong planning framework and clearly articulated strategies with attached targets, was a sense of little consensus as to how high level policy aims, such as choice, inclusion, participation and independence, are understood, in particular in relation to people with high and complex needs. As well as population data, a precursor to planning is a much better understanding of how policy principles translate into the life situations and needed relationships for people with high and complex needs. Greater clarity about the application of principles to people with high and complex needs also enables better targeting and prioritization among different groups. It was felt that many of the broader community development initiatives address issues more relevant to people with physical and sensory disabilities or milder intellectual disabilities. Articulation of what, for example, inclusion means for someone with more

complex needs assists in the development of ideas, targets and strategies both in the service sector and broader community development initiatives. Greater clarity supports more refined outcome measures that provide a clearer understanding of who is actually receiving support, and thus avoid responses based on lobbying or ease of provision that can mean people with the highest needs receive the poorest service responses. There was a sense too that core principles are being compromised for people with more complex needs, by for example; expectations that new housing and support options will not provide 24 hour support, thus excluding those who may require this level of staff support; the apparent quarantining of shared supported accommodation from growth or reform, and seeing this type of housing and support as quite separate from more 'acceptable' or newer models of independent living.

Practice issues

Impediments to good practice in supporting people with high and complex needs were discussed. Workforce issues figured prominently, including, the need to raise the low value attached to work in the disability field, to address staff shortages and skill deficits in the workforce. Strategies suggested were, equalization of pay and conditions across the government and non government sectors, greater collaboration with the higher education sector, and enhanced career structures.

Practice in this area requires significant judgments to be made that cannot be standardised. Further, there are competing forces. For example, staff making decisions about housing and support have to weigh tensions about what suits the individual best and or their expressed preferences which may not align well with designated service standard or occupational health and safety practices. Such tensions are not resolved by simply ignoring them.

The discussion focused on the need to develop the 'support capacity' of the system, along side development of housing options. This entails identifying the elements of a flexible support system able to deliver person-centered support in diverse locations to individuals or small groups of co-residents, and developing expertise in the management of such a system, particularly in regard to supervision, training, quality control, monitoring and recruitment. It was also considered that it was important to recognize and promote the specialist skills required to support people with high and complex needs to achieve, for example, inclusion or a typical life. Discussants noted a trend to keep re-inventing the 'answer' where 'recipes' mean staff stop thinking and just act, which can be inadequate with people with complex need who are the 'hardest to know'.

Measuring outcomes of staff support is often the most difficult for work with people high complex needs, as much practice is based on the development of a relationship. Although there are examples of good practices in Victoria there is little expertise about systems for achieving this. Allied to the need to develop service system capacity to provide formal support, was the recognition of the role of informal and or community based support for people with intellectual disability and high and complex needs, and the limited experience in Victoria of using formal services to foster such support in the form of linkages to community organisations or building circles of support. Consequently, there is significant need for experimentation and long term evaluation to understand the issues associated with fostering informal and community support for people with high complex needs within the context of their supported living arrangements.

Connections with other service sectors

Though policy refers to a whole of government approach to disability issues, it has been difficult to see this realized on the ground, particularly for people with high and complex needs. Whilst trying to claim specific resources for this group it is important to retain a perspective that sees them as a sub-group of larger whole such as people with disabilities or people with a low income. This avoids them being perceived as a minority group and retains their claim to 'mainstream' resources. Strategically it may be important to claim a proportion of funding available to a larger group rather than compartmentalizing funding into smaller discrete programs. Thus targets for people with high and complex needs within broader targets were thought to be a useful strategy. For example, housing availability for all is declining and there is a need for more, cheaper, affordable housing. The disability sector has not been part of wider national housing discussions.

It may also be a useful strategy to draw attention to the proportion of people with disabilities who are users of mainstream service or non-specialist disability services such as hospitals and community health centers, and pose questions about what adaptations are being made for them. Little is known about the ease with which people with high and complex needs and those whose needs are changing are able to access such services or the resources from the disability system that is required to support their access. (Unlike, for example, strategies to promote access for people who do not speak English). This is important to avoid resources allocated to an individual

for housing and support being drained away to support access to essential services such as health care or transportation.

Role of the disability sector

The relative lack of political power and influence exercised by the Disability Sector had been raised at the 2006 Roundtable, and was raised again. Despite a broad based coalition of disability interests in the lead up to the State election last year, little real ground had been won. Discussion focussed on why disability attracted such little attention, and how the influence of the sector could be increased – ideas included, forming broader alliances, exerting organisational power given governments are reliant on non government organisations to provide services, for example, refusing to fill respite beds with homeless residents, shifting issues from the operational sphere and reframing them to be key regional and statewide planning issues, using the new complaints mechanisms of the Disability Services Commissioner to raise systemic issues; continually put people with high, complex or changing needs back into discussions about policy and service provision; shift the initiative for policy development away from DHS by developing independent policy positions on issues like housing and support.

Postscript

Since the roundtable, an AIHW (2007) report on unmet need commissioned by the Federal government has conservatively estimated that:

there is substantial unmet demand (by people with disabilities) for accommodation support and respite services. The estimate of 23,800 people (nationally) with unmet demand for accommodation and respite services in 2005 is 11,300 more than the 2001 estimate of 12,500.

The policy implementation landscape is also changing, with the announcement in June 2007 that the Federal government will directly fund 1750 new accommodation places in 175 'facilities', an enquiry into housing and support barriers for people with disability, and further exploration of socially affordable housing. It is unknown how these initiatives will unfold and impact on the state and non government organisation planning, including the role for private sector and non-traditional non government providers, is unknown.

Christine Bigby and Chris Fyffe. 15.08.07 based on notes from the RT discussion groups.

HOUSING AND SUPPORT FOR PEOPLE WITH AN INTELLECTUAL DISABILITY AND COMPLEX AND CHANGING NEEDS

By REINFORCE SELF ADVOCACY

What is it like for people with high, complex and changing needs?

- ❖ They are not always able to tell people what it is like for them
- ❖ They put their lives in other people's hands
- ❖ They could be left in bed all day if they don't get good support

What we know about Housing and Support

We did some research called "Ownership of our own lives" with people who live in CRUS. This is what we found out.

- ❖ People have NO CHOICE where they live, who they live with and what support they get.
- ❖ Mainly staff and sometimes family make **these decisions**
- ❖ People *don't have a real say* about their housing and support
- ❖ Staff are **not trained** on how to find out what people with high and complex needs want, and how they want to live their lives.

We think:

- ✓ Support staff need better training on communication
- ✓ Self advocates need to get to know people with high, complex and changing needs so we can help them have a say about their support needs
- ✓ Let Self Advocacy Groups into CRU's to meet people

What else we found out from our research

- ✓ People spend too much time in their houses, they only see the people they live with and staff
- ✓ Big vans means big groups going out and doing the same things together not what different people might like to do

We think:

- ✓ People should get support so they can do the things they want to do with different people like friends, family, volunteers, other groups
- ✓ People with high, complex and changing needs should be able to meet more people, have more people in their lives so it is not just staff having a say, making the decisions and being with them all the time

How can we find out what people with high, complex and changing needs want, like and need?

- ✓ Find ways of communicating
- ✓ Train staff
- ✓ Help to connect people to friends, family, advocates and self advocacy groups

Policy talks about INDIVIDUAL; plans, supports and services. This is OK but:

- ✓ Services need to plan WITH the person when they need and want it
- ✓ Staff need to have the SKILLS to plan with all people with an intellectual disability
- ✓ Involve people OUTSIDE THE SERVICE who know and care about the person
- ✓ Use plans to DEVELOP GOOD SERVICES for people . This means they will not all be the same and might need to change as people change

BEST PRACTICE IN A RESOURCE VACUUM: Responding to the accommodation needs of people with high, complex or changing support needs.

Dr Erin Wilson Scope,

Dr Chris Fyffe, Disability consultant with Estelle Fyffe and Diana Heggie.

Preamble

This paper aims to identify current practice responses to the housing and support needs of people with high, complex or changing support needs. Case studies of current housing dilemmas and responses were provided by Annecto and Scope (Vic), and included data about the responses of other providers known to these agencies. The paper will first present case study data in three categories of accommodation: living independently (ie. living alone in self-rented or self-owned housing with or without formal support); living without a home (ie. living in non permanent or non secure housing); and living in the parental home and planning for change. The case studies are followed by a discussion of the key response strategies evident in each, and an analysis of significant 'lessons' for policy.

Case studies

These case studies are not presented as representative. In fact there is no way of knowing what is representative given the lack of systematic data collection in Victoria on this topic. The case studies present a diverse array of experiences across thirty two (32) individuals. The methods of case study documentation are also diverse. Rather than provide a pro forma for case study development that identified the specific data required, the authors asked agencies to identify case studies and provide details they felt to be most pertinent to the paper's topic. As a result, some case studies detail a sequence of events and the individual elements of the service system, others articulate a broad approach or set of ingredients. Whilst this suggests that agencies have been purposeful in their selection, in at least one instance, case study selection was opportunistic, with already documented case studies being supplied as the only readily available data. The authors then collated case studies into broad categories, and edited them to form cohesive narratives (note, all names are pseudonyms).

Case studies are presented in the section below with minimal interpretation.

Living independently

This category documents the experiences of people wishing to live alone or with a partner. In most situations, people seek to gain housing that is managed by them (ie rental or owned accommodation) and in which they live with or without formal support.

Case study 1: Searching for housing

In May 2004, 'Liam' undertook lifestyle planning and identified that he wanted to live with his girlfriend. During the next eighteen months, the disability agency supported the couple to search for appropriate accommodation. The search entailed a complex array of activities:

- *Two units were identified, however both were assessed as unsuitable for modification (being unable to accommodate over-head hoists) or being too far from local transport.*
- *An application was made to the Victorian Department of Human Services (DHS) Supported Independent Living Program. The application took seven months to finalise and a further four months to assess. Following assessment, a DHS representative was appointed to undertake further assessment of support needs and assist in finding appropriate housing.*
- *During this period, it was found that Liam's girlfriend 'Anna' was not registered with DHS nor had formal services in place (as these were currently being met via informal support within her current living environment). To increase the opportunity to get funding support, Anna required immediate registration with DHS and the development of an individual plan.*
- *At this time, an advocate for Liam and Anna was appointed via a disability advocacy agency to support the couple's autonomy within the increasingly complex set of activities involved in acquiring suitable accommodation.*
- *In March 2006, almost two years after commencing the search for a home, a referral was made to a non government housing agency to commence a search for housing, including via the Local Accommodation Support Project (LASP) run by the agency.*
- *Simultaneously, an application for Supported Housing was made to DHS and applications made to the Office of Housing in three districts.*
- *Despite concerns about the difficulty of finding housing to meet Liam's high physical support*

needs, throughout March to September 2006, the housing agency appealed for assistance to over three hundred landlords via the Real Estate Institute of Victoria.

- In September 2006, an application was made to a third DHS program, Early Housing and Supported Housing. Discussions commenced to determine the possibility of a Mixed Equity Arrangement with Supported Housing, however Liam was assessed as having insufficient financial resources to undertake this option. The housing agency commenced negotiations with DHS and the non government disability agency to determine if either could contribute funds to overcome the equity shortfall.
- In November 2006, an application was made to DHS for Support and Choice funding for Anna. This application took three months to approve. However, Anna received no actual funds due to the annual program budget being already expended.
- After almost three years of unsuccessful searching, Liam and Anna suggested moving into the house Anna now lived in (ie a private home shared with other people). The house was assessed as being too costly to refurbish. DHS determined that no capital funds could be provided with only one-off minor modifications funded.
- Meanwhile a fully modified house was identified as available for rent however Liam and Anna felt that this was too far from her family.
- In March 2007, Liam received word from DHS that his Early Housing application was rejected on the grounds that he was deemed to be currently in suitable accommodation and had not been asked to leave.

In summary, across three years of housing search, four separate applications were made to DHS for housing and for support. Of these, though two were approved, none yielded actual financial support. One application was denied on the basis that Liam already had suitable accommodation that was not being withdrawn, despite this accommodation clearly being inconsistent with his individual plan. Over this period, the activity involved three non government support and advocacy agencies, one real estate industry peak body, four program areas of DHS and multiple regional localities. After three years, Liam and Anna still do not live together, nor has any change in their housing occurred. The system has expended considerable effort and staff resources to reportedly achieve little for the couple.

Case study 2: Individualised support determines housing options

Over a period of three years, a non government disability support agency has provided support to three people - 'Bill,' aged 30; 'William', aged 50; and 'Linda' in her mid forties. In each of these instances, support enabled these individuals to remain in or move into independent accommodation, where each lives alone with formal support.

