family

ADVOCACY

Presenting the Evidence:

Accommodation and Support for People with Disability

Feb 2006

family

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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.

Contents

Section 1   Overview

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.

The Institute for Family Advocacy and Leadership Development (Family Advocacy) has developed *Presenting the Evidence: Accommodation and Support for People with Disability*, to contribute to the discussion through the provision of the evidence on the issue.

The Government Accommodation and Support (A&S) Paper recognises the need for change indicating an intention to develop:

> "a new disability system (that) will deliver greater levels of assistance and more flexible options for people with disability to live at home with the support of family and friends."

Family Advocacy supports this direction which provides the opportunity to make a significant difference in many lives. In addition, people with disability and families are excited that Government is committed to 'Building Expertise", believing that a system in which:

> "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."

will lead to a much better life for people with disability and their families.
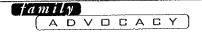
Presenting the Evidence: Accommodation and Support for People with Disability, focuses on the out of home services outlined in the Government A&S Paper. It is a response to the challenge of understanding what is required to build expertise in the area of out of home services and reflects the evidence of a review of academic and research literature undertaken by Family Advocacy in collaboration with Lesley Chenoweth, Senior Lecturer and Director of Internationalisation at the University of Queensland and Trudy Van Dam, Co-ordinator of Bachelor of Education (Habilitation) at the Australian Catholic University.

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.

According to the proposed NSW Accommodation and Support Paper many of the new out of home services will be provided within cluster models that congregate people with disability and segregate them from the community. In addition, the Government statements that:

"The location of out of home support will be dependent on ongoing demand, affordability and the availability of a suitable workforce"; and

"Whilst the provider, location and type of care will vary over time reflecting the person's changing needs, there is an ongoing commitment to continue support"

will mean that accommodation services will require people with disability to change services as their needs change and will require many people with disability to move away from their natural support networks and from their local community.

These features appear inconsistent with other principles and components of the system identified in the A&S Paper, including:

"Accommodation and supports for people with a disability complements family and community support";

"Mutually beneficial relationships are promoted and supported";

"Quality is measured by the outcomes delivered for people with disabilities and their families".
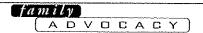
In addition, evidence from research indicates that cluster models of accommodation provide people with disability with significantly less opportunity to implement the acknowledgement that:

"People with disabilities have different needs that can be met in a range of ways";

"Services will promote skill development and independence" and

"Services (will) respond to the diverse cultures and languages of people with disabilities and their families".

There is a significant danger that cluster housing will become the institutions of the future because, inherent in the cluster model, are many of the features of institutional living that the NSW Audit Office and the NSW Community Services Commission recognised as difficult to remedy (Audit Office & Community Services Commission:1998:ix). These include the whole of life umbrella approach to the delivery of services, the custodial and impersonal nature of care, their segregation from the community, their inability to provide a homelike environment and their increased difficulty in meeting the physical, emotional, social and skill development needs of residents. The international evidence is unequivocal that institutions provided a very poor (and often neglectful and abusive) quality of life for people with disability. It is therefore with shock and dismay that people concerned for the best outcomes for people with disability sees the re-emergence of models of accommodation in which the institutional features are prominent.

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.

Family Advocacy developed *Presenting the Evidence* in order to set the record straight as to the messages from research and literature on behalf of the least powerful stakeholder, people with disability.

Presenting the Evidence critiques the selective use of research evidence that underpins the NSW Government A&S Paper. This is followed by a critique of the Government Accommodation and Support Paper by Professor Eric Emerson, Professor of Disability and Health Research, Lancaster University. The body of the Paper provides a summary of the evidence in the areas of cost and effectiveness, staffing, supporting people with challenging behaviour, supporting people with complex health needs and the self management of funds. Each section concludes with implications for policy that flow from the literature.

Research evidence that underpins the Government Accommodation and Support Paper
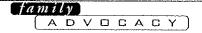
The Government Accommodation and Support Paper draws on a number of academic sources to develop the evidence for cluster housing. The sources are however, used most selectively with statements taken out of context to argue a point that is counter to the thrust of the argument discussed in the source.

For example, the Accommodation and Support Paper quotes Felce and Emerson (in Stancliffe & Lakin 2005:152) to report, accurately, that a number of jurisdictions have developed new campus-style accommodation. What is not acknowledged, however, is that the statement is taken from the introduction to a number of large scale evaluative studies undertaken by Felce and Emerson that conclude:

> "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 (Emerson:2005 in Stancliffe & Lakin:2005:168)"

Similarly, the Government Accommodation and Support Paper uses the Australian Housing and Urban Research Institute (AHURI) paper, *Deinstitutionalisation and housing futures: final report*, to develop the case for cluster housing based on the limitations of group homes. The A&S Paper fails, however, to take forward significant major themes of the AHURI paper including:

- "Evidence to suggest that people with higher support needs are those most likely to benefit from living in community rather than segregated settings." (Picton et al:1997a, 1997b in Bostock:2001:33)

- The view that the "development of new funding frameworks that 'tie' funding to individuals and are portable between service providers will help facilitate control, choice and flexibility in terms of housing and support." (Bostock:2001:10)

- The recognition that "while individualised funding is not a panacea, it might be part of a differentiated framework for supporting people with disabilities.... The move toward client focused services and individualised funding would mean that more service users would have the ability to determine their own accommodation and support packages, opening up a much more complex support scenario." (Bostock:2001:54)

- The fact that "The shift from funding services to funding outcomes for consumers is evidenced in all Strategic Plans of disability agencies across Australia. All plans emphasise the development of flexible or individualised funding and service models which are responsive to the choices and changing needs of individual consumers rather that the needs of services providers and program requirements." (Bostock:2001:54)

- Key messages in the conclusion of the AHURI Report that are absent from the A&S Paper include:
  - "It is suggested that smaller accommodation is considered more appropriate because it mirrors the way the many non-institutionalised

people live eg in small scale family like units as opposed to large scale congregate care facilities." (Bostock:2001:56)

- o "The development of cluster housing is a source of debate." (Bostock:2001:56)

- o "Ensuring inter-generational equity and sustainability in the housing options developed, present agencies with a challenge. The over-development of new cluster housing for currently institutionalised residents may lead to unfairness for future generations …. There may be a danger that future generations of people with disabilities will be placed in these facilities in spite of wanting a community based option." (Bostock:2001:53)

It can thus be seen that the use of sources out of context in the A&S Paper provides a different research message that seriously disadvantages the most vulnerable stakeholders, people with disability.

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[1]. 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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[1] definitions p18

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.
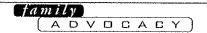
Staffing

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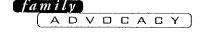
Increased control by families of respite and personal assistance services has been linked to increased satisfaction with services, more community participation by the person with developmental disabilities, less staff turnover and more hours per week of employment for mothers.

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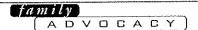
In addition, the 10 year Plan of which the Accommodation and Support Paper is a part, must:

- 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.
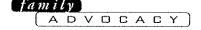
Implications for policy of the evidence on staffing

- 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:

  o the larger the staff:resident group, the lower the level of resident activity;

  o the extent and nature of staff:resident interaction is a critical factor in determining resident engagement in activity;

  o 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.
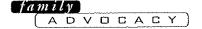
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The NSW Audit Office & Community Services Commission (1998) *Large residential centres for people with disability in NSW*, ppix

Section 2 Comment by Professor Eric Emerson

Comments on 'Accommodation and Support Paper: Working Draft'

New South Wales Government, November 2005

Professor Eric Emerson, Institute for Health Research, Lancaster University, UK

This brief paper has been prepared at the request of the *Institute for Family Advocacy & Leadership Development Assoc. Inc.* (NSW). In it I comment on the extent to which the proposed strategy reflects existing scientific evidence on the costs and benefits of supported accommodation services for people with disabilities (particularly people with intellectual disabilities).

