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# ***Presenting the Evidence:***

*Accommodation and  
Support for People  
with Disability*

August 2007

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**Vision:**

We have a vision of families being agents of positive social change so that people with developmental disability have inherent value as members of a just and inclusive society.

**Mission:**

To attain positive social roles for people who have a developmental disability through the development and support of advocacy by families and by strengthening the knowledge, role and influence of the family.

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## Introduction

Having ‘a good life’ is a goal to which most people, including people with disability, aspire. The challenge is to find ways to achieve this that are sustainable for the person, his/her family, the service system and Government.

In principle, Government policy supports a good life for people with disability. Unfortunately, many competing pressures turn positive rhetoric into services that future generations may seek to close.

The significant unmet need for accommodation services for people with disability is one such pressure acknowledged by Commonwealth and State Governments and is exacerbated by the growth in the number of people with disability and their increasing life expectancy.

The pressure of unmet need places stress on previous commitments to close institutions. Voices calling for a decent life for people in institutions are drowned by voices despairing that Government will ever make adequate provision in the community.

Today, Government policy recognises that the models of the past have not been effective and hence there is growing support for innovation. In addition, policy is underpinned by positive principles such as:

“Research and evidence will inform service development and practice” and  
“Accommodation and support options will build on practice that works for people with disability – both nationally and internationally.”

The practice, however, is inconsistent, especially for people who need intensive ongoing support. Increasingly, proposals to provide accommodation for people with high support needs, described as innovative, tend to be large, congregating people and segregating them from the community.

For a proposal to be innovative it must provide a discernable, positive difference in the lives of the residents. It must be based on evidence of what works in producing positive outcomes. Cluster housing cannot meet either of these criteria.

The Australian Housing and Urban Research Institute (AHURI) argues that cluster housing developed as a strategy of de-institutionalisation will present agencies with a challenge in ensuring inter-generational equity and sustainability in housing options. The over-development of cluster housing may lead to unfairness for future generations with a danger that people will be placed in these facilities in spite of wanting a community based option. (Bostock:2001:53)

The question is raised as to why the evidence of research is so distorted. One element of the answer relates to the fact that genuine debate is stifled when Government policy changes language but service practice remains the same. A major element, however, for the lack of congruence between the rhetoric of Government policy and practice on the ground, is that the lessons of research must compete with unconscious values and myths that are left unchallenged. Myths such as ‘*people do best with their own kind*’, ‘*individualised support is more expensive*’ legitimise the status quo and thwart responsiveness.

The Institute for Family Advocacy and Leadership Development (Family Advocacy) developed *Presenting the Evidence: Accommodation and Support for People with Disability* as a response to the challenge of understanding what is required to build expertise in supported accommodation. It reflects the evidence of a review of over 100 articles in peer referenced journals prepared in collaboration with Trudy Van Dam, Co-ordinator of

Bachelor of Education (Habilitation) at the Australian Catholic University and Lesley Chenoweth, Senior Lecturer and Director of Internationalisation at the University of Queensland.

This paper presents the evidence on the key issues of:

- cost and effectiveness;
- staffing;
- supporting people with challenging behaviour;
- supporting people with complex health needs; and
- the self management of funds.

The overwhelming conclusion from the literature is that larger forms of accommodation offer significantly poorer quality of life for people with disability than smaller forms of accommodation.

Much of the literature presented in this paper compares cluster housing with ‘dispersed housing schemes’, usually group homes. This paper should not be interpreted as being in support of group homes. In fact, Family Advocacy is on record in its concern about group homes and has worked assiduously to influence Government and service providers to improve quality and to consider other ways of supporting people as contributing members of their community.

Family Advocacy showcased examples of supported living projects and policy in Queensland, South Australia, Victoria and the ACT to Minister Della Bosca in October 2005. These policy directions are part of a world wide movement that moves decision making and authority in the lives of people with disability away from formal services and vests them in the person and their close circle of allies.

At this time, these forms of supported living hardly feature in the academic literature. Many fly ‘below the radar’ of formal service systems concerned that the delegation of authority to people with disability and families will be found to be ‘improper’ in the current service system. Most do not feature in the literature because the people involved are ‘busy getting on with the job’ and have little time and money to commission independent evaluative research. They present material at small modest conferences and seminars and so are not invited to be part of randomised evaluative studies comparing outcomes and costs. Many supported living projects have undergone external evaluations, but these are of an introspective nature, examining what is happening and how it could be improved so that the lives of individuals can be more enriched.