'Bill' had previously been confined to his residence under twenty-four hour supervision due to violent and impulsive behaviour. Through support over the course of three years he was able to develop greater understanding into and control of his emotions and behaviour and has moved into his own flat with in-home support. Bill now also has paid employment.

'William,' although living and wanting to stay in his own home, was becoming increasingly antisocial and violent and also neglecting his personal care. He seemed on a fast track to restrictive accommodation. The disability agency assigned a worker to work with William to develop and implement a detailed person centred plan and associated support services. Identified tailored support included:

- The provision of sixteen hours per week of in-home support (provided by the agency) for: assistance with health management; personal care; meal preparation; cooking; cleaning; washing; and access to community activities. Health management support included acquiring and learning to use a Blood Glucose monitor and personal alarm, as well as regular appointments put in place with a GP, podiatrist and dietician.
- Weekly house cleaning from the local municipality.
- An occupational therapist from the local hospital assessed William's home and organised rails for the bathroom and porch.
- Weekly home visits from the Royal District Nursing Service.
- Connecting William with group activities run by the agency and volunteers who occasionally work in his garden.

Health issues and isolation had been affecting William's behaviour and a key strategy was to support the appropriate management of these. The resulting effect on his behaviour has enabled William to remain living at home, with ongoing provision of health education, specialist medical interventions and greater social involvement with resulting friendships.

'Linda' has lived in staffed shared residences all her life, spending most of her time in her

bedroom and is described as antisocial and difficult. Through the development of a lifestyle plan, it became clear that: personal space was very important to Linda; she very much wanted to move into her own flat or unit; she had established relationships with local shop keepers and neighbours; she was a capable and passionate gardener; and was potentially able to manage a unit of her own with minimal support. Whilst her immediate family initially felt Linda would not be safe outside the community residential unit (CRU), engagement with the process of planning and their involvement in an evolving circle of support changed their minds. They recognised both Linda's unhappiness in the CRU as well as her ability to manage her own housing. A successful application was made to DHS for ongoing support funding including assistance to access seasonal paid gardening, personal care, meal preparation, cooking, cleaning, washing, and access to community activities. As a result, Linda has moved into her own flat and the family is considering purchasing a flat in the longer term. Important aspects of these arrangements are: staying in the familiar community; transformed relationships with her immediate family; being involved in the selection of her support staff; being assisted to become a paid gardener; and DHS funding to move out from the CRU.

In each of these instances, the quality of support determined housing possibilities and influenced the perceptions of those around the individuals as to what may be possible. Individuals have faced the prospect of lifelong residence in a staffed residential facility involving continual supervision as a result of perceived 'challenging' behaviours that have been assumed to preclude independent living. In each case, such an option did not reflect their preferences or meet their personal needs. The disability agency has worked creatively within both existing DHS funding already allocated to services, and with some newly identified funding and mainstream resources. The agency has worked to develop detailed person centred plans, provide training and coaching to key staff to support change at an individual level, and to identify and access a wide range of tailored supports. In each case, this has resulted in the person moving into or staying in less restrictive accommodation. The quality of preparation and provision of support has determined the range of housing possibilities and has clearly yielded benefits for the individuals, services and wider government disability system.

Case study 3: Broadening housing choices

A major non government disability agency is working with a specialised disability accommodation agency to access personalised support for people

with disabilities to find individualised housing options. The strategy focuses on working with real estate agents promoting to them the benefits of renting to someone with a disability, including the benefits of investing in physical accessibility in return for long term rental with few risks. Examples of widening housing and support options through rental include:

- *In a one instance, the agency is investigating possibilities around renting next door to, or in the same street as, the person's parents.*
- *The agency works with other agencies who are providing a 'lead tenant' type support for a person with a disability.*

Such work provides stable tenancing options to the private rental market and increases opportunities for independent living.

Living without a home: being homeless with high support needs.

This category documents the experiences of people who live in temporary, short term and non stable housing. In the instances below, this is as result of having no permanent home due to a change in their personal life circumstances. These people have high support needs and as such the system cannot deny access to some level of accommodation and support due to the significant personal and health consequences of such an exclusion. However, the resultant response does not constitute the provision of appropriate secure accommodation and support. They continue to lack stable living arrangements and are effectively homeless though not living on the streets.

This data is drawn from six case studies of homeless clients in one region of a single non government disability service provider. Two of these are narrated below. Four of these people are twenty-one years or younger, the others are 27 and 46 years of age. The case studies below are indicative of each of the experiences of these six people. All of these people now live 'permanently' in respite facilities due to a lack of options to move them into more appropriate accommodation. Two thirds of the six regional case studies are moved between two to five respite services regularly. In each case, this utilisation was preceded by extended overuse of 'respite', frequently over many years, whilst support at the primary residence became increasingly inappropriate or unavailable (sometimes due to carer illness or death). Most of these people have therefore experienced lengthy periods of housing instability with the associated stress, anxiety, loss of identity and personal space, and impact on health.

Case study 4:

'Samantha' is 19 years old, has been homeless for 21 months and living in respite facilities for most of this time. On occasions she is able to go and stay overnight with her boyfriend (who also has a disability) and his family. Samantha moves frequently between four respite facilities, one of which is a predominantly aged care facility which Samantha detests. She is often required to share a bedroom due to the fact that a respite service will only have two single rooms with most beds in double rooms. This means sharing with a variety of strangers (some not compatible), with very little privacy or personal space. Samantha's life is very unsettled as she is forced to relocate every one or two nights. She has been unable to stay at a particular respite service for any period of time to establish a routine or get settled. Samantha doesn't like having to go to different services and pack up all her luggage, medications and personal affects and be in another environment with less familiar carers and residents. She is finding this very unsettling and distressing, particularly when there are gaps in her respite and a bed at any service isn't found until the eleventh hour which has occurred on numerous occasions. This added pressure on Samantha has led to her going to a psychologist via one of the disability agencies providing respite accommodation. She has case management provided through another disability agency. Last year, Samantha required hospitalisation and surgery. On release from hospital, Samantha was unable to be consistently supported across residences, nor establish effective support from a single local doctor or chemist. Due to her constant mobility, Samantha is often placed in a respite facility at a distance from her day service which has meant increased transport costs (DHS funds taxis), travel times and difficulties in organising transport.

Case study 5:

'Betty' is 27 years old and has been homeless for two months. She has been registered as 'urgent' on the Disability Support Register for Shared Supported Accommodation (DHS) for the past four years, and has been using respite very frequently for more than two years. She is on the DHS waiting list for a case manager and has been allocated a short term case manager through DHS in the interim. Betty currently lives in two respite services on a 'permanent' basis. Betty's care has been compromised, through moving between the two respite services and her day service, primarily around her health and medical needs as well as in communicating Betty's daily progress and needs. Betty has very limited communication and relies on agencies to document her food and fluid intake, bowel motions, moods and needs. Betty has significant

health issues including constipation, pressure areas that need to be closely monitored, and epilepsy. Both constipation and stress can be triggers for her to have a seizure. She is also experiencing a physical reaction (primarily overnight) to stress and this can present, at times, like a seizure. As a result, in a period of six weeks, Betty has been sent to hospital via ambulance three times, two of which were not epileptic seizures.

The six case studies in this data set present a consistent theme: in no case does there appear any likely options for accommodation support other than continuing, 'permanent' respite. Hence, there are no known implications to being 'urgent' on the Disability Support Register. In all cases, extended accommodation in the respite system is attended by significant negative impacts on the people involved, as well as on services. Several situations evidence an increase in health risk, difficulties co-ordinating and establishing continuity of health and medical care, and increased stress and anxiety leading to new health and psychological conditions (as above in Betty's case where anxiety leads to the physical reaction of a seizure-like condition and high system costs as a result). These 'residents' of respite facilities have little to no privacy, no personal space, no control over their place of residence or support staff, and no security of housing. Individuals and families (where they exist) report significant anxiety regarding the costs of transport, as well as the cost of accommodation where families are paying for 'permanent' respite services. For all respite services involved, the provision of long term residence to these people has meant that other families and individuals can't access respite, which logically increases the likelihood of a crisis in their households. One respite service housed four homeless people significantly restricting respite availability. Such situations are resulting in significant negative impacts on individuals, families, services and increased costs within the service system more broadly.

Living in the parental home and planning for the future

The following case studies are provided by one non government disability agency and represent two methods of working to tackle the provision of planning and support for people currently living in the parental home with ageing parents.

Case study 6: Planning for the future

A group of fifteen (15) families with older carers with dependent children with intellectual disabilities living in the parental home were identified by a non government disability agency. The families largely had no plans in place for the

future accommodation of the dependent adult with a disability. Most hoped that a residential place, probably in a Community Residential Unit, would become available in the event of an emergency. Families evidenced variable levels of coping, with parents feeling they have to 'hang in' until this is no longer physically possible. Families expressed frequent comments such as 'I hope she dies before I do'. Funding accessed by families was predominantly related to out-of-home respite and did not address the fundamental issue of planning for future accommodation. In response to these issues, the disability agency assigned a worker to develop person centred plans for each individual, along with emergency, medium and long term plans regarding housing and support. Plans include the identification of necessary costs and resources required for implementation and the worker's role includes work to secure these resources. Families had pre-existing relationships with the agency and these generated significant levels of trust and confidence in the process. Families (including extended families) expressed positive feedback and relief that something was happening. Over the course of eight months, all families have undertaken all levels of planning. Negotiation for the allocation of matching resources has commenced. Resourcing of long term plans is anticipated to be the biggest challenge though not impossible.

This support activity was initially funded through existing agency funds to link the families into existing support and services. However, this funding was found to be insufficient. Subsequently, the agency gained DHS funding support for twelve months to target respite for older carers. These funds continue to be topped up by agency funds.

Case study 7: Circles of support

A group of six (6) families comprised of middle to older aged carers with dependent adult children with an intellectual disability living in the parental home were identified by a disability agency. Families lived in the same locality and all had stable accommodation circumstances with no plans for the longer term, other than a wish by the family that their dependent remain living at home or somewhere close by. The agency allocated a worker to develop person centred plans that included long term accommodation arrangements. In each case, a circle of support involving family and volunteers (and in one case paid staff) for each individual was developed. Circle members were coached to increase their understanding and skills around support. Initially, staff found it difficult to explain the project in ways that individuals

and their families could grasp. Workers had little experience with this type of conversation and families shied away from analysing the validity of their assumptions about the future. Families initially found it difficult to understand the tangible outcomes of planning and the development of circles of support. After twelve months, all families have Plans developed, including long term accommodation plans, and express relief at 'knowing that things are in place.' Circles of support range from fifteen (15) relatives of all ages keen to be involved to one situation where no one in the circle is a relative or volunteer. Even though the plans are in place and less intensive involvement from the worker is needed, the individuals and circles of support require ongoing back up and resourcing from a paid worker. Workers are keen to replicate the process with other people. To date the project has been funded via a DHS Accommodation Innovations grant.

Discussion: Key elements of practice response

Despite the underlying narrative concerning the inevitable search for appropriate housing, it is clear that developing appropriate housing for people with complex needs involves more than finding houses, though the targeted work of one agency to expand options through work with the private sector evidences a way forward here. Overall, the case studies suggest that a successful housing process is necessarily preceded by individualised, person centred planning that encompasses both housing and support needs and preferences. Support is revealed to include a wide range of supports encompassing social support, personal care, health management, employment support, and housing maintenance among others. Such support needs are frequently responded to in these case studies by the development of circles of support, along with dedicated resources to maintain these. Finally, and frequently in recognition of the lack of immediate appropriate resources, the development of formal short, medium and long term plans for appropriate housing and support appear to yield tangible outcomes for individuals and families.

Person centred planning and approaches

Case studies 1, 2, 6 and 7 evidence a productive use of person centred planning to identify individual aspirations and requirements around accommodation. In each case these plans have driven actions towards acquiring suitable housing. In case study 1, available housing options were repeatedly tested against individual preferences and needs. Similarly in case study 2, a thorough and sensitive understanding of individual likes,

dislikes, aspirations, strengths and needs clearly underpinned the process used to support these individuals to attain or maintain independent living. In these instances, targeted individual support was provided over time, based on these detailed understandings so that individuals came to more informed understandings of their circumstances and achieved particular life goals, such as employment. Unfortunately, not all case studies evidence such positive outcomes resulting from person centred approaches. Case study 1 highlights the inadequacy of resources to match person centred plans, suggesting that the acquisition of resources that match these plans is both a long term and far from guaranteed process (this is discussed further in the next section).

Individualised and specific emergency, medium and long term accommodation planning

Case study 6 provides an example of the provision of formalised emergency, medium and long term accommodation planning customised to individual requirements and desires. This example, along with case study 7, evidences the impact formalised and specific accommodation planning has on individuals and families. This is reinforced by case studies 4 and 5, along with the cohort of mostly young people they represent, where such formalised planning has not occurred despite strong early warning signs of extended overuse of respite. Case studies 4 and 5 represent the current scenario for people who suddenly become homeless without housing and support plans in place.