There is one particular area in which there is a clear disparity between statements made in the draft strategy and the existing evidence base. Specifically, 'evidence' is used to build a case for the redevelopment of large residential centres to 'provide care for people with complex needs and behaviours.' (p13).

The case for this recommendation appears to be based on four statements:

- an increasing number of people without disabilities choosing to live in medium and high-density housing, villages and intentional communities (p6)
- large residences may offer greater freedom to some (p6)
- group homes can now be as institutionalised as other forms of systematised, large-scale care without the benefits of space, comprehensive on-site support services and freedom of movement (p6)
- a number of jurisdictions including the United States, Ireland, United Kingdom, Victoria and Queensland have developed new campus-style accommodation for people with multiple disabilities and high support needs.

While the first statement may be true for people without disabilities, there is **no evidence at all** to suggest that either a substantial or increasing proportion of people with intellectual disabilities would wish to live in 'medium and high-density housing, villages and intentional communities'.

As phrased ('for **some**'), the second statement is probably true. However, the existing evidence **clearly** indicates that overall more choice and freedom are more likely to be available in smaller than larger services and in community-based when compared to more remote services.[2]

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[2] Emerson, E. (2004). Cluster housing for adults with intellectual disabilities. *Journal of Intellectual & Developmental Disability* 29, 187-197. Emerson, E., Robertson, J., Gregory, N., Kessissoglou, S., Hatton, C., Hallam, A., Järbrink, K., Knapp, M., Netten, A., & Linehan, C. (2000). The quality and costs of community-based residential supports and residential campuses for people with severe and complex disabilities. *Journal of Intellectual and Developmental Disabilities* 25, 263-279. Emerson, E., Robertson, J., Gregory, N., Kessissoglou, S., Hatton, C., Hallam, A., Knapp, M., Järbrink, K., Walsh, P., & Netten, A. (2000). The quality and costs of

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Again, as phrased ('group homes **can** be as institutionalised') this is undoubtedly true. However, the existing evidence **clearly** indicates that overall smaller community-based services are significantly less institutional in their character than larger services.[3]

The final statement is certainly true (and I should know as I wrote all the evidence quoted in support of this statement). What is missing, however, is any comment at all on either the evidence of the relative benefits of such developments when compared to community-based alternatives or on more recent policy developments in these jurisdictions.[4] This is somewhat surprising as the cited evidence addresses both of these issues, summarised below.

- Formal evaluation of campus-style accommodation clearly suggests that it provides (at marginally reduced cost) a poorer quality of support and quality of life for people with intellectual disabilities when compared to community-based services.
- As a result of this evidence (commissioned by central government in England and Ireland), the English government has instituted a major review of the acceptability of campus-style accommodation as a result of which there now exist plans to replace these early 'mistakes' in the process of deinstitutionalization with more appropriate smaller community-based services.

In summary, the case made for the redevelopment of large residential centres to 'provide care for people with complex needs and behaviours' is based on spurious logic (the use of 'some' 'can') and runs directly counter to the existing international literature on the benefits (and cost-benefits) of such developments.

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village communities, residential campuses and community-based residential supports in the UK. *American Journal of Mental Retardation* 105, 81-102. Emerson, E., Robertson, J., Hatton, C., Knapp, M., & Walsh, P. (2005). Cost and outcomes of community residential supports in England. In R. Stancliffe & C. Lakin (Eds.) *Costs and Outcomes: Community Services for People with Intellectual Disabilities.* Baltimore: Brookes. Robertson, J., Emerson, E., Hatton, C., Gregory, N., Kessissoglou, S., Hallam, A., & Walsh, P.N. (2001). Environmental opportunities for exercising self-determination in residential settings. *Research in Developmental Disabilities* 22, 487-502. Tossebro, J. (1995). Impact of size revisited: Relation of number of residents to self-determination and deprivatization. American Journal on Mental Retardation, 100(1), 59-67.

3   See footnote 1 and Emerson, E., & Hatton, C. (1994). *Moving Out: The Impact of Relocation from Hospital to Community on the Quality of Life of People with Learning Disabilities.* London: HMSO. Stancliffe, R., Emerson, E., & Lakin, C. (2004). Residential supports. In E. Emerson, C. Hatton, T. Thompson & T. Parmenter (eds), *The International Handbook of Applied Research in Intellectual Disabilities.* Chichester: Wiley.

4   Emerson, E., Robertson, J., Hatton, C., Knapp, M., & Walsh, P. (2005). Cost and outcomes of community residential supports in England. In R. Stancliffe & C. Lakin (Eds.) *Costs and Outcomes: Community Services for People with Intellectual Disabilities.* Baltimore: Brookes. Emerson, E. (2004). Deinstitutionalisation in England. *Journal of Intellectual & Developmental Disability* 29, 17-22.

There is undoubtedly a considerable problem with any 'one size fits all' policy founded on the provision of group homes. Current developments in the UK, Ireland, US, Canada and elsewhere suggest that the solution to this problem lies in a combination of increasing the individualization of funding allocations, increasing the flexibility of potential living arrangements in ordinary domestic scale housing dispersed within the community and more rigorous performance management of services based on the actual outcomes achieved for people with intellectual disabilities.

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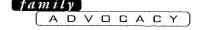   and Academic Director, Lancashire Doctorate in Clinical Psychology

Editorial Activities

* Associate Editor of the *Journal of Applied Research in Intellectual Disabilities (1996-)* and *Journal of Intellectual and Developmental Disabilities* (2002-). Member of the editorial board of *Journal of Mental Health (1990-), Tizard Learning Disability Review (1995-), Journal of Intellectual and Developmental Disabilities* (1998-2002) and *Handicap Grave. Ritardo Mentale e Pluriminorazioni Sensoriali* (2000-).
* Guest editor of special issues of: *Journal of Applied Research in Intellectual Disabilities* (1995, with Professor Bob Remington, Dr Richard Hastings & Dr Chris Hatton; 1996, with Professor David Felce); *Journal of Intellectual and Developmental Disabilities* (2000, with Dr Roger Stancliffe & Dr Charlie Lakin); *Mental Retardation and Developmental Disabilities Research Reviews* (2000, with Professor David Felce); *Tizard Learning Disability Review* (2000, with Professor Peter Farrell).
* Guest reviewer for the journals *Journal of Intellectual Disability Research, American Journal of Mental Retardation, Mental Retardation, Research in Developmental Disabilities, British Journal of Learning Disabilities, Hospital and Community Psychiatry, Behavioural and Cognitive Psychotherapy, British Journal of Clinical Psychology, The Psychologist, Health & Social Care in the Community, International Journal of Geriatric Psychiatry, British Journal of Special Education, Journal of Community & Applied Social Psychology.*
* External referee for Australian Institute of Health and Welfare's report *Australia's Welfare 2003.*

Publications

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For more information: http://www.lancs.ac.uk/fass/ihr/staff/ericemerson.htm

Section 3   Costs and Outcomes

Key messages from the literature

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 (Stancliffe & Lakin:205:3).

In the US, extensive 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 (Stancliffe & Lakin:205:11).

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. (Eidelman, Pietrangelo, Gardner, Jeisen & Croser:2003 in Stancliffe & Lakin:2005:11-12).

Two large scale studies undertaken by Emerson that compared the nature of support provided to, and outcomes achieved by, residents of campuses, villages and dispersed housing schemes found stark differences between the different models of accommodation. 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 (Emerson:2005 in Stancliffe & Lakin:2005:168).
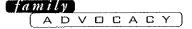
In relation to costs, the Emerson studies found that:

- Village communities[5] were cheapest, followed by residential campuses with dispersed housing schemes costing 15% more than residential campuses.

- There were no statistically significant differences in costs between supported living schemes, small group homes supporting 1-3 people and large group homes supporting 4-6 people.