This is the second edition of *Presenting the Evidence*, reprinted in response to the demand of people with disability, families and services to build their knowledge of what the evidence says. Information about what works is a threshold step in building better lives for people with disability. A belief in the inherent value of people with disability and tenacity are other ingredients that are needed.

## Summary of the evidence

Each statement in this Summary of Evidence reflects research for which sources are cited in the full body of the Paper.

### Costs and outcomes

Effectiveness in achieving high quality outcomes and good quality of life is a critical factor when considering expenditures for services. Higher-cost services that deliver better outcomes ought to be supported strongly on cost effectiveness grounds.

Extensive US studies of both costs and outcomes of de-institutionalisation reveal a consistent pattern across states and over time of better outcomes and lower costs in the community.

UK cost studies, on the other hand, indicate that community services are more expensive than institutional services because there was an acceptance that reform of institutional care in the UK should be accompanied by increasing costs per resident as this additional investment was necessary to avoid replicating in the community the often scandalous conditions found in UK institutions.

UK research demonstrates stark differences in the nature of support provided to, and outcomes achieved by, people with intellectual disability who live in campuses, villages and dispersed housing schemes<sup>1</sup>. Across a range of measures of resource inputs (eg staffing ratios, buildings), non resource inputs (eg social environment) and process and service recipient outcomes (eg choice, activity, social networks, social integration, medical usage), residential campuses offered significantly poorer quality of life than dispersed housing schemes.

Whilst dispersed housing schemes were found to be 15% more costly than cluster housing, the pre-eminent UK researchers conclude the additional costs of dispersed housing schemes may be justified in light of the substantial benefits.

Increasingly, research is drawing attention to the benefits of the more individualised support provided through supported living schemes, suggesting that for similar costs,

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<sup>1</sup> **Intentional or village communities** represented approximately 2% of supported accommodation for people with intellectual disability in England (UK Department of Health, 1999 in Emerson:2004:188) and were described as “typically campus arrangements that are operated by charitable foundations, often with strong religious or philosophical foundation. They have evolved over a period of time relatively independent of public services and tend to support relatively more able individuals with intellectual disabilities who have moved from either the family home or residential educational facilities.”

**A campus community** was defined as “a setting in which housing for people with intellectual disabilities was clustered together on one site and shared some central facilities (eg day centre, church, shops)”. In a subsequent study (Emerson:2004) cluster accommodation was defined as “accommodation located either as part of a campus development (three or more houses with an on-site day centre) or in a cluster of houses for people with intellectual disability (eg a dead end street with three or more houses for people with intellectual disabilities).”

**Dispersed housing schemes** included “all forms of long term residential supports that provided 24 hour support in dispersed housing for no more than 8 people. **Supported living schemes** (a subcategory of dispersed housing schemes) were defined as examples of residential supports in which no more than 3 people with intellectual disabilities were living in the same house as co-residents and the provider organisation defined the arrangements as examples of supported living.”

supported living schemes may offer distinct benefits in the area of resident choice and community participation.

The UK interest in new cluster housing arrangements as ‘intentional’ communities led to a large scale evaluative study which concluded that government developed cluster housing schemes exhibited none of the defining characteristics of ‘village’ communities which developed independent of deinstitutionalisation.

In addition, the research found that cluster housing arrangements offer, overall, a poorer quality of life when compared with dispersed housing. Once any effects attributable to participant characteristics had been taken into account, people supported in cluster housing were more likely (statistically significant difference) to live in a setting that was also used for short term care, share their house with more people, be supported by a lower ratio of staff, be supported by casual staff, have a key worker, not have an individual plan, have seen a dentist in the previous year, be underweight, engage in fewer episodes of moderate or vigorous exercise, be prescribed psychotropic and two or more different forms of anti-psychotic medication, be exposed to seclusion following an episode of challenging behaviour, have participated in fewer and a more restricted range of leisure, social and friendship activities over the preceding four weeks and have participated in fewer community based activities in the preceding four weeks.

The research found no statistically significant differences in rated satisfaction of residents or their relatives between the different models of accommodation. This supports other research that discrimination in the views of service recipients and relatives is only likely when it is possible for the service recipients and relatives to make comparative judgements.

Finally, the costs of service provision were found to be unrelated to outcomes.

## **Staffing**

The way staff provide support to the people they serve, the way they plan, the way they select and schedule activities and the way they arrange the support, has been singled out as a key determinant of service quality and outcome for residents.