In both case studies 6 and 7, a disability agency has been proactive in identifying the issue prior to crisis point. The agency has 'grouped' families together in order to make viable the allocation of a worker to each project. In the first instance, the agency has commenced project work from within existing funds, and then identified further, mostly short term, funding to continue the project. It should be noted that the agency suggests that resourcing such projects is not fully within its existing funding parameters. Such innovations are unlikely to be continued or extended in ongoing practice if they are dependent on the vagaries of agency funded or short term government funds.

Circles of support

Case studies 2 (Linda) and 7 provides a positive example of the use of circles of support, in conjunction with person centred planning, to address long term accommodation support needs. Key elements of this approach appear to be the provision of coaching to both individual circle of support members as well as to the groups as a whole. Importantly, families of individuals need to learn the tangible value of this mechanism

and gain confidence in their family member's ability to function in a new environment. Again, the disability agency has 'grouped' families and individuals together in order to make viable the allocation of worker. This approach evidences that significant gains are achievable over twelve months with circles of support developed for six individuals, (it should be noted that the circle of support in one case consisted of no relatives or volunteers - ie only of paid workers). In all cases, the agency identifies the need to continue the provision of coaching and support to the circles established despite a lessening of workload. This suggests that the maintenance of informal support requires the provision of formal support. Again, it appears that, though the agency contributes resources, this activity has been made possible largely through a short term Innovations grant and is not yet systematically funded. Without further data it is difficult to establish the benchmarks for best practice in this area and the resources required to achieve this. For example, do circles of support comprising only paid staff yield differential outcomes for the individual; what are the necessary characteristics of successful circles of support; and what resources are required to foster as well as to maintain these in the long term?

Use of the private real estate industry

Case studies 1 and 3 both include the work of a disability agency that works directly to increase the opportunities available through the private rental market. This approach is based on community education and relationship building with this sector, linked with targeted support to individuals. Whilst both case studies document 'work in progress' rather than actual results, such an approach would appear to be both necessary and beneficial. Additionally, these case studies identify the role for a specialised, 'boutique' agency that is able to focus attention on the real estate industry, rather than a strategy that requires all disability agencies to individually acquire knowledge of this sector and build effective relationships to utilise it. The approach articulated here is an effective partnership between several disability agencies including the 'specialised' agency providing the linkages to the mainstream real estate industry.

Lessons for policy and programs

Taken together, the above case studies, representing thirty-two (32) individuals with high, complex or changing support needs, evidence a system that is largely unable to respond to individual needs and preferences around housing and support. While the actions of the disability agencies in these scenarios, appear to enact the policy positions of the State Disability Plan (for example, embracing

individualised support, proactive planning and a whole-of-community approach), the government service system appears to offer support largely at the fringes of program parameters (ie. 'innovations' and short term funding) to those individuals who present with changing needs. This is an important area in which the case studies provide a useful context for analysis towards both policy and program improvement.

Mitigating the 'trade offs' of a resource vacuum

The overarching and heavily present context for all case studies is the shortage or lack of appropriate housing which compromises decisions and actions. This resource vacuum is largely incapable of delivering housing and support consistent with an individual's own choices and their individualised plan. Contrary to the concepts articulated in the State Disability Plan, an "individualised planning and support framework" will NOT deliver tailored supports or enable people to exercise choice, just by virtue of its existence (DHS, 2002:18). These elements of the State Disability Plan are currently suffocated by the resource vacuum in which they are implemented. This is difficult for government and non government staff, as evidenced by the extent of effort in case studies to find possibilities from various programs.

In such a context, there is an urgent need to explicitly name the 'trade-offs' confronting individuals and services. Stakeholders in this compromised system need a process for decision making around these trade offs, (for example, under what circumstances should Anna and Liam be expected to trade off proximity to family for the provision of a house?). Each trade off comes with its own attendant costs, for example, the cost of travel to a day service now far away from Samantha's respite 'home', or the cost of personal care for Anna and Liam where their families are now too distant to provide it. Services have become accustomed to these trade offs as evidenced by the respite accommodation scenarios of case studies 4 and 5. Because people with complex needs are frequently dependent in many ways on the system, the option of completely denying them accommodation where no *suitable* accommodation is available is untenable. The lack of monitoring of the respite use of homeless people represents an underlying acceptance of this 'trade off' in the face of massively inadequate resource allocation to this demanding area of need. This culture of acceptance reinforces crisis based responding not planned responding. If we continue to operate within this resource vacuum, trade offs need to be explicitly named and costed, and a process developed for identifying and allocating the resources subsequently needed

to manage these. Importantly case studies demonstrate how families can plan in other ways if they know what is /is not available. (Case study 6 shows families responding productively to information that challenged their belief in the ready availability of community residential housing.) Transparent monitoring and reporting of resource availability is not only necessary but a condition of productive responses by individuals, families and services.

While a number of case studies showed service agencies responding with considerable creativity to develop appropriate supports from a range of resources (community members, local neighbourhood, mainstream health and municipal services, real estate industry, short term DHS funding), it is also clear that the maintenance of these requires ongoing resource input. Participation in inclusive communities and stronger social networks for people with complex needs are likely to need ongoing staffing and resources over an extended, if not indefinite, period of time. Case studies 6 and 7 identify this as an ongoing issue, highlighting that maintaining informal support is not 'free' but requires the provision of formal support and resourcing. This suggests further demand on insufficient resources, but one that should not be discounted as part of widening options..

The core question underlying such analysis is: in the absence of increased resources, what is the best use of those available?

Making the system person centred

The case studies highlight a government and service system that lacks an explicit and consistent definition of appropriate or suitable housing and support. These case studies evidence tensions and conflicts between an individual's and the system's definition of appropriate housing, along with conflicting analyses about the way an individual's support needs should be understood and appropriately responded to. Person centred plans and processes are undermined by antagonistic DHS policies and procedures that operate counter to an individual's self definition of need and suitable response. There are both insufficient resources and a lack of ability to customise those resources available to meet the individual goals identified via a person centred planning process. While this may be inevitable that the system is resource limited, the boundaries are not explicit making the imposition of some government processes appear contradictory and unexpected.

The goals of a person centred plan are seen to be repeatedly in conflict with government program eligibility or funding criteria throughout case study 1. Though Liam and Anna identified a

desire to live in her existing accommodation, home modification costs were not supported by the Department of Human Services. Additionally, Liam's application for Early Housing was rejected by DHS on the basis that his current housing was 'suitable'. The departmental definition of suitability in this instance bore no relationship to, and was in fact directly opposed to, notions of suitable accommodation identified in both his, and later Anna's, individual plan. This case study highlights that decisions on separate program areas (and applications for these) are made currently by government staff within a very limited set of criteria, with no program inter-relationships. There appears to be no reference to the broader context in which a person makes an application (eg, the person's plan, likelihood of other options, history or activity to date, outcomes of other program applications etc). In Anna and Liam's case, they were denied access to both home modifications and Early Housing funding on program-specific criterion, rather than a sensible assessment of their whole situation and available options. This situation suggests that unless there are identified resources and mechanisms to resource individual plans in customised and non-compartmentalised ways, then plans offer little likelihood of success. This suggests the need to be more explicit, (both at the level of information to the individual as well as acknowledgment by government), about the limitations and barriers of the context in which a person centred plan aims to achieve outcomes.

Overall, the case studies suggest that person centred planning processes are a key factor in identifying accommodation aspirations and requirements, and function to appropriately target work to achieve this. The next question is whether any or how much resourcing for person centred plans necessarily falls to government? Case study data questions the value of person centred planning where existing government funding and program procedures operate within guidelines that override individualised definitions of suitable accommodation and retain significant obstacles to eligibility.

Key questions for policy and program improvement include:

- What is the definition of appropriate housing and support and / or who defines it?
- What role does the disability sector have in solving, planning, funding, responding? (This sector alone can't have all the answers.)
- Who are the decision makers in an individualised planning regime?
- Is individualisation enhanced by creating multiple programs targeted at small sub sets

of populations, needs or circumstances, or do the program criteria for each operate to overly exclude?

- How can the disability system be inclusive of the needs and preferences of diverse households (including those comprised of both people with a disability and those without who may or may not be family members)? Or, how can the system support people with a disability to live in diverse household types?

The system maze

The system comes complete with considerable incongruencies. Case study one clearly evidences the maze of the system, and the analysis above identifies the way multiple program criteria function to exclude individuals. Multiple points of application and multiple assessments (conducted by first an agency, then a government appointed case or program manager) are characteristic. Application and assessment processes are time consuming but operate with no apparent review of decisions or results. Individuals appear to have to negotiate across multiple agencies and manage services received from these. In this context, case management can appear to be simply another layer of bureaucracy or complexity, or appointed to manage the complexity created by the system since the onus is on the individual to do so not the system.

People working with people to plan and implement

Most of the case studies here present examples of person centred planning in action. In each case, a paid worker has worked in a detailed way for at least one year with individuals and their families, where appropriate. A key aspect of the work is the ongoing follow up to identify, develop and maintain customised supports, whether these be social networks, employment, housing, health professionals, personal care or housing. The work has a necessary longevity to it, both to develop the appropriate relationships with and understandings of individuals involved, and to conduct the necessary leg work to enact the plans developed and maintain these actions. In all cases, one initial worker has drawn in others, as the work expands.

Conclusion

The case studies provide a grounded context for the discussion of policy and strategy development in the arena of housing and accommodation supports for people with a disability in Victoria. They each illuminate different aspects of the policy and service system and the intersection between these and the individual needs of the people seeking to utilise this system. Significantly, there is an

absence of data collection, review and monitoring within the service system to note the frequency of both positive and negative experiences of people with a disability who access this system. There is no systematic quantification of problems nor a development of improvements based on analysis of these. In the absence of such as system of review, we cannot know the extent to which the case studies provided here are representative. Anecdotally, these types of experiences and the service responses to them are not infrequent. As case studies of current practice, they provide a mechanism to illuminate policy, gaps and contradictions. Most starkly, they evidence the resource vacuum in which services seek to respond appropriately to the housing and support needs of people with high, complex and changing needs.

In short, the system is overly complex and under responsive despite staff at all levels working hard within their roles and program guidelines.

What is clear from the case studies is that ongoing planning and implementation work is not systematically funded. If people with a disability are to be enabled to achieve Goal 1 of the State Disability Plan (“Pursuing Individual Lifestyles”, DHS, 2002:11), reliable mechanisms, including dedicated funding, with longevity and a consistent base must be identified. The central question is: how can resources be best administered to enable individuals to pursue individual lifestyles (Goal 1, State Disability Plan, DHS, 2002: 11)? There is a gulf between the policy ideals and the pressures of day to day resources allocation which, without explicit recognition, cannot be directly tackled.

References

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AN ANALYSIS OF THE CURRENT POLICIES ON HOUSING AND SUPPORT FOR PEOPLE WITH INTELLECTUAL DISABILITY AND COMPLEX OR CHANGING SUPPORT NEEDS IN VICTORIA

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Aim and focus

The aim of this paper is to set out the current Victorian policy on housing and support for people with intellectual disability who also have complex or changing needs, and discuss its impact and implications.

The focus of the paper is people with intellectual disability who cannot manage or steer their own lives without significant support. That is, people 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 of people's support requirements (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, and not only personal or attendant care but also assistance to complete tasks, and monitoring and supervision to ensure both wellbeing and participation in everyday activities. This group of people has severe or profound intellectual impairment, typically including difficulty with cognition, communication, comprehension, problem solving, memory and frequently physical and sensory impairments. Their ability to exercise choice or participate in activities is dependant on the presence of opportunities and the availability of appropriate support and assistance to take advantage of the situation or through proxy/representation. For ease of writing, the rest of the paper refers to this group as people with complex needs. The challenge is understanding and implementing a rights framework from the perspective of this group of people. Unlike some people with disabilities, meeting housing needs alone for this group is not enough. The removal of social, economic and environmental barriers to housing will not suffice although they

will benefit from social change in areas such as community attitudes, physical accessibility and affordable housing. Irrespective of such change these people also require ongoing, reliable and specialised support to assist with personal care, communication, planning, choice, inclusion and participation in the community. This group was differentiated from others with disabilities by a key report on housing and disability in 1991, which stated.

All people on very low incomes require affordable, secure housing, control over their living environment, reasonable access to services in the community and a more realistic choice of where to live and what type of housing to live in. For people with disabilities, there is an array of additional housing barriers. The main issue is the need for personal support for, without it, people with severe disabilities cannot even start to address housing issues (Sachs 1991).