- The additional costs of dispersed housing schemes were explained by significantly higher performance in relation to quality indicators of choice, variety of recreational activities, total size of social network, number of 'others' in social network, number of days and hours of scheduled activities and reduced perceived risk of exploitation.

- The additional costs of dispersed housing schemes may be justified in the light of the substantial benefits noted (Emerson:2005 in Stancliffe & Lakin:2005:168).

In relation to costs and outcomes within dispersed housing schemes, the Emerson studies found that:

- Larger group homes were consistently associated with poorer outcomes than either smaller group homes or supported living schemes.

- Smaller group homes and supported living schemes were associated with different patterns of benefits – consistent with other results suggesting that for similar costs, supported living schemes may offer distinct benefits in the areas of

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[5] Definitions provided p24

resident choice and community participation (Emerson:2005 in Stancliffe & Lakin:2005).
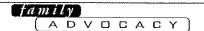
In relation to the new cluster housing arrangements, the Emerson studies found that:

- Government developed cluster housing schemes exhibited none of the defining characteristics of 'village' communities which developed independent of deinstitutionalisation (Emerson:2004:190).

- 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 (Emerson:2004:192).

In relation to access to friendship, "there were no differences between cluster and dispersed housing in either the frequency or overall access to friendship activities undertaken with others with intellectual disability" (Emerson:2004:195). In previous research, people living in cluster housing had smaller social networks, including having fewer people with intellectual disability and 'inclusive' relationships in the person's social network compared to people living in dispersed housing (Emerson et al:2000 a in Emerson:2004:189).
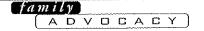
Of note is the fact that Emerson found no statistically significant differences in any domain of rated satisfaction of either participants or their relatives. These finding are consistent with other research that indicates that discrimination in the views of service recipients and relatives is only likely when it is possible for the service recipients and relatives to make comparative judgements (Emerson:2005 in Stancliffe & Lakin:2005:168).

Finally, Emerson found that the costs of service provision were unrelated to outcomes though some extremely modest positive associations were found between costs and selected outcomes in dispersed housing schemes (Emerson:2005 in Stancliffe & Lakin:2005:168).

Policy implications

- 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.

Background

Effectiveness in achieving high quality outcomes and good quality of life is a critical factor when considering expenditures for services. Without satisfactory outcomes, expenditures on services are a poor investment for society, resulting in deprivation, increased disability and even danger for some service recipients and families (Stancliffe & Lakin:2005:3).

Stancliffe (2005:3) argues that "a focus on costs should not imply that lower cost is self evidently better, or that cost outweighs other considerations. Higher-cost services that deliver better outcomes ought to be supported strongly on cost effectiveness grounds. For example Emerson, Robertson, Hatton, Knapp & Walsh found that institutional services in UK cost significantly less than community services but concluded that additional expenditure on community services was warranted in the light of consistent benefit of these services".

US studies on costs and outcomes of de-institutionalisation

Stancliffe (2005:11) presents US studies of both costs and outcomes of de-institutionalisation revealing a consistent pattern across states and over time, of better outcomes and lower costs in the community. Quoting cost effectiveness studies by Jones in Pennsylvania (1984), Knobbe, Cary, Rhodes & Horner in Oregon (1995) and Stancliffe & Lakin in Minnesota (1998), he reports positive outcomes that are consistent with broader US literature (Kim, Larson & Lakin:2001). These studies further demonstrate institutional services in the US to be more costly than community services. (Campbell & Hela:1995, Schalock & Fredericks:1990)
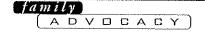
Eidelman, Pietrangelo, Gardner, Jeisen & Croser (Stancliffe & Lakin:2005:11-12) argue that it is not whether institutional or community services are cheaper, but which supports and yields the best outcomes. It is interesting to note that UK cost studies indicate that community services are more expensive 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.

But regardless of cost comparisons, there is consistent and compelling evidence that community services result in better outcomes than institutions. (Emerson et al:2000, Kim et al:2001 in Stancliffe & Lakin:2005:12). Stancliffe argues that in the light of such evidence, cost comparisons between institutional and community services are of limited importance.

Emerson (UK) cost benefit analysis

Evidence in this report draws heavily on the Emerson cost benefit analysis of community-based residential services drawn from information collected from residents in village communities, residential campuses and dispersed housing schemes commissioned by the UK Department of Health (Emerson et al in Stancliffe & Lakin: 2005:153).

This broad based study of 500 participants across 17 services included 86 participants in 3 intentional or village communities, 133 participants in National Health Service (NHS) campuses and 281 participants in 10 dispersed housing schemes (of the latter, 63 people

were identified as being supported in supported living schemes). Potential services were identified through a process of consultation to identify examples of "good" or "better" practice. Models were compared on 94 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, medication usage).

Definitions of accommodation models (Emerson:2005 in Stancliffe & Lakin:2005:154)

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."

Results of the Emerson study

1. Nature of support provided to participants

Stark differences were found between models in the support provided in campuses, villages and dispersed housing schemes (Emerson et al:2000b, 2000c, Robertson et al:2000a in Emerson:2005 in Stancliffe & Lakin:2005:161).

"People in dispersed housing schemes were supported in small homelike non institutional settings with high staff ratios and reasonably well developed internal planning and management procedures. They were less likely than residents in other facilities to be prescribed anti-psychotic medication, to receive routine health checks and to have seen a psychologist or psychiatrist."

"Participants in village communities were supported in larger, less homelike settings with moderate levels of institutional climate, low staff ratios and well developed internal planning and management procedures. They were less likely than residents in other facilities to be prescribed anti-psychotic medication or to have seen a psychologist/ psychiatrist and were more likely to receive regular health checks."

"Participants in residential campuses were supported in larger, less homelike institutional settings with low levels of staff ratios and poorly developed internal planning and management procedures for activity planning, allocating staff support to residents and the training and supervision of staff. Their home was more likely to be used for short-term respite. They were most likely to be prescribed anti-psychotic medication versus residents in other facilities."

Comparison among types of dispersed housing

When compared with small group homes, participants in supported living schemes experienced higher staffing ratios and better internal procedures for allocating staff support on the basis of resident need. They had more frequent contact with lawyers and were more likely to have their hearing checked. They were less likely to have a designated key worker, an individual habilitation plan and were supported in settings with poorer internal procedures for assessment and teaching.

The only significant difference between small and large group homes was that large group homes evidenced greater levels of depersonalisation.

2.   Outcomes

Participants in dispersed housing schemes experienced relatively greater choice, more extensive social networks with people intellectual disability and local people and overall, a more physically active life, fewer accidents in their home and a greater number and variety of activities .They were however, also more likely to experience exposure to crime and have a shorter working week (Emerson:2000 in Emerson:2005 in Stancliffe & Lakin:2005:162).
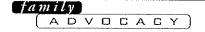
Participants in villages experienced relatively more extensive social networks overall, less exposure to crime and a longer working week but they could also expect to experience relatively less choice and a reduced number and variety of leisure activities (Emerson:2000 in Emerson: 2005 in Stancliffe & Lakin:2005:163).

Participants in residential campuses experienced relatively less 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 and a shorter working week (Emerson:2000 in Emerson:2005 in Stancliffe & Lakin:2005:163).

Comparison among types of dispersed housing

When compared to small group homes, participants in supported living schemes experienced greater choice overall, greater choice over with whom and where they lived and a greater number of community based activities. They also had fewer hours or days per week of scheduled activities, were more likely to have their home vandalised and were considered at greater risk of exploitation from people in their local community.

When compared to large group homes, people in small group homes had larger social networks, more staff in their social networks and more people in their social networks who were not staff or family and did not have intellectual disabilities (Emerson:2000 in Emerson:2005 in Stancliffe & Lakin:2005:164).