The extent and nature of staff:resident interaction is important in determining the extent of resident engagement in activity. A high level of staff support for those with greater disability brings their levels of engagement in activity up toward those with greater independence.

Evidence shows that the smaller the home, the higher the level of staff attention to, and engagement with residents. The evidence is clear that resident gains only occurred when the resident group size was reduced. Of particular note is the fact that arithmetically identical staff:resident ratios did not produce similar activity patterns. In every case, the larger staff:resident group was associated with lower resident activity. Further, levels of engagement and staff attention to residents were higher in smaller homes than in larger community units, which in turn were higher than in the institutions, even under similar staff:resident ratio conditions.

The literature demonstrates that real opportunity for people with high support needs appears dependent on the coming together of three factors:

- available activity for all which involves moving from the ‘hotel’ model to resident participation;

- available personal support including well developed methods for staff:resident deployment and activity planning;
- effective assistance to help those people who lack skills to accomplish an activity successfully. This includes well defined outcome targets, a systematic approach to work with residents to support and motivate particular patterns of activity and managerial monitoring to ensure it happens.

*Active Support*, developed and evaluated in the UK, provides a coherent, well researched package of training in staff working practices and group home organisational procedures. Evidence demonstrates that the implementation of *Active Support* results in more direct support for resident participation by staff and higher levels of engagement in activities by group home residents both at home and in the community.

## **Effective support for people with challenging behaviour**

The research demonstrates that service systems continue to support people with challenging behaviour using punitive methods that do not achieve success. This results in heavy use of psychotropic medication and physical restraint, and poor implementation of behaviour support plans.

Environment has been shown to contribute to a person's behaviour with maladaptive behaviour arising in maladaptive circumstances. Environments that group individuals with challenging behaviour, that provide little stimulation, little opportunity for control and choice, and segregated settings, have been shown to contribute to a person's challenging behaviour; are not conducive to positive adaptive behaviour; are not cost effective, and, are associated with a range of poor outcomes and lower staff contact.

Specialist services for people with challenging behaviour were associated with restrictive behaviour management strategies and greater use of physical restraint and medication.

Evidence indicates that people with challenging behaviour are those most likely to benefit from living in community rather than segregated settings.

*Positive Behaviour Support* that integrates the principles of applied behavioural analysis with the principles of inclusion and person centred values, has been internationally accepted as the proactive way to support people with challenging behaviour.

## **Supporting people with complex health needs**

Accommodation for people with complex health needs has been characterised by institutional and highly medicalised settings with most activities oriented to feeding and personal care. These centres have been shown to provide little or no opportunity for development of communication skills, community activities and the development of relationships. Residents have even been shown to have less access to screening for cancer, cardiovascular disease, anaemia, flu shots, hearing aids and glasses.

More people with complex health needs are being cared for in the community with education as a critical component

A growing number of programs in the US (and one in Queensland) have developed the infrastructure of services and supports to enable people with intellectual disability and complex health needs to live in the community. The care is co-ordinated with the family or the person with disability himself/herself through a team of medical and allied health

professionals. All services either provide directly or ensure the provision of highly individualised support teams with a key worker approach, care coordination and flexible individualised support. The capacity to develop a unique set of resources and supports for each individual is a critical.

## **Self management of supports**

Current research is drawing attention to the worldwide shift in paradigm away from professional control towards an emphasis on self determination and community involvement. The availability of an individual budget, control over services and decision making, using person centred planning, independent support brokerage and a fiscal intermediary are documented as features that increase self determination for people with intellectual disability.

In the late 1990s, the Robert Wood Johnson Foundation funded 'Self Determination Initiatives' in 19 states of the USA. Early results have documented that control over funds have led to improvements in quality of life and increased community membership for people with intellectual disability. It has led to an increase in power of traditionally disempowered people in terms of hiring and firing direct support staff, choice of agency support person, choice of people to live with, choice of house or apartment and choice of case manager. Significantly, the review found that individualised funding led to an overall cost reduction.

Increased control by families of respite and personal assistance services has been linked to increased satisfaction with services, more community participation by the person with developmental disabilities, less staff turnover and more hours per week of employment for mothers.

## **Policy implications**

The Accommodation and Support Paper acknowledges Government responsibility to establish the framework for services and practice based on research and evidence of what works for people with disability. The cluster options of villages, inner city town houses, special purpose, complex behaviour units and 8-10 bed units are not supported by the literature presented in this review.