A second group with whom this paper is concerned is people whose requirements for support in the areas described are changing over time due to getting older and aging, the progressive nature of their disability and the time since the onset of their disability or other factors.

The pre-eminence of the social model of disability has moved attention away from the characteristics of people with disabilities to the barriers and obstacles created by society. This was an important progression from understanding people with disabilities as 'the problem.' In terms of the social model, the numbers and characteristics of people with disabilities are not relevant – only the removal of society's barriers. As a result of the adoption of this approach the size and characteristics of the group with complex needs are not well distinguished by Victorian disability policy. The current policy is no longer concerned to differentiate or categorise people on the basis of their diagnosis or the level or type of support but rather is focused on individual needs. However, the implications of this approach are that there is no common framework in Victoria for recognition or assessment of the support needs of people with disabilities, which can be used as a basis for service planning and monitoring, to replace knowledge about specific diagnostic groups. There are few specific targets for particular sub groups of people with disabilities. A common assessment framework was discussed in the recent Senate Enquiry into the CSTDA as assisting in system planning, determining priority of access and recognising and addressing the special needs of people with dual or multiple diagnoses (TSSC, 2007). The enquiry recommended:

That the next CSTDA incorporate a nationally consistent assessment process to objectively and

comprehensively determine the support and care needs of each person with a disability. These assessment processes should also assist people with disability by making determinations of eligibility for services and priority of need as well as facilitating access to appropriate services (para 3.79).

The use of a common framework would go some way to addressing the absence of data in Victoria on unmet need for housing and support and the characteristics of people with disabilities either waiting for, currently using services, or potentially seeking services.

Choice, diversity and flexibility

The clear intention of disability policy at the level of the State Plan is that people with complex needs like others with a disability should have access to a range of housing options broadly similar to that of others members of the community and have support available to maintain these living arrangements. For example, talking about the policy of the State Plan one departmental document states:

With respect to housing and support, the Plan outlines the Government's commitments to people with disabilities by:

- Providing more housing options
- Giving greater choice, and
- Enabling participation in local communities.

The Victorian Government believes that as much as possible, people with disabilities should be able to choose where they live, with whom and in what type of housing just like other members of the community (DHS, 2006a).

The policy emphasis is on 'more housing options' rather than ensuring everyone has somewhere to live within the parameters of what is considered appropriate.

These visions are being implemented through the development of mid level policy and strategy and it is these that are the focus of this paper.

The DHS policy direction is to separate housing from support, which has long been advocated as a way of achieving greater flexibility and choice for people with disabilities (McNelis, 1977). Ideally this separation, together with mechanisms for individualised funding mean the level of support a person receives is not tied to any one place of residence, and they are not locked into a fixed package of housing with support which could limit their future options. Support can be adapted as needs or preferences change without the necessity to move house, and the person has greater flexibility to move house if they wish as their support can be moved to a new location. Separation of housing

and support can also facilitate greater choice over living situation, enabling the person to live alone or with people of their choice. It means too that issues associated with tenancy management do not become entangled with support related issues. It important to be clear, however, that there are gradations and variations to this separation and just having different providers for housing and support may not make the system flexible. It is also important to recognise that housing and support are not independent and do have to be planned and coordinated together, and over time, especially for people with complex needs.

The separation of housing and support reflects a whole of government approach to disability policy by encouraging various sources for the supply of housing for people with disabilities, including more clearly with the parts of government responsible for housing policy and the provision of housing for low income or disadvantaged groups. Potentially this can open up new sources of housing for people with disabilities, and reduce the demand placed on disability specific funding. It is not clear how well people with disabilities will fare in relation to other low income groups in the allocation of social or affordable housing if they are not differentiated as priority groups (or sub groups).

The establishment of the Disability Housing Trust is a targeted strategy that separates housing from support and aims to expand the range of housing options available to people with disabilities, through shared equity or other innovative arrangements for raising capital and providing housing. This strategy has an initial quantifiable number of places (100 people) and an identified target group, with priority given to people leaving shared supported accommodation or living with older parents. The Trust was established in June 2006 with \$10m and is still in the establishment phase, although has called for initial expressions of interest in the creation of housing options and has established several properties for people with disabilities within larger housing developments. It not clear at this stage of its development how this approach differs from the already well established Supported Housing Trust.

The Disability Accommodation Innovation Grants were also designed to increase available housing. The projects in this program have undertaken a range of strategies including locating private rental properties, developing housing, and coordinating formal and informal support to maintain or enable housing. Some of these projects have also explored the relationship between formal and informal support to develop and maintain housing. It is apparent that there is an array of different ways to generate housing across the public, private and disability housing sectors.

On the support side there is a concerted policy to expand individualised packages of support, though the “support and choice” program, which together with other overlapping programs, that have either specific and or broader target groups, such as Outreach, Home First or HACC, will provide support wherever people are living in typical community housing arrangements. Such programs are complemented by the provision of aids and equipment. This approach to planning and funding is intended to ensure greater control over the nature of support and that it is more individualised and responsive. It is based on the sense that traditionally block funded services (particularly day or recreation services) were unable to provide flexible ‘person-centred’ support. Individualised funding arises from a market model of the ‘consumer’ exercising choice and control.

Whilst individualised funding can have positive aspects for individual control, it is also apparent that at times something is lost in terms of the system flexibility to respond over time to individuals fluctuating needs which is possible through block funding of funding at a service level. Furthermore how such models can operate for people who are not self directing, self interested, well informed ‘consumers’, and who have difficulty and require significant ongoing support to exercise choice and control, has not been articulated in the current support and choice model. Reliance has generally been placed on the families or service providers of people with more complex needs to act as the proxy ‘consumer’. How to do this is poorly understood, as it is often undemonstrated how well, and on what basis, others can represent the wishes of the person and unresolved how conflicting needs are reconciled. Strategies adopted overseas to confront these issues more transparently and comprehensively are the development of micro boards or circles of support, all of which require the investment of resources to maintain and develop, particularly for those without significant existing informal support.

Missing details of implementation

Whilst the direction of policy is clear in terms of the separation of housing and support and the expansion of individualized support funding packages, the two are interdependent giving rise to significant complexity in implementation. Many of the details of implementation are less clear than the overarching policy direction and leave a number of unanswered questions. For example:

- What are the implications for existing shared supported accommodation arrangements, particularly in the government sector, where the pairing of housing and support is most entrenched?

- If the goal is more options for housing for people with disabilities, it can be assumed that people with complex needs can chose to live alone or with others. Will there be an upper limit on individualised funds which will effectively preclude people from living alone?
- How can informal support be developed in partnership with available formal support?
- If people requiring substantial support chose to live alone, what mechanisms are in place to enable agencies to ‘cluster’ support for a group of individual people, for example, living nearby each other?
- If housing and support are recognised as interdependent, how will decisions about priority of access to support packages be reconciled with decisions made elsewhere about access to housing options? Is housing going to be recognised as one of the essential foundations to other aspects of quality of life?
- If people choose to live together what mechanisms will be put in place to fund, plan and manage collective household as well as individual needs and to ensure individual needs are not compromised by the group? How will aspects of group living be supported in an individualised system of funding?
- How will choice about support providers be realistically exercised, and what will be the limitations on this, for example some existing situations only allow an annual decision about choice of support provider or there are no choices.
- From a housing provider perspective the key issue is the ability to maintain tenancies. How will the tension be managed between having ‘good tenants’ that pulls in the direction of providing housing for people with stable, low support needs and providing housing for people who might have fluctuating support needs and changes in support providers making their tenancy less predictable?
- How will support infrastructure, such as supervision and training of staff or community development initiatives such as recruitment and support of volunteer friends or support networks such as those based on the Key Ring model be funded in an individualised system.

Families have always been important providers of housing for people with an intellectual disability. One concern about the changing policy direction with options for equity is the apparent reduced role of government in meeting housing needs and the increased responsibility placed on individuals and their informal networks to provide housing. Arguably this is not new, but people’s increasing life spans is changing the timeframe within which

families are planning and providing housing. For some families with strong financial or other means this may be a welcome change that means families/individuals do have option of providing equity as this has locked out people from housing in the past. For example, one policy document (DHS u.d.) talks about people with disabilities being about to “locate and receive support in own accommodation” and if people take the “independent option, housing is the responsibility of person, family or other networks”. This approach seems most relevant for people who do work, are not reliant on the disability support pension, or those with strong family or other forms of informal and private support. It is not clear how many individuals and/or families or community groups will be able to take responsibility for contributing to provision of housing or housing equity. The questions arise how will people with complex needs, without substantial means or informal support benefit from this approach and will their inclusion be monitored? This is similar to the recent Federal initiatives on the preferential way in which Disability Trusts established by families for people with disabilities will be regarded for social security purposes. These policies create incentives for families with substantial means to take private responsibility for the provision of housing and support, which potentially creates a dual private/public system of housing and support for people with disabilities. Whilst such approaches increase the pool of available funds and may reduce demand on the public sector, little discussion has occurred about processes for monitoring and ensuring equitable access to public funding for those with and without private sources of support

The Disability Housing Trust, the Accommodation Innovation Project, together with broader initiatives about social and affordable housing, are strategies to develop and test out different ways of providing housing and support. They foster experimentation and new ideas but also lead to substantial diversity, and risk inconsistency, in the options available across the State. An important but missing part of these developments is a research and evaluation framework to enable the learnings for these initiatives to be captured overall, and identified key dimensions to become more systematized over time in developing models.

Options limited by support needs

Policy documents (DHS 2006b, 2006c and u.d.) as well as presentations by departmental staff (Kihl-Larsen, 2006) refer to the search for alternatives to the dominant model of community residential units (CRU's) and 24 hour rostered support. It seems however, that these goals are not equally applicable to all people with disability. The policy strongly suggests that only people who do not have high support needs or do not require 24

hour support can take advantage of the more independent or innovative housing and support options. For example, “Future Directions for Housing and Support in Disability Services” (DHS u.d.) refers to people with “less intensive support requirements” and those who “need 24 hour support” or “rostered 24 hours support” and suggests for the two latter groups, community residential units will remain the main option. Such documents appear to foreclose alternative options for people with high or complex needs who require 24 hours support without any clear rationale for why this might be so, or the range of possibilities for the provision of such support. This policy risks re-instating the traditional continuum model in which the options available are based on the level of support required, ‘the least restrictive alternative’. A rights model in contrast suggests that each person has the right to live in the community whatever level of support it takes to accomplish this. The policy also tends to ignore the possibility that people with lower support needs may want to share with variations to staffing support requirements. These positions require further debate and articulation.

Policy documents also suggest that the CRU model is a less than ideal and outdated model. For example, a diagram in DHS u.d. shows the CRU model as belonging to the 1980s/1990 and a “range of models” being for the 2000s and onwards. It also suggests that the models for the 2000s will not include a skill development focus, which is left behind with the CRU model. This policy appears to leave people with complex needs in an outdated model with no access to new models that will offer flexibility, person centred aspirational support as required, implying CRU's cannot offer this type of support. When people with an intellectual disability have by definition difficulty with learning, it is impossible to understand how skill development can be irrelevant – the more important question is which skills. This may not be the policy intention but it is certainly the message given by policy documents.

There is some evidence from overseas that more flexible individualised options do work for people with complex needs (Taylor, Bogdan, Racino, 1991; Taylor, Bogdan, Lutfuyya, 1995; Racino, O'Connor, Taylor, 1993). The danger from the stance being implied in Victoria of reintroducing stages of housing and support matched to support levels, is that if people with more complex needs are not expected to take up such options consideration of their needs will not figure in the developmental thinking about detailed implementation (such as the questions raised in the previous section) which may only reinforce their exclusion – contrary to all aspirational flavours of the State Disability Plan.

The relegation of people with complex needs to the existing shared housing model with set staffing rosters and rigid boundaries with day programs, raises a number of issues. Significant changes will result to the nature of the CRU program if there is a progressive change to serving only people with high and complex needs. This will impact on funding requirements, staff, managerial and organizational skills and capacity, and require transitional arrangements as the profile of residents' changes. There appears to be no indication of the potential for the CRU model to become more flexible and individualized, although there are some examples of more flexible CRU arrangements in the non government sector. It is not clear for example how a group tenancy model for residents who need a high level of support differs significantly from a CRU model, and why the learnings from the former cannot be used to reform the later. Also the option for instance of reducing the level of support in a CRU rather than moving residents to alternative housing options does not seem to have been explored which effectively cuts off one set of choices for some residents.

Reform of some of the structural factors that impact on the capacity of the CRU model such as such as industrial agreements, differential funding between the sectors, risk management strategies and occupational health and safety requirements is necessary. Yet it appears that such factors largely remain outside the scope of housing and support policies. The impact of these however needs to be recognised and integrated into policy and implementation statements. Policy attention tends to focussed on the CRU program run by the government sector and by the non government sector which have important operational differences.