3. Relationship between costs and outcomes

Costs were cheapest in village communities, then residential campuses and then dispersed housing schemes. However, there were no statistically significant differences in costs between supported living schemes, small group homes supporting 1-3 people and large group homes supporting 4-6 people (Emerson:2000c in Emerson:2005 in Stancliffe & Lakin:2005:159).
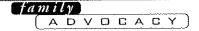
When seeking to explain variation in costs of service provision within and across service models, Emerson examined relationships between total costs of participants' care and the 13 outcomes that discriminated between the service models. These analyses were undertaken within each of the 3 service models and found that in **village communities**, increased costs were associated with increased performance of 1 of the 13 quality indicators (physical activity), in **residential campuses** increased costs were associated with increased performance on 3 of the 13 quality indicators (physical activity, number of recreational activities and variety of recreational activities) and in **dispersed housing schemes** increased costs were associated with increased performance on 6 of the 13 quality indicators (choice, variety of recreational activities, total size of social network, number of 'others' in social network, number of days and hours of scheduled activities, reduced perceived risk of exploitation).

Emerson explored the relationship between resource inputs (eg cost, staff qualifications, service recipient characteristics), service processes (eg internal management arrangements, institutional practices) and selected outcomes across the 12 outcome domains that discriminated between the 3 service models. Data indicated that costs were not significantly associated with any outcomes.

4. Conclusions

Emerson (2005 in Stancliffe & Lakin:2005:168-169) concluded that:

1. 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. It seems plausible that the additional costs of dispersed housing schemes (15% greater than residential campuses) may be justified when considered in the light of the substantial benefits noted.

2. There are distinct patterns of benefits associated with dispersed housing schemes (choice, size of social networks, social integration, recreation/leisure activities) and village communities (size of social networks, reduced risk of exposure to verbal abuse and crime, greater number of hours and days per week in scheduled activities).

3. Within dispersed housing schemes:

   a. larger group homes were consistently associated with poorer outcomes than either smaller group homes or supported living schemes;

   b. smaller group homes and supported living schemes were associated with different patterns of benefits. This was consistent with other results suggesting that for similar costs, supported living schemes may offer distinct benefits in the areas of resident choice and community participation.

4. There were no statistically significant differences in any domain of rated satisfaction of either participants or their relatives. These finding are consistent with other research that indicates 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.

5. The costs of service provision were unrelated to outcomes though some extremely modest positive associations were found between costs and selected outcomes in dispersed housing schemes.

Can Government-developed cluster housing be an intentional village community?

The proponents of cluster housing arrangements in the UK continued to draw attention to the benefits associated with 'village' and 'intentional' communities of adults with intellectual disability. The rationale for their arguments have included cost as well as the possibility that cluster housing schemes will offer a better quality of life through the creation of separate communities based on the spatial proximity of adults with intellectual disability(Emerson:2004:188).
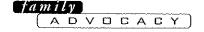
Emerson argued that "a critical issue for social policy, however, is whether in the context of de-institutionalisation, public agencies can either provide or stimulate the provision of cluster housing that shares the benefits of village communities" (Emerson:2004:188). The study, reported below concluded that none of the cluster housing arrangements exhibited the defining characteristics of 'village communities' (Emerson:2004:190).

The public debate around this issue in the UK led the Government to commission a new study comparing quality of supports provided in cluster and dispersed housing schemes that had developed in the context of deinstitutionalisation.

Comparison of cluster and dispersed housing schemes developed in the context of de-institutionalisation

In the new study (Emerson:2004), data was collected from 169 adults with intellectual disability living in cluster housing and 741 adults with intellectual disabilities living in dispersed housing while controlling for a range of participant characteristics, on a range of input, process and outcome variables.

The results of this study indicate that, once any effects attributable to participant age, gender, adaptive behaviour, challenging behaviour, reported psychiatric disorder and type of previous residential centre 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 results of this study were consistent with previous research indicating that cluster housing arrangements offer, overall, a poorer quality of life when compared with dispersed housing.

The assertion that cluster housing provides a 'connected' community of people with intellectual disability is not supported by evidence from this study which found no differences in either the frequency or overall access to friendship activities undertaken with others with intellectual disability between cluster and dispersed housing.

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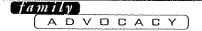
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Section 4   Staffing

Key messages from the literature

The way staff provide support to the people they serve has been singled out as a key determinant of outcome for people with disability. This is based on evidence drawn from a wide range of comparative studies across settings and over time (Mansell:2005:25).

The way staff plan, select and schedule activities and arrange the support necessary to enable residents to participate fully are key determinants of service quality (Mansell:2005:25).

The extent of staff support (ie 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 (Felce, de Kock & Repp:1986 in Felce:1998:109-110).
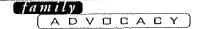
The smaller the home, the higher the level of engagement and the greater is the staff attention to residents. Felce showed the impact of staff:resident ratios as follows:

- when the number of staff to a given size of resident group was increased from one through two, three or four, gains for residents were either not found or were marginal;

- resident gains were found when resident group size was reduced;

- 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 institutions, even under similar staff:resident ratio conditions (Felce:1998:110).

Structural reform is shown to be insufficient to provide real opportunities for people with extremely limited independence. Felce argues that real opportunity for people with high support needs appears dependent on the coming together of three factors:
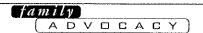
- available activity for all which involves moving from the 'hotel' model to resident participation;

- 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 (Felce:1998:116).

Active Support, developed and evaluated in the UK, provides a coherent, well researched package of training in staff working practices and group home organizational procedures that has been shown by UK research to result in staff providing more direct support for resident participation and higher levels of engagement in activities by group home residents (Stancliffe et al:2005:viii).

Policy implications

- 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:

    o the larger the staff:resident group, the lower the level of resident activity;

    o the extent and nature of staff:resident interaction is a critical factor in determining resident engagement in activity;

    o 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.

Background

Mansell (2005:25) argues that the way staff provide support to the people they serve has been singled out as a key determinant of outcome. His argument is based on results of comparative studies of houses versus other settings (Felce:1996, Felce:1998, Felce et al: 1986, Felce et al:1991, Mansell:1994, Mansell:1995, Mansell et al:1984), in experimental studies within houses (Bradshaw et al:2004, Jones et al:2001, Jones et al: 1999, Mansell et al:2002) and in regression studies (Felce et al: 2000, Hatton et al:1996, Mansell et al:2003)

The way staff plan, select and schedule activities and arrange the support necessary to enable residents to participate fully are key determinants of service quality (Felce:1996, Felce:1998, Felce et al: 1986, Felce et al:1991, Mansell:1994, Mansell:1995, Mansell et al:1984 in Mansell:2005:25).

Jones et al (1999 in Mansell:2005:25) have demonstrated experimentally the beneficial impact of staff training. In their study, residents engaged in more activities at home as a result of staff being trained to give more assistance.

Studies to explain the variability in service quality

In a report of multiple studies designed to investigate the characteristics of residential services which result in high resident involvement in the activities of everyday life, Felce (1998) attempted to answer the question of why some community services have significantly improved outcomes and others do not. He used observed engagement in activity as a sensitive indicator of one aspect of quality of life drawing on the work of Jones, Risley and Favell (1983) and Sackett and Landesman-Dwyer (1977).

Felce argued that one of the consequences of the restricted skill development associated with severe and profound intellectual disability is a relative inability to engage independently in the activities of daily living. People with severe and profound intellectual disability therefore need staff or others to facilitate opportunities and provide them with help to participate in typical activities.

The role of staff and the nature of interaction with residents

The role of staff and the nature of their interaction with residents were examined in a study of dispersed houses in Andover (Felce, de Kock & Repp, 1986 in Felce:1998:109) (Study 1). Residents with high support needs in the Andover houses received significantly higher levels of instruction, physical prompting and physical guidance compared to residents in institutions and this resulted in people with greater disability receiving more staff support. The impact of high levels of staff support for those with greater disability was to bring their levels of engagement in activity up toward those with greater independence. The analysis of the data from this study strongly suggests that the extent of staff support (ie the extent and nature of staff:resident interaction), was important in determining the extent of resident engagement in activity.