Evidence of this literature review leads to a number of policy directions that are quite different to those identified in the Accommodation and Support Paper. At the broadest level, the Government policy in accommodation and support must:

- provide accommodation to people in small dispersed housing and supported living schemes;
- focus attention on the way in which staff provide support through evidence-based methods;
- introduce evidence-based ways to support people with challenging behaviour;
- develop services and supports to enable people with complex health needs to live in the community;
- provide greater opportunities for people with disability and their families to have control of the funding allocated.

In addition, the 10 year Plan of which the Accommodation and Support Paper is a part, must:

- provide the significant injection of funds required over time to move NSW from a situation of crisis management to prevention and early intervention in which adults with disability can plan to move out of the family home in a timely fashion;
- recognise the importance of building capacity in NSW through multiple grass roots and Government led strategies;
- recognise the importance of leadership development and skill development;
- establish a fund for innovation so that people with disability, families, services and government can work in partnership to find ways to enable people with disability to 'have the good life' that are sustainable for the person, the family, the service and government.

### **Implications for policy of the evidence on costs and outcomes**

- Effectiveness in delivering high quality outcomes for people with disability must be valued as highly as cost considerations when decisions are made to develop and fund services.
- Only models of accommodation that produce positive outcomes for people with disability should be part of Government policy in line with the Government principle that "Quality is measured by the outcome/s delivered for people with disability and their families/carers".
- Village communities and intentional communities are campus arrangement with strong religious and philosophical basis that have historically developed in complete independence of deinstitutionalisation. Since the evidence is clear that Government-developed cluster housing lacks the distinctive features of village accommodation, Government should not attempt to create villages or intentional communities for people with disability.
- Small dispersed housing and supported living schemes should be the preferred option for accommodation based on the evidence that they lead to better outcomes for people with disability.
- Options for supported living must be encouraged in Government policy based on the evidence that their cost is similar to those associated with dispersed housing schemes with distinct additional benefits.
- Since discrimination in the views of service recipients and relatives is only likely when it is possible for them to make comparative judgements, it is critical that Government fund options for supported living that are not yet widely available in NSW.

## **Implications for policy of the evidence on staffing**

- The significance of staffing in achieving positive outcomes for people with disability must be emphasized in Government policy.
- Government funded accommodation must provide staffing formulae based on evidence of what produces the most effective staff:resident interaction and promotes the highest level of engagement of people with disability.
- Staffing policy must take into account research evidence that:
  - the larger the staff:resident group, the lower the level of resident activity;
  - the extent and nature of staff:resident interaction is a critical factor in determining resident engagement in activity;
  - the way staff are organized through systems of activity and support planning has a significant impact on what staff do with residents.
- Staff working with people with disability must be trained, supported and supervised to provide effective assistance that promotes increases independence and resident participation in valued social roles.
- Staff in supervisory positions must be trained, supported and supervised to:
  - lead direct staff in positive behaviour support and technical aspects of support for people with disability;
  - implement methods for staff:resident deployment and activity planning; and
  - monitor quality of support provided to people with disability.

## **Implications for policy of the evidence on supporting people with challenging behaviour**

- Government and service policy must prohibit practices known to produce poor outcomes for people with challenging behaviour including:
  - punitive approaches;
  - housing options that group people with challenging behaviour together;
  - the indiscriminate use of psychotropic medication and physical restraint;
  - placing people in unstimulating environments that provide little opportunity for control and choice, and in environments that segregate people from the community.
- People with challenging behaviour must be accommodated in small scale living environments.
- *Positive Behaviour Support* must be recognised and implemented as a proactive and effective way to support people who display challenging behaviours. This will involve:
  - highly individualised and comprehensive person centred planning processes;

- service systems that actively support and encourage the rearrangement of environments to meet individual needs;
- service systems that value and support the involvement and collaboration of families, advocates, friends and staff;
- changes to existing agency and staff practice including:
  - significant staff development, support and supervision;
  - support for service management to change systems.

### **Implications for policy of the evidence on supporting people with complex health needs**

- Government policy must facilitate the development of an infrastructure of services and supports to enable people with intellectual disability and complex health needs to live in the community with their families or in small dispersed housing and supported living schemes using person centred planning schemes.
- Innovation funds should be used to establish the necessary supports in one geographical area. This should be monitored and evaluated in order to then extend the supports to people across NSW.

### **Implications for policy of the evidence on the self management of supports**

- The self management of funds must be one option available for the delivery of services and supports.
- Once a number of self managed projects have been funded, Government should undertake action research to identify what is necessary to enable people to manage their own funding.

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