Lack of targets

The search for new models appears to take priority over consideration of the volume of housing and support places to be provided. The aim does not appear to be to ensure that everyone has appropriate housing and support, which means there is little analysis of the things such as the reduction that will occur in waiting lists, or the sub groups on basis of disability type or levels of needs that are the target of policy. An emphasis on increasing housing options, does not equate with meeting the unmet need for housing.

An absence of population based targets means there is no clear prioritization of people with complex needs and the danger of a slide towards provision for those who have lower support needs, and are cheaper and easier to make provision for within the targets of set funding programs

such as the 100 places for the Disability Housing Trust. The approach of calling for expressions of interest from the Disability Housing Trust, allows for innovation and variation but in a population planning sense adds to the inequalities between regions and experiences of the past where submission based funding processes favoured regions with stronger, wealthier and more effective DHS regions and community organizations. Strategies adopted by the Disability Housing Trust and the Accommodation Innovations Project are a project-style approach to implementation and do not consider the implications for the target population overall. There are no population based targets for the provision of housing and support for people with disabilities by which to gauge progress or to provide the rationale for increased funding. Comparison with overseas suggests Australia falls far behind optimal volume of provision. For example Stancliffe, 2002 found that Australia had 86.7 places per 100,000 people, compared to the UK's 106 and the US's 141.7. Population based planning is more critical for people with complex support needs who as well as change to the social environment also require specialised individualised support arrangements. Arguably, targets in Victoria for housing and support for people with intellectual disability would be comparable to those found overseas. There continues to a high level demand for housing and support in Victoria for which there is no adequate response. This compromises the reality of choice, quality and the efficacy of person centred planning- particularly for people living with families, often parents across the life span and including older parents. The allocation strategies adopted based on urgency of need are necessarily reactive rather than proactive and compound a crisis based approach to meeting needs, which limits opportunities for both existing and new residents in shared housing to exercise choice about co residents, housing location, type (see roundtable paper by Wilson and Fyffe for further discussion). Such approaches ironically are not the best use of the available formal and informal resources.

Quality of practice and outcomes of support

The focus of this section is the quality of support in shared housing, as little attention has been paid to the quality of support in other settings for people with complex needs and the policy suggests that shared housing is likely to continue to be the primary housing and support option for people with complex needs. This means it is important to consider the strategies designed to ensure that shared supported house provides individualized and flexible support that result

not only in high quality personal care but also the exercise of choice, participation and inclusion for residents. Policy documents point to a broad range of strategies that aim to improve the quality of disability services, such as revision of disability quality framework, completion of a Victorian Disability Industry Development Plan, a 10 year workforce planning strategy, improvements to the monitoring of disability supports and development of a health promotion strategy (DHS, 2006b; Kihl-Larsen, 2006). Few further details of the way these initiatives are to be implemented are available in public policy documents.

Research in Victoria, like that overseas has shown the outcomes for residents of shared housing to be extremely variable, with a greater likelihood of achieving community presence than participation and development of relationships with community members (Clement, Bigby, Johnson, 2007; Bigby, Frederico & Cooper, 2007). This is despite evidence that small scale housing arrangements (1-4 people) are the most likely means to achieve these outcomes. One of the critical issues for improving outcomes noted in a presentation by the DHS in 2006 was the role of the direct care staff to actively support people with disability build family/informal support networks and promote engagement and community inclusion. A few specific strategies have been put in place to achieve this but none appear to be systematically implemented across the government and non government CRU programs. Strategies such as person centred active support have been implemented in some Victorian government and non government CRU's though the longer term success of implementation of these initiatives is not yet known. Policy documents do not suggest this approach is to be more systematically implemented across the sector. Similarly broad statements promoting person centred planning approach is to be adopted but little detail is available as to the way this will be organised and resourced for current residents in CRU's with complex needs.

Recent literature suggests undertaking such planning with people with complex needs, particularly those who do not communicate verbally, and have few others who know them well is both complex and resource intensive. See for example Lyng's work in Norway that demonstrates the skills and long term nature of work to support house staff to "get under the skin" of residents with intellectual disability and autism (Lyng, 2007). Similarly action research in Victoria suggests supporting staff to understand and support inclusion for people with complex needs is a long term undertaking (Clement & Bigby, 2007). This and other research suggest that direct care staff may not be very well aware

of the State Plan's goals and that concepts such as inclusion and participation remain fairly ambiguous for some staff and hard to interpret in relation to people with high and complex needs (KPMG, 2006). This illustrates the importance of shifting implementation strategies beyond a generic dedifferentiated approach to ensure intended outcomes are more clearly articulated in practical ways in respect of people with complex needs. Revision of practice guidelines and various other initiatives are occurring both centrally and at the regional level that aim to improve direct staff practice and the performance of supervisory staff. However, it is not evident that quality training materials grounded in research are being developed to support such guidelines across the state, nor that more user friendly "Guidance" such as the type used in the UK is being developed to interpret policy intent in relation to people with complex needs. The difficulties of implementing policies of inclusion at the practice level, suggest the importance of trialling and evaluating approaches, identifying factors that support and undermine good practice and ongoing monitoring of implementation strategies with mechanisms to share learnings across the whole system.

One key initiative stemming from the 2006 Disability Act is the establishment of the Office of Senior Practitioner which has a mandate to improve practice with people who have challenging behaviour, around issues such as restraint and seclusion. Initial indications are that the office is taking a broad approach and will implement a range of strategies designed to improve the overall quality of staff practice in CRUs, consistent with research evidence about positive behaviour support practice.

A useful framework for thinking about the dimensions that affect the outcomes for residents in shared housing was developed by Felce et al (1998) from their research on the implementation of the All Wales Strategy. They suggest the importance of three dimensions; 1) structural, such as ordinary housing, household autonomy, domestic size and standard, resident status; 2) service orientation and procedures, such as staff training, selection, working methods, ratio, job descriptions and monitoring; and 3) the staff user interface, such as provision of support for everyday activities, exercise of choice, use of community relationships, effective teaching, active support, behaviour change and individualisation. Many of the elements in each of these dimensions are not systemically tackled in current policy strategies, but may be present at agency / delivery level. For example, structural dimensions such as size have not been resolved and there appears to be a trend towards this increasing in new initiatives, such as new housing for younger people with

complex needs transferred from nursing homes, establishment of 8 bed CRUS's in some regions for older residents. One reason for this is that funds are limited, demand is high and the goal is variation in housing options. There is an ever present risk that people with the highest support needs are relegated to the poorest housing and support models for reasons unrelated to quality.

Responding to changing support needs

Ageing clients and or those with complex health care needs were pinpointed as a significant issue in improving the outcome for residents in shared housing in a departmental presentation on housing and support policy (Kihl- Larsen, 2006). Improving the interface between the aged care and disability sectors and access to generic services was also a priority in the 2002- 2007 bilateral CSTDA agreement between Victoria and the Commonwealth. Progress on these priorities appears to remain at the stage of scoping the problem (Australian Health Care Associates, 2006). The only mention of responding to issues associated with aging in current policy documents is in the State Plan Implementation Plan and in regard to day support and helping older people with a disability make a smooth transition to retirement options. It appears that Victoria has no mid level policies or systematic strategy in place (apart from individual funding arrangements negotiated one by one with providers) to adapt the level of support that is provided in shared supported accommodation (or for people in receipt of support and choice packages), for people whose needs change as a result of aging or other factors, that would enable residents to age in place. Rather a reading of the program information on CRU's and the entry and exit policy suggests a contrary policy direction, that aging in place is not expected, and residents cannot regard the CRU as their permanent home and may be expected to move.

SSA provides long term support that is attached to a housing option, however the duration of stay in a particular SSA service may vary. For example, where an individual's support needs change to such an extent that their existing service can no longer provide adequate support within existing resources, there may be a requirement to move to another service (DHS, 2005).

This statement contrasts quite significantly from the aspirations of found in the State Plan and is an example of operating/managerial policies being out of step with overarching policy aims as the system responds to pressures. The position is also contrary to the position adopted by States such as South Australia and the recommendation

by the recent Senate Enquiry into the CSTDA that mechanisms be put in place to enable people with disabilities to age in place. The question of who funds additional support needs as a result of aging is unresolved between the States and the Commonwealth, with each asserting the other should bear the responsibility. Evidence suggests that in both the government and non government sector increased costs associated with changing support needs are negotiated on an individual basis or absorbed by government and non government organisations (Cooke, 2007; Fyffe, Bigby & McCubbery, 2007).

The impact of a lack of policy to support aging in place is compounded by policy that aims to reduce the inappropriate admission of younger people (aged under 65 years) to residential aged care, which has been driven primarily by the campaign about younger people in nursing homes. Guidelines recommend to Aged Care Assessment Services that all other alternatives must be considered before admission to residential aged care for a person with disabilities aged under 65 years. Yet no guidance is provided to these services as to when admission may be appropriate nor initiatives taken to support and develop their capacity to assess people aging with a life long disability. It seems that policy has left a significant gap, in considering the needs of people whose needs are changing due to aging but may still be classified as younger by the aged care system.

If people with intellectual disability are to now reach middle age and go on to age in place in their homes the broader interfaces between community care, disability, aged care, the health and specialist geriatric health systems must be considered and access to a range of services provided by these sectors addressed. The health promotion and other strategies alluded to in policy document to develop the skills of direct care staff and the capacity of health professions to respond to people with disabilities are important in this regard. However, it not clear that these initiatives will extend their scope to geriatric services as well or develop the capacity of the hospital sector to work with direct care staff and residents with complex needs. Initiatives to improve the interface between disability services and health services, are occurring in the ACT and South Australia and there are examples, such as, Barwon South West region in Victoria through the Regional Disability Advisory Group and Primary Care Partnerships initiatives.

Unanswered questions

Much of the policy about housing and support in Victoria remains at a vague and rhetorical level making it difficult to analyse. The shortage of adequate housing for all is recognised as the back

drop which is not being specifically responded to (TSSC, 2007). This means many issues are left unconsidered, a few of which are raised below.

- How does the concept of homelessness that is considered in other populations to include people in inappropriate housing apply to people with complex needs? Should homelessness be monitored in terms of what is not an acceptable standard of housing and support for people with complex needs, given people will not be 'on the streets' - does this include residence in pension only Supported Residential Services, in residential aged care for people well under the average age of other residents, in families with respite support but who would prefer an alternative option, long term in a respite setting/s, residents in facilities with more than 4, 6 or 8 residents?
- How is the disparity in funding between the government and non government shared supported accommodation sectors, which is greater in Victoria than any other state, being tackled?
- What strategies are in place to avoid a tendency towards favouring people with lower support needs?
- What is happening for people in congregate living arrangements of greater than 4 people, for example the remaining institutions, Sandhurst and Colanda, and people in Supported Residential Services
- What strategies are being developed to foster consultation and dialogue with the families of people with complex needs and what strategies are being developed to support the families of a group of residents to work together to support a household rather than simply their own family member.
- What strategies are being developed to connect people with complex needs to independent support or advocacy separate from service providers? Who is representing the voices of people with complex needs in policy development, and what is their representative base?
- What strategies are in place to develop quality easy to read materials about housing choices targeted at people without language or written comprehension? What strategies are being developed to enable more localised regional planning and consultative mechanisms?

Postscript

Housing responses for people with intellectual disability and complex needs require planned approach with identified high priority groups. With the current shortage of affordable housing, additional questions arise:

- How is the housing shortfall best communicated? While AIHW (2007) refers to the level of unmet need in housing, there is negligible public debate.
- Whose role is it to develop a housing strategy which systematically encourages various public and private ways to generate housing for people with disabilities, together with the planning and coordination of formal and informal support arrangements consistent with the person's preferred lifestyle and maintenance of housing?
- If there is no goal to ensure housing for all people with disabilities, whose role is it to communicate this to individuals and families and what are the implications for those with the highest needs?

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WHAT DOES THE RESEARCH SAY ABOUT ACHIEVING HOUSING AND SUPPORT OUTCOMES?

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Introduction

Recent academic papers continue to highlight the importance of housing to the success of community care policy (Bochel, Bochel, & Page, 1999; Bostock & Gleeson, 2004). Marsh and Mullens (1998) argue that ‘...social exclusion through housing occurs where housing processes deny certain groups control over their lives and reduce access to wider citizenship rights’, (p.753). Housing therefore provides the ‘opportunity structure’ through which the wider benefits of community living and socio-economic advantage can be accessed and experienced. Yet in much academic literature outcome variables relating to residential options for people with intellectual disabilities have almost inevitably measured changes to adaptive and challenging behaviour as a primary concern while outcomes associated with community living playing a supporting role.