The effect of staff:resident ratios

Staff:resident ratios were thought to be of relevance in securing high resident engagement. A second study by Felce, Repp, Thomas, Ager & Blunden (1991 in Felce:1998:110) was designed to explore its impact. The study recorded the staff:resident

ratio, the extent of staff:resident interaction and resident engagement, and the size of the staff:resident group in the room occupied by the person being observed.

The results of this study showed that when the number of staff to a given size of resident group was increased from one through two, three or four, gains for residents were either not found or were marginal. However, gains were found when the resident group size was reduced. Moreover, 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 in institutions, even under similar staff:resident ratio conditions.

These results suggest the positive results achieved in the Study 1 (Felce, de Kock & Repp, 1986 in Felce:1998:109) were achieved by the way in which the staff were organised through systems of activity and support planning. Planning tended to ensure that staff members were separately allocated to support individuals or small groups.

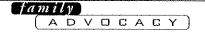## Impact of environment on staff attention and resident behaviour

A third study designed to explore the sequential relationship between staff attention and resident behaviour (Felce, Saxby, de Kock, Repp, Ager & Blunden:1987 in Felce:1998:111) using data from Study 2 that examined staff ratios. This was based on evidence from previous experimental studies that attention contingent on engagement in activity increased engagement (Porterfield, Blunden & Blewitt:1980, Mansell, Felce, de Kock & Jenkins:1982 in Felce:1998:111).

The study showed that when residents were appropriately engaged (as opposed to being passive, having nothing to do or behaving inappropriately), they received attention from staff more quickly and more frequently in small community houses than in larger community units or in institutions. The study postulated that the level of engagement in small community houses might owe something to the different motivational climate established in the smaller homes. This was less strong in larger community units and no-existent in institutions.

Structural reform without attention to procedural organisation

Changed environment on its own was found to have a disappointing effect on resident engagement in a 4th study by Felce, Lowe & Blackman in 1995 (Felce:1998:111). The study found no significant differences in engagement in activity between 8 residents living in institutions and 8 matched residents in community services with the average levels of occupation in personal, household and leisure activities as 16% and 21% respectively. In other words, almost 50 minutes in every hour was spent by residents without constructive occupation. These results add to the evidence that the overall staff:resident ratio may be a weak influence on staff performance and resident activity, if other measures are not taken to ensure that staff work effectively.

A fifth study by Felce & Perry (1995: in Felce:1998:112) explored the relationship between staffing levels, staff resident interaction and resident engagement in activity in 15 small staffed homes in South Wales. Felce compared the results to those of the houses in the 1986 Andover study (Felce, de Kock & Rep) (Study 1) and found that participation in domestic activities among residents of the 1986 Andover study was

greater than the highest in any of the Welsh houses, twice the average level and 4 times the level in any of the houses with residents of lesser ability.

Felce argued that this comparison reinforces the emerging conclusion that structural reform has to be complemented by procedural organisation, with working methods allied to aims and values. Felce argues that the Welsh houses would be seen as having advantages over the 1986 Andover houses. They were on the whole smaller in size and much better staffed and they were more recently provided at a time when there was more general acceptance of a philosophy of valued social roles. However, all of the houses had less well defined outcome targets. None had any systematic approach to how staff should work with residents to support and motivate particular patterns of activity. None had any well developed methods for activity planning or working out staff:resident deployment. It is perhaps not surprising, but it is still salutary in policy terms, that small, decent, homelike, architecturally typical, well staffed and managerially autonomous community homes do not maximize the quality of life for their residents under these conditions. It is also salutary to find repeated evidence that investment in the number of staff alone does not produce quality of care and quality of life changes in itself.

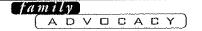## An experimental evaluation of *Active Support*

Felce designed a sixth study to evaluate the impact of introducing working methods initiated in the 1986 Andover houses, an approach which in Britain was called *Active Support* (Emerson & Hatton, 1994, McGill & Toogood, 1993 in Felce:1998:114) in a number of existing housing services for people with severe intellectual disability. This was then compared to the 15 staffed houses in South Wales examined in Study 5 (Jones et al:1997 in Felce:1998:114).

Prior to the introduction of *Active Support*, all houses had underdeveloped ways for ensuring residents had adequate opportunities for participation in activity. The staff role was broadly defined in terms of giving residents support but members of staff were left to their own initiative as to how to put this into practice. All settings arranged their own in house induction and training, with other training opportunities organised in response to staff requests. Training in assisting people to have valued roles was a particular priority.

Active Support is a system for planning resident activities which also involves staff in working out how to allocate their resources to support resident activity coupled with practical training for staff in how to interact with residents to provide effective support. In the study, training was conducted in each house as a 2 stage process: a 2 day workshops followed by a trainer working with each individual staff member, in situ, to teach how to give effective assistance. This stage took 2 trainers approximately 3 days per house to complete.

Significant changes resulted in all houses with the introduction of *Active Support*. There were significant increases in the level of assistance residents received and significant increases in the level of resident engagement in domestic activities. Significant increases in total engagement in activity occurred in all but one of the houses. In the one exception there was still a positive effect.

The introduction of *Active Support* changed the baseline pattern where staff gave more attention and assistance to people who were behaviourally more able. During post baseline, receipt of attention was unrelated to ability and there was a tendency for those who were less able to receive more assistance. Although resident engagement in activity

was significantly related to behavioural ability in both phases of the study, the change in the patterns of staff support resulted in the reduction of the disparity in activity between residents who were more or less able. The study hypothesised that variability in performance in the one house may have been explained by senior staff turnover or absence through sickness and the consequent loss of managerial input and increased use of untrained relief staff.

These results were recently repeated in Sydney where the implementation of *Active Support* resulted in higher levels of engagement for residents of group homes both in domestic activities as well as activities in the community. The representativeness of the study's findings is strengthened by the fact that it involved two different agencies and residents with diverse abilities (Stancliffe et al:2005:ix).

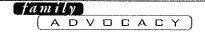## Staffing that enables people with severe intellectual disability to experience life as others live it

Felce (1998:115) argues that these studies illustrate the complexity of factors which need to be determined well for people with severe intellectual disability to experience life as others live it.

He argues that structural reform has contributed a necessary context congruent with that which provides opportunity for independent people. But for people with extremely limited independence, such normal opportunities are insufficient. Real opportunity for such people appears dependent on coming together of three factors at a more detailed level of analysis: available activity, available personal support and effective assistance.

Such a pursuit involves changing performance:

- away from traditional care or 'hotel' models (where staff relieve residents of all responsibility for household management as if staying in a hotel) and creating an alternative which emphasises resident participation;

- away from the traditional allocation of activity to residents on the basis of their ability to do activities independently and creating an alternative which emphasises the absence of exclusion of residents on the basis of their ability to do activities independently and the provision of support to help those people who lack skills, to accomplish activity successfully.

- away from traditional laissez faire attitude to what residents may or may not do and creating an alternative which gives positive motivation to achieving that level of functional activity which everyone else transacts to live an ordinary life.

- away from the traditional low emphasis on the organisation of opportunities to participate in activity and creating an alternative which establishes a level of commitment, staff competence and managerial monitoring to ensure that this happens.

"These changes are required if institutionalisation is to be reversed and not resurface in the community" (Landsman, 1988 in Felce:1998:116).

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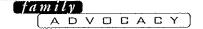
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Section 5 Supporting people with challenging behaviour

Key Messages from the literature

Approximately 10% – 15% of people with intellectual disability show behaviours which are deemed challenging for their families, carers and service systems (Emerson et al:2000) with residents of institutions displaying higher levels of challenging behaviour than those in the community (Allen:1999).