The heritage of ideas around the educability of people with intellectual disabilities and to their adaptive behaviour goes back to the nineteenth century reformers such as Seguin (1866), who argued that ‘most idiots...may be relieved in more or less complete measure of their disabilities by...education... idiots have been improved, educated and even cured’. It was nearly a century after Seguin that the ‘lunatic asylums’ as the setting in which to accomplish such education was rejected after public recognition of the atrocious conditions in which people lived (cf Barton, 1959; Goffman, 1961). Points worthy of note in this hugely simplified history are that using traditional institutions as a baseline against which other residential options are compared is likely to place other options in a favourable light. Secondly, linking *stage of adaptation* to *choice of residential placement* implies a system of uneven provision, if not unequal privilege, amongst different groups of people with intellectual disabilities (Taylor, 2001).

In making these assumptions Taylor (2001) argues there is likely to be an inequity of outcome across a number of dimensions:

Most restrictive		less restrictive
Least integrated	←→	most integrated
Least normalised		most normalised
Most intensive services		least intensive services

In terms of residential options the hierarchy created is as follows: institution, nursing home, intermediate care facilities (such as hostels, long term specialist facilities and cluster housing), group homes, foster care, semi-independent/ supported and then independent living. It has led Taylor (2001) and others (DHSA, 2001; Disability Advisory Council, 2004; Bleasdale, 2006) to argue that there is a vital need to ensure that the *system of support* from *choice of residential provision* are viewed as equally important in themselves. In this view the system of support in place to accomplish outcomes in the community is equally as important as the residential options that provide the setting and opportunity structure for their experience. But, true community presence cannot be experienced in any setting where the nature of that support is over-restrictive.

The general consensus, repeated in a substantial number of studies, has been that small-scale community homes dispersed in the community provide the best outcomes for their residents and this has led Governments around the world to adopt the small dispersed group home model. Stancliffe (2002) is able to point to a slow but consistent decline in large residential facilities but points out that accommodation support in Australia for people with an intellectual disability is around 86.7 per 100,000 compared to 106 in the U.K. and 141.7 in the U.S. Even in the U.S. the provision does not fully meet needs and Emerson (2005) has pointed to the ageing population, change in family form and breakdown in informal care as further future factors that will raise demand.

Emergent counter-positions to small-scale community housing are also providing a focus for strong lobbying based on: evidence of ‘bad experiences’ (Cox and Pearson, 1995); expressed choice, particularly of parents (Burbridge, 2002); the better interpersonal support and reciprocity of intentional communities (Fulgosi, 1990); cost (Cox 1995); and upon the failure to provide for ‘difficult to place groups’. Those identified as significantly challenging services have been the last to leave the old institutions. It is accepted that they are more costly to support in the community and require a range of health and support services. Their experience has also been one in which repeated breakdowns of placement and readmission to large scale settings (Bruininks *et al.*, 1994; Mansell, Hughes and McGill, 1994; Xenitides *et al.*, 1999; Felce *et al.*, In preparation). The result has been a retrenchment in policy and,

‘Part of this debate is the suggestion that cluster style and large scale congregational living may be more desirable...An alternative construction is that failure of small group living to reach expectations

is integrally related to the confounding of closure with deinstitutionalisation and the failure to implement the broader complementary policies required to achieve deinstitutionalisation', (Bigby & Fyffe, 2006: 579).

There is substantial pressure on the public purse and government expenditure; the projected costs of community care for people with a disability are likely to rise in the foreseeable future; given consumerist principles different voices are lobbying for varied residential options; questions are emerging about what outcomes really count in measuring the success of community residential options; and deinstitutionalisation seems to have hit a problem in terms of decisions about how best to house those for whom it is most difficult to provide long term community residential placements. Yet providing homes for the most vulnerable may indeed be the final test of community care. So what can the evidence tell us about the relative merit of different residential options?

Method

The following paper draws upon a wider review the aim of which was to carry out a systematic literature review (Ramcharan, Nankervis and Abdilla, 2007) about the relative merits, appropriateness and efficacy of various residential options for the support of people with the most significant challenging behaviours, i.e. at a prevalence of around 1.24 to 1.47 per 10,000 of the population (Felce *et al.*, 1998; Felce *et al.*, 2000 and Lowe *et al.*, 1998). Experiences and outcomes in different residential settings may be as much dictated by aspects of the setting characteristics as they are by the setting itself. In addition, therefore, the literature was reviewed to examine other factors: accommodation design (architecture, ambience etc); Client mix; and cost.

Literature around significant challenging behaviours and residential options over the past ten years was examined using a number of databases and decisions made around which fit the criteria for 'significant challenging behaviours'. The outcomes of these and associated studies comparing the outcomes of residential options for people with intellectual disabilities were read and comparative outcomes of the studies placed into an appendix. The outcomes were grouped and categorised to compare which residential outcomes were found to have produced the best results for residents.

In all 225 abstracts seemed potentially relevant and having reviewed abstracts 32 articles downloaded and read. Of these 13 were not specifically relevant, leaving 19 for review. However, despite the residential options literature

for people with intellectual disabilities being a well researched area it was found that there only 6 studies related to the most significant level of challenging behaviour. In examining the outcomes of residential options it was therefore necessary to look at the wider literature and to assess to what extent these findings could be extrapolated to the target group. In what follows some key issues around the wider literature on residential outcomes are outlined and issues relating to challenging behaviour, commented upon at relevant points.

Findings

Comparing outcomes of residential options

Findings in a number of literature reviews have been consistent and favoured smaller dispersed settings (Emerson and Hatton, 1996; Kim *et al.*, 1999; 2001; Mansell, 2006). Emerson and Hatton (1996) are able to cite evidence from 71 publications that smaller community services are "generally, though not inevitably" likely to produce better outcomes. They point to a number of areas of better outcome in smaller dispersed housing:

- increased user engagement
- increased contact from care staff
- increased use of community facilities
- increased adaptive behaviour
- increased opportunities for choice
- contact with family and friends
- better material standard of living
- increased acceptance by the community

Additionally, these improvements seem to have been sustained over time (Felce and Emerson, 2001). In a recent publication Mansell (2006), is no less unequivocal in relation to the overall outcomes of new residential options,

'Early attempts to replace institutions led to relatively large residential homes such as the intermediate care program in the US...the Wessex experiment in England...or the residential home programme in Sweden. These gave way to group homes...More recently, dissatisfaction with group homes has led to the development of what is generally called "supportive living"... Over and over again, studies have shown that community-based services are superior to institutions...In terms of adaptive behaviour 19 studies showed significant improvements while two studies showed significant decline...', (Mansell, 2006: p.67).

It will be noted that change in adaptive behaviour has featured significantly in the research literature. Indeed Kim *et al.*, (2001) reviewed 33 US studies found that,

'...almost all of the reviewed studies found statistically significant increases in overall adaptive behaviour scores associated with deinstitutionalisation. Three studies published since 1990 reported statistically significant improvements in challenging behaviour...and nine reported no differences...compared with persons who remained in institutions', (Kim *et al.*, 2001: p.35).

However, whilst the early studies concentrated on the differences between the outcomes of institutionalisation and community living, it was argued earlier that using institutions as the baseline was likely to place community residential options in a positive light. More recently a second

trenché of studies has begun to emerge which have compared differing community residential options (Emerson *et al.*, 2000; Stancliffe and Keane, 2000; Robertson *et al.*, 2001; Stancliffe *et al.*, 2002; Emerson, 2004; Young, 2006). In a series of papers (Emerson *et al.*, 2000a; 2000b; 2000c; 2001; Gregory *et al.*, 2001; Robertson *et al.*, 2000a; 2000b, 2001a; 2001b; Walsh *et al.*, 2001) from perhaps the most systematic comparison Emerson and colleagues compared 3 samples of 30 from village communities, 5 samples of 30 from residential campuses, 10 samples of 30 from dispersed housing has been widely reported. The results are summarised in Table 1 below.

Table 1 – Summarising comparative outcomes of dispersed housing, village communities and residential campuses.

Type of residence	Dispersed housing	Village Communities	Residential campuses
Positive outcomes:	<ul style="list-style-type: none"> • Greater choice • More extensive social networks • More physically active life • Fewer accidents in the home • Greater number and variety of leisure activities 	<ul style="list-style-type: none"> • More extensive social networks overall • Less exposure to crime and verbal abuse • Longer working week 	
Negative outcomes:	<ul style="list-style-type: none"> • Exposure to crime and verbal abuse • Shorter working week 	<ul style="list-style-type: none"> • Less choice • Reduced number and variety of leisure activities 	<ul style="list-style-type: none"> • less in choice, • less extensive social networks • a less physically active life • more accidents in their home • a reduced number and variety of leisure activities • greater exposure to crime and verbal abuse • a shorter working week

(Adapted from Emerson *et al.*, 2005; p.162-3).

There have been a number of issues with the findings reported above. Firstly there have been variations in the performance of settings,

'...the considerable overlap in the ranges of scores indicates that better large institutions can produce outcomes as good as weaker smaller settings; and that better smaller institutions can achieve outcomes as good as weaker staffed housing' (Emerson & Hatton, 1996: p.18).

Commenting on Emerson's (2004) finding that small dispersed group homes produce better

outcomes on all measures than cluster housing, Cummins and Lau (2004) argue that the two housing groups were different, with the cluster housing group being younger, having lower adaptive but higher challenging behaviour as well as a different housing history. 'Emerson deals with this by statistically controlling for the influence of these variables before testing between group differences...the statistical procedure has destroyed the group difference', (Cummins and Lau, 2004, p.198-199).

However, even in studies which have introduced controls the findings still seem to favour smaller residential options. For example: after controlling for resident characteristics 'fewer residents living together' was a predictor of 'choice' and 'individualisation' (Tossebro, 1995; Stancliffe, 1997); '...Controlling for the effects of adaptive and challenging behaviour, increased costs were only associated with increased performance on 1 of 13 quality indicators within village communities (physical activity), 3 of 13 quality indicators within residential campuses (physical activity, number and variety of community activities) and 6 of 13 quality indicators within community housing schemes', (Felce and Emerson, 2005: 56); and semi-independent living was found to be associated with lower costs and better outcomes than staffed group homes (Stancliffe and Keane, 2000). These results are not without challenge. Young (2006) in her longitudinal study of 30 matched pairs resettled to cluster and group homes found residents in both groups had increased in their adaptive skills, choice-making and life quality and that these changes were sustained over time.

It should also be noted that the most common outcomes measured in studies comparing residential options have been those relating to adaptive and challenging behaviour. There are key authors involved in the collection of data who have consistently built their publication portfolios on an evidence-base that operates across time as well as within study. Not surprisingly other academics have to a large degree adopted aspects of this seminal repository of knowledge. Below some of the key findings are outlined taking into account the various study outcomes.

Studies reporting 'relocation syndrome' (Cochran *et al.*, 1977) or 'transfer trauma' (Saloviita, 1996) indicate the possibility that any change in residence might produce a spike of increased problem behaviour. As with the population as a whole moving house is exceptionally stressful and where there has been little participation and where people are unable to express their emotions this finding is understandable. However, the minority of studies indicate any lasting improvements on global measures of challenging behaviours after a move to the community (Conneally *et al.*, 1992; Cullen *et al.*, 1995). In the literature relating to those with significant challenging behaviours very little positive long-term effect on the frequency or intensity of challenging behaviours has been found in the move to community residential options (Conroy *et al.*, 1991; Mansell, 1994; Conroy, 1995; Stancliffe *et al.*, 2002; Young, 2006). In some cases, as increase has been reported (Lowe *et al.*, 1998; Felce *et al.*, 2000). Individual item changes reported are in a minority but include reduction in externalised threat or aggression

(Fortune *et al.*, 1995) and lower levels of self-injury (internalised) (Rose *et al.*, 1993).

The findings seem on the face of it to question the model which asserts that environment affects behaviour. However, the studies reported also point to interesting contrasts around the varying techniques used to control behaviour in the differing environments. In the behaviour relating to those with the most significant challenging behaviours Lowe *et al.*, (1998) found more adaptations for limiting movement and Felce *et al.* (in preparation) found more verbal intervention in specially designed smaller community residences than in institutions; he found correspondingly more physical restraint by one or more members of staff in the institutions. In the wider literature there also seem to be differences between community settings. Perhaps not surprisingly, Stancliffe and Keane (2000) found more block treatment in group home as opposed to semi-independent settings; Young (2006) found that rigidity of routines reduced in *both* cluster and group homes after resettlement from institutions with a slightly better performance by cluster options; Emerson (2004) found higher levels of both medication and anti-psychotic medication as well as sedation in cluster settings as opposed to group homes and that residents were more likely to be ignored and those with challenging behaviours to receive *least* attention; Robertson *et al.* (2005) found that congregate as opposed to non-congregate (mixed functional groupings) settings used more medication and anti-psychotic medication.