Applied Behaviour Analysis (ABA) is an approach to people with challenging behaviour based on the principles of operant conditioning. ABA relies heavily on the manipulation of consequences and its implementation has frequently been associated with the use of aversive punishment procedures. Serious concerns have been raised about its effectiveness and its disregard for the human rights of people with challenging behaviour (Horner et al.:1990, Scotti et al:1999, Dunlap et al: 2000, Meyer & Evans:1989).

Evidence indicates that service systems continue to respond to individuals with challenging behaviour using punitive approaches. (Carr et al:2002, Felce & Emerson:2001, Horner, et al:1990, Robertson et al:2005, Scott & Meyer:1999, Mansell et al:2004). Evidence demonstrates that staff lack the skills required, resulting in heavy use of psychotropic medication and physical restraint (Emerson:2000) and poor implementation of behaviour support plans (Stanclife, Hayden & Lakin:1999). The outcomes for people with disability are not positive.
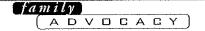
Maladaptive behaviour will arise in maladaptive circumstances. Environments that provide little stimulation, little opportunities for control and choice, and segregated settings, have long been acknowledged as contributing factors to a person's behaviour (Scotti & Meyer:1999).

Support systems that group individuals who display challenging behaviour create environments that are not conducive to positive adaptive behaviours, are not cost effective and are associated with a range of poor outcomes and lower staff contact (Mansell et al: 2003, Beadle-Brown:2003, Robertson: 2002 in Mansell & Beadle-Brown: 2004:9).

Robertson found that specialist services for people with challenging behaviour reported no significant improvements in the challenging behaviour displayed by people using the services. In addition, Robertson found that the specialist services were associated with reactive behaviour management strategies and greater use of physical restraints and medication (Robertson et al:2005).

The practice of grouping people with challenging behaviour together in residential settings has been shown to produce worse outcomes than supporting people in homes where residents have a variety of needs (Mansell:2003, Mansell:1994, Mansell:1995).

Evidence indicates that people who display challenging behaviour are those most likely to benefit from living in community rather than segregated settings (Bostock et al:2001:33). This is supported by evidence that small scale living environments lead to better outcomes for people with challenging behaviour (Felce &Emerson:2001).

Positive Behaviour Support (PBS) has been internationally accepted as the proactive and effective way of supporting individuals who display challenging behaviour (Dunlap et al:2000). Its goals are to improve both the behaviour and the quality of life of individuals.

PBS delivers a sustainable and comprehensive system for supporting individuals through the integration of:

- the principles of applied behaviour analysis (providing a framework for identifying the function of behaviours and the basis for educative methods);

- with the principles of inclusion (an understanding that the opportunity for people to live a valued lifestyle contributes significantly to addressing difficult behaviours);

- and person centred values ("the guiding hypothesis is that if an individual's needs are met, then quality of life will improve, and problem behaviour will be eliminated altogether" (Carr et al., 2002)).

"The primary intervention strategy involves rearranging the environment to enhance lifestyle and improve quality of life instead of only operating directly on reducing the problem behaviour" (Carr et al: 2002).

The positive impact of environmental modification and effective staff support is documented by Felce & Emerson (2001) who found that engagement in household and community activity was strongly related to adaptive behaviour, that there were better outcomes for people in small scale living environments and that positive outcomes were achieved when staff training and support were matched to residents.

Systems that facilitate the implementation of PBS in services have:

- a genuinely person centred planning processes;

- support for self determination for the person with challenging behaviour;

- capacity to reallocate resources and rearrange environments to meet individual needs;

- active involvement of, and collaboration with, people significant to the person;

- commitment to skill development in staff.

Policy implications

- Government and service policy must prohibit practices known to produce poor outcomes for people with challenging behaviour including:
    - reactive strategies without a comprehensive positive behaviour support program and significant preventative strategy;
    - the indiscriminate use of psychotropic medication and physical restraint;
    - housing options that group people with challenging behaviour together;
    - 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.

Background

The support of individuals categorised as displaying challenging behaviours has presented considerable issues and difficulties for service systems. Approximately 10% – 15% of people with intellectual disability show behaviours which are deemed challenging for their families, carers and service systems (Emerson et al:2000) with residents of institutions displaying higher levels of challenging behaviour than people in the community (Allen:1999).

The issue of so-called "challenging behaviour" is a world-wide phenomenon and has been addressed by research in Australia, the US, UK, Canada and New Zealand. Research has focused on issues including:
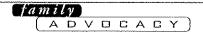
- the causation of such behaviours;

- factors associated with challenging behaviours;

- assessment and treatment interventions;

- what works in terms of support and services;

- the relationships between challenging behaviour and community living setting including factors such as size of household, staffing ratios, service costings etc.

Traditional approaches – Applied Behaviour Analysis (ABA)

Until the mid to late 1980s, the appropriate response to challenging behaviour was applied behaviour analysis. This involves the application of the principles of operant conditioning and heavily relies on the manipulation of consequences and the use of aversive punishment procedures. These procedures are based on the principle that if something unpleasant consistently follows a particular behaviour, the person will stop the behaviour in order to avoid the unpleasant consequences (Dunlap et al:2000).

From the 1980s concern arose about ethical and effectiveness issues in the application of applied behaviour analysis. Some of these concerns are listed below.

- The use of punishment and deprivation often disregarded human rights (Horner et al., 1990; Scotti et al., 1999; Dunlap et al., 2000).

- Behaviours displayed are a functional means by which the individual attempts to control his/her environment. As suppressing the behaviour does not necessarily address the underlying cause, new problem behaviours often replace the original behaviour (Meyer & Evans:1989).

- In complex, real world settings, improvement in behaviour in one setting does not necessarily result in generalisation to other settings and situations. New problem behaviours may be generated by negative and/or punitive interactions between staff and the individual (Meyer & Evans:1989).

- Any beneficial change may be of short term duration. Once the behaviour change program is phased out, the behaviour problem is likely to return or other behaviours may take its place. The individual may be locked in a cycle of temporary improvements and eventual setbacks (Meyer & Evans:1989).

The impact of grouping on residents with challenging behaviour

Behaviour is best understood in the context in which it arises. Maladaptive behaviour will arise in maladaptive circumstances. An individual's surroundings are therefore an important factor in their behaviour. Environments that provide little stimulation, opportunities for control and choice, and segregated settings, have long been acknowledged as contributing factors to a person's behaviour (Scotti & Meyer: 1999).

There is considerable research that has shown that support systems that group individuals who display challenging behaviour create environments that are:

- not conducive to positive adaptive behaviours;

- not cost effective;

- associated with a range of poor outcomes and lower staff contact (Mansell et al:2003, Beadle-Brown:2003, Robertson: 2002 in Mansell & Beadle-Brown: 2004:9).

The practice of grouping people with challenging behaviour together in residential settings has been shown to produce worse effects than supporting people in homes where residents have a variety of needs (Mansell:2003, Mansell:1994, Mansell:1995). These findings are consistent with earlier studies by Mansell (Mansell: 1994, Mansell: 1995). In addition, Beadle-Brown et al (2003) found that people without challenging behaviour were not disadvantaged by living with people with challenging behaviour and there were no differences in care practices and outcomes between people living with no-one with challenging behaviour and those living with at least one other person with challenging behaviour.

Traditional approaches produce poor outcomes

Contrary to the popular belief that such services have the specialist expertise to address challenging behaviour, Robertson et al., (2005) found that very few specialist services for people who display challenging behaviour had documented intervention programs that consisted of more than reactive management strategies. They also found that such services were associated with greater use of physical restraints and medication and reported no significant improvements in the challenging behaviour displayed by people using the services.

There is considerable evidence that service systems continue to respond to individuals who display challenging behaviour using traditional punitive approaches (Carr et al:2002, Felce & Emerson:2001, Horner et al:1990, Robertson et al:2005, Scott & Meyer:1999, Mansell et al, 2004). Staff lack the skills required, resulting in heavy use of psychotropic medication and physical restraint (Emerson:2000) and poor implementation of behaviour support plans (Stanclife, Hayden & Lakin:1999). The outcomes for people with disability are not positive.