The evidence seems to be that against institutions, all community settings rate well. Smaller residences produce fewer constraints on personal freedom and fewer invasive and physical restraint procedures.

Adaptive behaviour, like challenging behaviour features strongly in the literature on the outcomes of residential options. Unlike findings relating to challenging behaviour though, research indicates significant initial gains in terms of adaptive behaviour on moves to the community not least in relation to vocation (Conneally *et al.*, 1992; Conroy *et al.*, 1995); independent skills (Young, 2006); social interaction (Conneally *et al.*, 1992) and self/personal care (Mansell, 1994; Golding *et al.*, 2005).

Furthermore, domestic tasks, practical tasks and chores (Mansell, 1994; Felce *et al.*, 1998; Felce *et al.*, 2000; Golding *et al.*, 2005, Felce *et al.*, in preparation) have also featured regularly in the findings. The latter may not be such a revelation; after all, in the old institutions kitchens were distant, cleaning contracted out and initiative or risk-taking discouraged. It is hypothesised that the environment plays a key role in providing the opportunity structure given the wider availability of household items, creative materials, personally owned goods

and the closeness to community options and, finally, the development of a sense of responsibility for the home. That the opportunity structure may become 'exhausted' may also explain why studies have found a levelling out of improvements in adaptive behaviour over time. Moreover, what is more important is that when a residence becomes a home, people are more likely, with the correct support, to take pride in it and become involved in those duties tied to its maintenance. They are also likely to see the home as a reflection of their personal identity and choice.

Indeed, the issues relating to choice, self determination, autonomy and independence also appear in the outcome literature though to a lesser degree than does behaviour. Felce *et al.*, (1998) (and, by implication, Felce, Lowe and Blackman, 1995 and Lowe *et al.*, 1998) as well as Golding *et al.*, (2005) report choice was found to be significantly better in community houses than in institutions for those with the most significant challenging behaviours. However, Robertson *et al.*, (2001) found overall, that although greater than in institutions choice in group homes, staffed housing, or supported living arrangements remained low. For example, though many had choices about their clothes and about what leisure they participated in, ten percent or less had been involved in choosing their home, with whom to live or the home furnishings and below 30% in choosing day activities, jobs or household routines.

Robertson *et al* (2001b) go even further in identifying those aspects of residential settings that are associated with more choice. These are: 'home-like' architectural features; living in a smaller setting with fewer people; and with organisational procedures for individual planning in place. Moreover, although participant ability is a predictor of choice and self-determination, some research is now showing that even people with severe and complex disabilities can make tangible choices (e.g. Lancioni, O'reilly and Emerson, 1996). 'Thus it appears that the observed relationship between ability and self-determination may reflect the combined effects of intellectual impairment and the failure of services to provide appropriate environmental supports' (Robertson *et al.*, 2001b: 497).

The use of leisure seems to have grown in community settings and for people with the most challenging behaviours also (Mansell, 1994; Golding *et al.*, 2005). In the wider literature Golding *et al.*, (2005) found larger social networks in the community than in hospital as did Stancliffe and Keane, (2000) whilst Emerson (2004) and Emerson *et al* (2000) found that leisure and social networks as well as community activities were higher in dispersed group homes than in cluster housing. Integration into any community should be a key

factor in making judgements about the nature and success of community care initiatives but the level of information and data reporting on leisure, social networks and community activities was disappointingly low in the literature as a whole.

Wider factors may complicate the assessment of outcomes with the 'privatization' of community living for the majority of the population. Along with greater mobility this tends to mean people being involved in activities to which they travel to find 'friends' who share an interest. The same may apply to local politics, decision-making around inclusion and to citizen democracy. Given these changes in society as a whole it is vital that further work on neighbourhoods (including rurality) and social capital (including cultural and linguistic) are developed to support new developments within 'communities of interest'. This means nothing less than restructuring some of the ways in which judgements are made about the success of community care and, associated with this, the ways in which support staff seek to engage communities of interest. The interest should be neither in perpetuating life-long social training and behavioural change nor in the replacement of a range of meaningful activities with a singularly leisured class of the disadvantaged.

If people with intellectual disabilities are to be supported to experience better outcomes in the community the central role of staff support cannot be underestimated. Being engaged constructively is a prerequisite to a life of variety, new experiences and consolidation of control over the environment around. The salient points from studies of engagement are that such engagement tends to increase in smaller community environments in terms of personal engagement (Golding *et al.*, 2005), staff attention (Felce *et al.*, 1998; Felce *et al.*, in preparation) and to engagement in domestic activity (Felce *et al.*, 2000). Studies which started with engagement have over time transformed into more systematic approaches to working with people with challenging behaviours. Active support and positive behaviour support represent the most recent evolution of the studies on engagement and require further evaluation (Carr *et al*, 1999; Felce *et al.*, 2002; McVilly, 2002; Stancliffe *et al.*, 2006).

In recent literature there have been some debate about the place of well-being as a key outcome in studies of residential options. Cummins and Lau (2004) argue the need to include measures of quality of life and subjective well-being in future research. Young (2006) used such measures in comparing moves to cluster and dispersed group homes from institutions. She found that material, physical, social/emotional and resident well-being improved to similar levels in both

cluster and dispersed housing. Only in the case of physical well-being was the cluster housing a little more successful than dispersed housing though not at levels of significance. However, measures of subjective well-being have been criticised on a number of grounds. Firstly, people tend to be happy with what they have (better the devil you know) until they have experienced other options. Moreover, there are likely to be practical and methodological difficulties in engaging users themselves and significant issues around using proxies in their place. So, whilst efforts should be made to ensure that relevant measures of quality of life are adopted in future research, questions still remain about around its operationalisation.

Above, the major 'outcomes' represented in literature on the outcomes of different residential options for people with intellectual disabilities have been rehearsed. There are a number of key points that emerge from this review:

- There is incontrovertible evidence that community living produces better outcomes for people with significantly challenging behaviour
- The evidence is very strong that changes in behaviours that challenge are not a direct product of the environment alone. This means separating environment from intervention is essential.
- Generally speaking the evidence for people with significant challenging behaviour favours, like the majority of research in this area, smaller settings rather than larger ones.
- Questions still remain about the level of these improvements in lifestyle between community residences.
- Much work has been done in measuring changes in behaviour and adaptation. A new focus on community outcomes and quality of life needs to be developed alongside new interventions in these areas.

Understanding explanatory factors that mediate outcomes in different residential settings

So far the outcomes for residents have been the focus of this review. In the following section some of these and other factors that mediate outcomes in different residential settings are discussed.

There are a number of further factors that seem to have an affect on the outcome of different residential options. Studies that look at the relationship between *residential type* and outcome have assumed that each residential type *named* (e.g. cluster, hostel, group home etc) has an identifiable set of well known characteristics. Because of this, the vast majority of studies fail to discuss in sufficient detail those architectural,

design and other features of the homes under study nor, indeed, the outcomes associated with each of these characteristics.

Studies of 'homelikeness' (Thompson *et al.*, 1996; Egli *et al.*, 2002) have found positive staff to client interactions and reductions in stereotyped behaviour and physical aggression in such environments in which:

- Space devoted to long corridors is limited
- Ground floor is for daily living
- Wall, floor and ceiling materials are homely and of the residents' choice
- Number and type of light fixtures are designed for home not institutional use and to produce a homelike ambience
- Numbers and style of furniture are similar to those in everyday houses
- Disability specific adaptations (U-shaped toilet rings, rows of sinks) are kept to a minimum and reflect the resident's needs and not the needs of all people with disability

However, the work does not take the argument around homely environments very far in terms of describing the relationship between architecture and design, and outcomes. Felce *et al.*, (2000) along with Mansell (1994) distinguish between settings in the following ways:

Institutions:

- Hospital wards (average 19 residents, 629 m sq per resident) or units (average 9 people, 409 m sq per resident) are large, with large area per resident,
- Restrictions on movement to kitchen, bedrooms, bathrooms, staff office, rest room, cleaner's cupboard, laundry and store
- Half the residents lived in locked wards
- Material environment dilapidated, barren and bizarre (17 sideboards)
- Little to do but sit, walk about and watch television
- Few therapies and little day care and excluded from many because of behaviour
- Staffing levels low (but always qualified nurse)
- All other residents had behaviour problems

Specialised group home:

- Home planned for each individual
- To live with one to three other people without challenging behaviours

- Ordinary properties on ordinary streets
- Less space per person 92 m sq than institutions but all space available to resident
- Full range of furnishings and equipment
- Staffing level higher but not necessarily qualified
- Specially trained in normalisation and behavioural methods
- Emphasis on structured enrichment
- Management of demands and opportunities
- Still few day services.

In the literature around residential options positive outcomes in smaller settings were more likely where there were:

- More activity planning and written intervention programmes
- Greater levels of staff training
- Better staff:client ratio
- Lower levels of medication
- Lower levels of anti-psychotic medication
- Less physical restraint by one or more staff
- Less inconsistency in living arrangements (Short term care, bank staff or long term respite)
- Lower verbal direction and intervention

Moreover smaller homes were more likely: to have individual plans for residents (2 out of 3 studies); to have higher psychological input; to have fewer adaptations for limiting movement; to have higher staff support to residents; to be less rigid in routines and sedation; and that residents were not ignored. In only one comparison was the larger residence found 'better'. This was in Stancliffe and Keane's (2000) comparison of semi-independent living versus group homes, where it was found there was more planning in group homes than semi-independent settings. This finding is probably understandable if it is assumed that those living semi-independently are likely to be both more able and independent and therefore more able to plan their own lives.

However, even with these studies basic things still remain unknown: How close are houses to a road, to public transport? How have they been developed to maximise the chance of contact with neighbours or the community? Which direction do the windows face? How are necessary adaptations made to be as inconspicuous as possible? How are areas and zones managed for privacy? Where and how are drugs kept securely? Are there facilities for staff independent of residents? How can personalisation of private space such as bedrooms be maximised? There is a real need for

good practice around these mundane areas to be collated, codified and made available to support staff and others working in the field.

In addition to issues around architectural features, client mix is also an important factor in distinguishing outcomes. A minority of research evidence indicates that positive outcomes for homogenous groupings (Knobbe *et al.*, 1995), i.e. those groupings in which individuals share some characteristics (e.g. similar levels of challenging behaviour). Emerson, Beasley, and Offord (1992) found that homes which grouped people with very severe challenging behaviours achieved *no improvements* in client outcomes over institutional care.

Mansell (1995) found that specialised placements in mixed homes achieve better results and later identified consistently worse practices and outcomes for people with challenging behaviour in functionally homogenous groups and better care practices and outcomes were associated with higher adaptive behaviour and mixed groups (Mansell, 2003a). A concentration of study in this area provides very good scientific grounds against homogenous settings even for those with the most severe challenging behaviour (Mansell and Beadle-Brown, 2004, Mansell, Beadle-Brown, Macdonald and Ashman, 2003a, Robertson *et al.*, 2004). Moreover, Robertson *et al.*, (2004) comparing homogenous and non-homogenous settings found non-homogenous settings to be more cost-effective, to achieve better person-centred planning (PCP), assessment, teaching, activity planning and staff support. No differences were identified in relation to choice, social networks, activities within home or community involvement.

The data on whether it is better to place people into homogenous groups with specialised services or whether to place them into groups that are mixed assumes a number of things: firstly that they should be 'placed', an approach that takes away their choice; secondly that they must live in a group that may not necessarily be the best option; and also that the interests of other residents can be served where other residents have dissimilar characteristics, all of which may be an erroneous assumptions.

The features of the setting and the mix of clients are important factors in the success of different community residential options. However, earlier it was argued that there was a need to separate residential option from support. Both need to be of a high standard and getting the intervention correct is vital. Mansell may well be correct in asserting that,

'In general, it appears that, once the material and social deprivation found in institutions is addressed by their replacement with small-scale services in the community, the main predictors

of at least some important outcomes are: resident need for support (adaptive behaviour) and the care practices of staff, in particular the extent to which they provide facilitative assistance or "active support" (Brown, Toogood & Brown, 1987', (Mansell, 2006, 70),

More research is required to evaluate the success of new options around active support and positive behaviour support to supplement studies which incorporate new outcomes such as those suggested earlier.

One of the central issues for Government in the future remains the cost of residential options. It is well known that there is an under-provision of community residential options for people with intellectual disabilities. It is also well known that the costs increase, the smaller the housing option (Knobbe *et al.*, 1995; Stancliffe & Lakin, 1998 Dockrell *et al.*, 1995; Felce *et al.*, 2000). Staff can represent the biggest recurrent cost in the provision of residential services to people with intellectual disability living in the community. However, the data on costs is further complicated by the repeated findings that increased staff input does not necessarily lead to better outcomes (Perry *et al.*, 2000; Felce *et al.*, 2000). Rather, importantly, it is the quality of staff input that matters most and not the number of staff provided. Some consideration should therefore be given to the ways in which staffing for an active support intervention might produce optimum outcomes.