Significance of accommodation setting

Accommodation setting has been shown to have an impact on individuals who display challenging behaviour.

In a review of Australian studies of deinstititutionalisation, Young et al (1998) quoted reviews which demonstrated that generally individuals who moved from institutions to dispersed community based supports show:

- improvement in quality and standard of life;

- increased adaptive behaviour;

- increased autonomy in self-care, domestic, community, leisure and choice making skills;

- increased amount and quality of interaction with staff, family and friends.

In the context of the tendency for deinstitutionalisation in Australia to favour people with milder intellectual disability leaving people with higher health and social support needs to last, Bostock et al (2001:33) documents evidence that people who display challenging behaviour are those most likely to benefit from living in the community rather than in segregated settings.

Emerson et al (2000) showed that accommodation setting (amongst other factors) predicted the likelihood of individuals being subjected to punitive behaviour support measures. This included increased likelihood of:
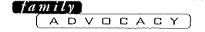
- the use of physical restraint in residential campus;

- the use of sedation in institutional settings;

- the use of anti-psychotic medication in residential campus; and

- written intervention programmes in supported living situations.

The Emerson study concluded that, "While community location is not necessarily associated with a reduction in challenging behaviour (Larson & Lakin:1989, Emerson & Hatton:1994, Young et al:1998), the present results must call into question the quality of specialist support available in National Health Service campus provision for people with intellectual disabilities."

Bigby (2004) argues that, "Outside the UK and work done by Emerson and his colleagues, limited evidence exists about the nature and quality of cluster developments. Data that does exist is not rigorous but appears to coalesce with Emerson's findings that cluster housing compares unfavourably with small group community living on a range of dimensions."

Communication and staff issues

Since the 1980s, it has been recognised maladaptive behaviour serves a communicative function. For most people with intellectual disability and challenging behaviour, their main communication partners are their carers – families or paid staff. These relationships require close interaction and knowledge of the person, which research reveals is often lacking in practice. Effective communication also requires the availability of augmented or alternative communication systems and staff need to have training and a positive attitude to the use of such communication systems (Smidt et al: 2001).

Staff behaviour has a direct effect on the quality of life of people in services (Felce & Emerson:2001). There is evidence that staff in direct support roles experience high stress levels (Roberston et al:2005). Absenteeism and turnover also indirectly affect quality of life through loss of continuity of care, service inefficiency and loss of knowledge and skills. Robertson et al (2005) found that staff turnover may be related more to lack of support and job insecurity rather than the challenging behaviour of residents.

Positive Behaviour Support

Research indicates that most services continue to use inadequate behaviour strategies even research though there is significant evidence as to the efficacy of *Positive Behaviour Support* (PBS) as the proactive and effective approach to supporting individuals who display challenging behaviour.

PBS was developed in the late 1980s in response to the ineffectiveness of traditional approaches. It has become accepted as a proactive and effective way of supporting individuals who display challenging behaviour (Dunlap et al:2000).

The goals of PBS are to improve both the behaviour and the quality of life of individuals who display challenging behaviour. It emphasizes collaborative, assessment-based approaches which integrate behavioural science and a person centered values framework. PBS emphasises community participation, system and environmental modifications and social relationships. The approach hypothesises that if an individual's needs are met, then quality of life will improve, and problem behaviour will be eliminated altogether (Carr et al:2002, Dunlap et al:2000).

PBS builds on the principles of applied behaviour analysis and integrates this with principles from the inclusion movement and person centered values (Carr et al:2002) to deliver integrated, sustainable, and comprehensive systems for supporting individuals. The importance of the incorporation of these three areas in obtaining sustainable behaviour outcomes is:

1. an understanding that the opportunity for people with a disability to live a valued lifestyle, with the same rhythms, roles, responsibilities and respect as others in the community, contributes significantly to addressing difficult behaviours (Carr et al., 2002);

2. the principles of applied behaviour analysis offer a framework and techniques that contribute significantly to identifying the function of behaviours and provide the basis of educative methods. Whilst the limitations in the traditional implementation of applied behaviour analysis are recognised, the significant contribution that it has made is recognised and built on (Carr et al:2002; Dunlap et al:2000);

3. the person centred planning framework provides systems and principles for addressing individual needs in a comprehensive manner. "The guiding hypothesis is that if an individual's needs are met, then quality of life will improve, and problem behaviour will be eliminated altogether" (Carr et al:2002).

The goals of PBS are to improve both the behaviour and the quality of life of individuals who display challenging behaviour. It emphasises collaborative, assessment-based approaches which integrate behavioural science and a person centered values framework.

"The primary intervention strategy involves rearranging the environment to enhance lifestyle and improve quality of life instead of only operating directly on reducing the problem behaviour" (Carr et al:2002).

PBS focuses on:

- comprehensive functional assessment;

- collaboration of all stakeholders;

- system and environmental modifications that adapt to the individual's needs;

- educative initiatives;

- community participation; and

- social relationships.

Systemic and environmental modifications

PBS requires multi-component interventions. Whilst there is a significant element of education and skill development targeted at the individual, significant changes will need to be made by individuals and agencies responsible for supporting the individual. This will include programmatic changes to the ways in which routines, supports, staff approaches, resources and environments are structured (Horner et al:1990; Carr et al:2002, Koegel et al:1996, Scotti & Meyer:1999).

Felce & Emerson (2001) research recognises the importance of systemic and environmental modifications concluding that:

- engagement in household and community activities is strongly related to adaptive behaviour. In turn, household and community is enhanced by working methods and staff orientation which is focused on providing choice and meaningful participation opportunities to the person with challenging behaviour;

- small scale living environments that are within the range of people who typically live together lead to better outcomes for people with challenging behaviour. It is preferable for community based supports to use architecture, decor and furnishings usual within an ordinary home;

- staff training and performance needs to be matched to the support needs of residents.

Collaborative approaches

PBS seeks to obtain lifelong changes for the individual that are applicable to complex community environments in which the individual lives. The active involvement and support of people involved in the individual's life are crucial because they offer insights to understanding the individual and strategies that are likely to be successful or not successful. Browder (1997) cites family involvement as an essential feature of programs with positive outcomes. Families and other supporters will be the individual's chief supports in the longer term and they must therefore be an integral part of the planning and implementation of any plan (Lucyshyn et al:2002; Meyer & Evans:1989; van Dam & Cameron McGill:1997; Carr et al: 2002; Koegel et al:1996). They need to "function as

active participants and collaborators with professionals in the process of reciprocal information exchange" (Carr et al., 2002).

Social validity

The focus on ensuring that interventions are durable, practical and able to be implemented by the individual's supporters, is an important aspect of positive behaviour support that has allowed it to obtain sustainable results (Carr et al:2002, Koegel et al:1996). This focus links closely with the focus on a collaborative approach. Working closely with, and actively involving and valuing the views of supporters of the individual, leads naturally to strategies that have a high level of social validity.
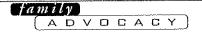
Preventative Measures

PBS relies heavily of preventing problematic behaviour from occurring by the arrangement of supports and environments that meet the individual's needs thereby negating the need for the problematic behaviour (Horner et al:1990, Koegel et al:1996, Scotti et al:1999; Carr et al:2002). This requires early intervention with a focus on development of competencies that result in the individuals acquiring a wide range of adaptive behaviours to enable them to deal with their environment (Felce & Emerson, 2001).

The arrangement of supports and environmental factors to meet the individual's needs plays an important role in preventing future occurrences of challenging behaviour. Van Dam & McGill (1997) present case studies that involved changing accommodation settings, support structures and skill development to prevent future occurrences of problematic behaviours such as aggression and property destruction.