Semi-independent living has been found to be cheaper than dispersed group homes (Stancliffe and Keane, 2000), highlighting the important relationship between resident ability with cost (Knapp *et al.*, 1992; Cambridge *et al.*, 1994; Beecham *et al.*, 1997; Felce *et al.*, 2003). In this regard Felce *et al.*, (1998) found community housing for people with the most severe challenging behaviour in Wales to be about twice as expensive as institutional provision. Hallam *et al.*, (2002) adjusted their calculations of costs to account for the 'characteristics of users' and found that dispersed housing provision was 15% greater than that for residential campus and 20% greater than for village communities. However, even using the most up-to-date techniques of statistical modelling, the Hallam *et al.* (2002) study could not account for 62% of the cost variation.

Finally, there is much yet to be learned about the relationship between costs and the use of individualised budgets, whether managed by the person themselves or by an intermediary brokerage or micro-board system. It may be that the close relationship between choice, self-determination and such funding may yet prove even more cost-effective in the long term.

Conclusion

An attempt has been made above to summarise the findings of a large literature relating to the residential options for people with intellectual disabilities. The review has points to a number of key findings:

- It is hypothesised that there is a direct relationship between the sense of ownership of a home and the desire to take pride in its appearance. At the cognitive level the avenue of opportunity for adaptive behaviour within the home is supported by the development of this sense of ownership. Developing a sense of ownership is an important policy ideal and one that should be developed as an outcome measure in future studies.
- The comparative data on the benefits of cluster and group homes for people with intellectual disability, including those with challenging behaviour, is conflicting and does not allow valid conclusions to be drawn about which is preferable. Generally though smaller residence size, in this case dispersed group homes, are rated as providing better outcomes. Even in the study rating both on matched samples which is most positive to cluster housing options, group homes were still found to be 'marginally better'.
- Generally it has been found that there are fewer constraints on personal freedoms and fewer invasive or physical restraint procedures in smaller community residences when compared to institutions. Data comparing cluster housing with dispersed group homes in these terms is contradictory across studies though for houses which congregate people with significant challenging behaviours the outcomes appear to be more negative.
- Adaptive behaviour has been one of the signal successes of the move to community living options. Many studies have reported positive outcomes in a number of areas of adaptive behaviour. It is hypothesised that community residences provide an opportunity structure, (with availability of household items, creative materials, personally owned goods and proximity to the community alongside more freedom to engage in household activities), a reorientation of staff support which links household ownership with responsibility and home pride, and a freedom of self-expression and activity which directly links the person with their home.
- By-and-large, increases in leisure, community networks and activities is associated with smaller dispersed residential options. Both these and cluster options produce better

outcomes than larger settings and institutions. Despite this, the successes in relation to community participation have been mediocre when set against the ultimate aim of full social and community integration.

- Smaller homes have a greater chance of reproducing homelike features and resisting the slide back to 'institutional' characteristics and practices. Hand-in-hand with non-institutional environment and practices seems to go better individual case management practice, a growth in training and an environment developed on a model of 'structured enrichment' and choice rather than barren incongruous space and both social and physical forms of control.
- Although active support may improve behaviour, services should not expect behaviours to improve simply because of a residential move. To maintain a link between home and identity, residential options must be produced that are able to withstand behaviours that challenge without having to move the person, except where this becomes a matter for mental health services or for forensic services. Maintaining a person in their own home is made more problematic in seeking to maintain such residential options *with* other people. It also implies breaking the long held association based on a model of graduation (i.e. breaking the very old tradition of linking level of adaptation to what residential option is seen as most appropriate).
- New measures of outcome need to be developed to supplement the concentration of adaptive behaviour that characterises the literature. The importance of life quality, of neighbourhoods and of social capital are implicated in this regard. Additionally, asking the broader questions around how disadvantage and housing are related, will be an important aspect of future research and policy planning.
- It is important to ensure that the type of residential support provided is viewed independent of the support and intervention received by each resident. *Both* have to be of a high standard and, although interdependent, both have been thought through, structured and delivered very carefully.
- In choosing client mix it is necessary to take into account research that shows that homogenous groupings produce worse outcomes. Developing residential options that have a client mix should be organised to take account of both group needs and the right to individuality and privacy.
- Generally speaking, and even for those with the most significant challenging behaviour,

there are indications that smaller dispersed community residences produce better outcomes. The data here is not yet incontrovertible but is, nevertheless, very strong.

- Continued research is required to evaluate the outcomes of different residential options chosen. This research should use samples matched by characteristic (including challenging behaviour) and should extend their outcomes to incorporate more community-based and quality of life measures.

Finally, any literature review has its own limitations since it can only report on options already available, tested and reported. Hence, new forms of home and shared ownership and rental, semi-independent and independent living options, all of which represent more recent introductions to the repertoire of community residential choices, do not yet feature in research. Where such inventiveness in the production of future possibilities for housing occur, but where no evaluative material is available to judge their merits, we are led back to the values that underlie the decisions made about people's lives. We are led also to the importance of continuing research in this area.

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LOOKING FOR THE NUMBERS

Professor Jim Mansell, Tizard Centre,
University of Kent

What do we already know?

- Level of supported accommodation for people with intellectual disabilities in Australia much lower than in England or USA
 - 22% less than England
 - 71% less than USA (Stancliffe 2002)
- **Zero growth in Australia**
 - 11% in USA 1997-2003 (Stancliffe 2005)

What do we know about Victoria?

- Data confounds disabilities, making international benchmarking and tracking over time difficult
- 8,371 users of CSTDA-funded accommodation support in 2004-5 (Victorian State Disability Plan Implementation Plan 2006-2008, Appendix 1)
- 13,199 users of state/territory CSTDA-funded accommodation services in 2004-5 (Ibid, Appendix 2)
- 2,824 users of supported accommodation in 2004-5 (6,093 users in 'Domestic scale supported living') (AIHW, 2006)
- No data on estimates of need or projections of supply

Unmet need: Just because you pretend it isn't there, doesn't mean it isn't there...

How much supported accommodation do we need?

- What is the policy goal?
- How many people are there?
- How many of them need support?
- What do we mean by 'supported accommodation'?

What is the policy goal?

- **Explicit policy goals are**
 - That everyone should have same opportunities as rest of population – ie everyone should be able to leave family home and set up own home in early adulthood
 - Transitions are supposed to be individually planned and to meet person's needs
- **Implicit policy goals are**
 - To expect families to care for as long as they can, even into very old age
 - Transitions typically occur only in crisis

How many people are there?

- About 25,000 people with intellectual disability in Victoria using disability services
- Between 7,600 and 16,600 disabled people always need help in activities of daily living, but no data presented on nature of their disability or where they live
- 2,800 people (estimated) with carers over 65 but no data on disability or where they live
- No data on life-course; numbers entering adult services, numbers dying

How many of them need support?

- Many people will not need any support from services; those who do will need everything from occasional visit or telephone call to 24 hour support face-to-face
- Expanding drop-in support for people with lower needs may be worthy but largely doesn't touch the problem of not enough supported accommodation

What do we mean by 'supported accommodation'?

- Do people all have to live in groups of the same size?
- Does property all have to be the same design?
- Does it all have to be owned and funded by the government?
- Do staff all have to follow administrative procedures as if the place was a CRU?

How have other people tackled this problem?

- Using the housing market to supply a much wider range of options
- Developing shared-equity schemes
- Much greater use of not-for-profit sector (because more efficient)
- Focusing on outcomes not micro-managing process

Postscript

Information

- *'Knowledge is power'* (Bacon Meditationes Sacrae (1597))
- Which may be why you haven't got any...

The information needed

- Number of adults classified as having a primary or subsidiary disability type of 'intellectual disability'
- In Victoria
- In residential care
 - With place of residence other than private home

- Likely to need supported accommodation
 - Aged over (say) 25
 - With severe or profound activity limitations
 - With place of residence as private home
 - By carer status

Getting the information

- All this information is already held by AIHW

- But no national or state documents seem to contain it, so you could
 - Ask for access to the raw data and analyse it yourselves
 - Ask MPs to ask for the information through Parliamentary Questions
 - Use the Freedom of Information Act

ROUNDTABLE ON INTELLECTUAL DISABILITY POLICY AND PRACTICE – LA TROBE UNIVERSITY, APRIL 2007

Plain English Summary

Why the Roundtable forum was held

The Roundtable was held so people could talk about disability policy and other policy that affects people with an intellectual disability. The aim was to bring together a group of people who were interested in talking about the issues, being clear about what was happening, looking at the challenges, thinking about solutions and putting forward ideas that could change policy and the way people with an intellectual disability are supported to live their lives.

The theme in 2007

This year the people at the Roundtable came together to talk about Housing and Support for people with an intellectual disability who also have high needs, complex needs (a lot of needs or ones that need specialist supports), and changing needs (because of getting older, serious health problems or different things that happen in their lives like family not being able to look after them any more).

A lot of services and supports are more accessible for people with lower support needs. We need to be able to make sure policies and new supports and services don't forget these people.

The papers presented and what they said

Colin Hiscoe from Reinforce with Patsie Frawley described how people with high, complex and changing needs "are not always able to tell people what it is like for them; have to put their lives in other people's hands and could be left in bed all day if they don't get support". Erin Wilson with Chris Fyffe, Estelle Fyffe and Diana Heggie presented some case studies from disability services that made us think about how difficult it is to provide great services and supports when there are no new resources for this group and policy doesn't talk about this group. Chris Fyffe and Chris Bigby's paper was about new housing and support services and how they did not meet the needs of this group. Also these support services don't always have staff who can support people with high, complex and changing needs.

Paul Ramcharan with Karen Nankervis and Geraldine Abdilla presented a paper that talked about what other research has found out about how to support these people and how important it was to meet their needs. Jim Mansell talked about the need for some information about what is going on for this group in Australia so we can describe it and compare it with what is happening in the USA and UK.

Summary of discussions at the Roundtable

After the presentations people talked in their groups about the issues. The main ideas that came out of these discussions were:

- The need to find out what it is like for people with high, complex and changing needs from them and looking closely at their lives and to use this to train staff
- Policies need to say how they are going to support this group of people
- We need to know how many people there are with these needs so we can plan better supports and services for them and advocate for and with them
- People thought that the money that is available in disability housing and support isn't always used in the best way and if it was used differently people with these needs might not miss out
- People who think about and talk about disability housing and support should talk to other people who are talking about these issues for other people in the community

Other things talked about

- We were mainly talking about people who are in services not with their families.
- The groups decided that housing is a right and if people have good housing that is like a home other good things can happen in their lives
- How do we really find out what people with these needs want in their lives and when they can't speak for themselves who should speak for them?
- Planning needs to be done that is based on how many people have these needs now and how many might in the future.
- Individual planning should happen when people know what resources they can have
- How can we make sure people with these needs have choices, are included in the community, gain skills and are able to participate?

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.

Continued on next page

<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.

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Janine Bush	Office of the Public Advocate
Jeffrey Chan	Office of the Senior Practitioner
Tim Clement	LaTrobe University
Lynne Coulson Barr	IDRP
Daivd Craig	Action for Community Living
Stephan Dunns	St John of God
Patise Frawley	LaTrobe University
Chris Fyffe	Grimwood
Estelle Fyffe	annecto
Liz Gillies	Helen Mcpherson Smith Trust
Colin Hiscoe	Reinforce
Brian Howe	Disability Housing Trust
Hilary Johnson	Scope/LaTrobe
Kirsty Kihl Larsen	DHS Head Office
Kathryn Lamb	DHS Head Office
Daryl Lang	Office of the Senior Practitioner
John Leatherland	DHS-Eastern Metro Region
Micheline Lee	Office of Disability
Daniel Leighton	Jewish Care
Kolbein Llyng	Molde University College Norway
Ian McLean	Golden City Support Services
Jim Mansell	Tizard Centre University of Kent
Gerry Naughtin	Brotherhood of St Laurence
Christine Owen	DHS Eastern Region
Elizabeth Ozanne	Melbourne University
Paul Ramcharan	RMIT
Fiona Reidy	LaTrobe University
Andrea Rosewarne	RMIT
Marsha Sheridan	Yooralla
Janice Slattery	Reinforce
Kevin Stone	Valid
Deb Thurect	Melbourne City Mission
Ilan Vizel	Melbourne University
Lynne Webber	Office of the Senior Practitioner
Erin Wilson	Scope
Nicola Wood	Municipal Association of Victoria