Key features of PBS

- Highly individualised and comprehensive person centered planning processes which focus on overall health and wellbeing. These processes are in "sharp contrast to the traditional program centred planning, in which individuals with disabilities are provided with those pre-existing services that a particular agency or institution has available. In person centered planning, the specific needs and goals of the individual drive the creation of new service matrices that are carefully tailored to address the unique characteristics of the individual" (Carr et al:2002).

- Empowerment of the person using the service by actively working towards choice, problem solving and self determination. "People with disabilities are often told what they can do, with whom they can do it, and where, when, and how they can do it. In contract, enhancing the process of self determination involves changing systems and redesigning environments with a view to minimizing external (often coercive) influences and making the person with disabilities the primary causal agent in his or her life" (Carr et al., 2002).

- Active support and encouragement for the rearrangements of environments to meet individual needs.

- High value placed on, and support for the involvement and collaboration of families, advocates, friends and staff.

- Genuine commitment of resources and time to develop the skills of all staff in all aspects of service support but most importantly educative supports, person centred approaches and PBS.

- Knowledge and commitment of key decision makers to PBS to enable the necessary reallocation of resources and systemic, environmental and programmatic changes that may be necessary.

- Integrated community-based residential support. Felce & Emerson (2001) report on studies which have repeatedly confirmed that the move from institutional to community based services result in significant increases in adaptive behaviours.

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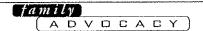
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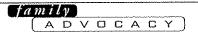
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Section 6 Supporting people with complex health needs

Key messages

There are an increasing number of people with disability and complex health needs worldwide.

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 (Kerr:2003).
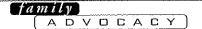
More people with complex health needs are being cared for in the community with family and in community housing.

Education for families is a critical part of moving people from institutionalised to community housing because families and professionals often hold erroneous beliefs that people with complex health needs cannot live safely in the community (Bezanson:2005).

There is little published research about outcomes and effectiveness of different service models.

A growing number of programs in the US (and 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 coordinated 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 including:
    - provision of technology to support living in the community;
    - home visits for assessment and follow-up;
    - consultation with physicians, specialists, nurses and allied health professionals;
    - development of health care plans and emergency protocols;
    - support and advocacy during hospitalisations;

- flexible individualised support including:
    - the capacity to develop a unique set of resources and supports for each individual;
    - training of the person with disability, their families, friends and staff.

Policy implications

- 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 utilising person centred planning processes.

- 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.

Background

Many terms have been used to describe the group of people with intellectual disability and who have complex health needs, for example, medically fragile, profound intellectual disability, multiple disabilities and high support needs. It is important to make some comments about this group of people as a whole but at the same time we need to stress that every person is an individual and will have different characteristics, needs and strengths. While two or more people might be described as having high support needs, each person will have different needs and require different ways of having them addressed.

Many people who are labelled as having severe to profound intellectual disability often have other conditions such as cerebral palsy, sensory impairment, epilepsy with severe and constant seizures, skeletal problems and medical problems such as inadequate nutrition, recurrent respiratory infections, muscle wasting, heart problems and dehydration.

Another group which has similar needs and experiences are those people with severe brain injuries (ABI) who are often placed in nursing homes for elderly people. There is now considerable evidence that younger people are very poorly supported within nursing homes and that creative and responsive models are required (Chan:2004).

The lived experiences of many people with these conditions is characterised by multiple hospitalisations and visits to the doctor or emergency departments, needing multiple medications many times per day, needing nutrition via feeding tubes, peg feeding or tummy buttons, needing catheterisation and assistance with breathing eg with a ventilator. Some people who have complex health needs have inadequate speech to meet their communication needs and so communicate by eye movement or expression. This usually means that family members, carers or staff anticipate and interpret the person's needs and wishes.

Institutional approaches

Historically, accommodation for people with disability who have complex health needs have been characterised by institutional and highly medicalised settings. The dominant rationale has been – and continues to be – that such complex needs cannot be managed within community settings and that it is too risky to consider any alternatives.

Such approaches have been oriented to feeding, bathing, toileting routines and supervision with little or no opportunities for the development of communication skills, community activities or the development of relationships. There have also been powerful arguments and in some cases legal requirements that such supports have to be provided by medical personnel eg registered nurses. Therefore, in these models, most resources available to support people are taken up in addressing health care needs within expensive institutional settings.

Another feature of the experiences of many people with complex health needs is that, while it is strongly argued that their needs must be met through medical services and supports, many of their health needs are poorly addressed or ignored (Kerr et al:2003). Studies have shown that institutionalised people with complex health needs do not receive:

- regular screening for cancer such as mammography for women (Davies & Duff:2001), pap smears; skin cancers etc;

- regular screening for cardiovascular disease, eg cholesterol monitoring, monitoring of people with increased risk of heart disease;

- regular blood tests for anemia;

- flu shots for people with increased respiratory problems;

- hearing aids and glasses.

Models of support that facilitate community living

In a special issue of *Impact* published by the Institute on Community Integration at the University of Minnesota, several articles outlined some of the key elements of successful programs of support for people with disability and complex health needs. These are summarised.
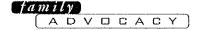
Care Coordination

There is a call for new paradigms that more effectively address the needs of this population, and a stress on coordination of primary care physicians and specialists with other human service supports – housing, transport, education, child care etc. (Abery, Cady & Simunds, 2005). This paper further argues that a shift from case management to care coordination for people with multiple and chronic conditions.

Care coordination is founded on self determination principles whereby the individual or family takes responsibility for determining what they need and adopts a primary role in how best to provide for them. Care coordinators have extensive knowledge of health, housing, transport and other human services. They build the skills of families to advocate on behalf of their family member and advocate directly only when necessary.

Research into these models is preliminary to date though early findings have indicated that persons receiving care coordination have 50% less hospitalisations (thereby reducing costs and disruption) and 89% have reported higher levels of satisfaction with their health care services one year after the new system was in place. In addition, 94% reported they wanted to be in control of their own health care decision making as much as possible.

Currently at least 10 states in the USA are piloting care coordination schemes. Preliminary findings from 7 sites have indicated that these schemes are all using a team approach with generalist and specialist nurses and social workers. They all coordinate both medical and behavioural supports with approximately 60% of all recipients in the 7 states having behavioural issues as well as health and disability support needs. All are exhibiting a deep commitment to partnering with the individual that goes beyond merely day to day management (Palsbo & Mastal:2005). There are differences across each state in how these programs are funded reflecting the US systems.

Bezanson (2005) reports on the transition of persons with disability and complex health needs from nursing homes to the community and argues that it is necessary to provide education for families and professionals who often hold erroneous beliefs that people with complex health needs cannot live safely in the community. Providing this education produces safe living arrangements and increased consumer satisfaction.

Even extreme medical conditions need not be a barrier to living in the community. In a UK study of 141 children requiring ventilation for breathing, Jardine et al (1999) found that approximately two thirds were supported at home by their families with assistance from healthcare professionals. Of the 43 who remained in hospital, 38 were unable to be discharged home because of lack of staff in the community and/or funding for community supports. This study also reported that more than half the children of school age attended regular mainstream schools.

Services that support people with complex heath needs to live in the community

Several services have developed innovative and successful ways of supporting people with complex health needs in ordinary community settings, as children within families or in ordinary homes. These summaries are derived from reports and information provided by the services. Some material is based on formal evaluations of the programs but there is little published empirical research in this area of disability.

Xavier Children's Support Network, Queensland

In the early 1990s, the Xavier Hospital for Children, an institution catering for 52 children from 2 to 16 years of age began the shift to a family and community-based model of support.

Xavier Principles

- family is viewed as the primary care giver;
- inclusion in family and community is promoted;
- natural family supports are valued;
- a flexible and individual support response is ensured;
- family integrity must be protected;
- empowerment and responsibility by the family;

Xavier offers flexible family support, shared care and a Hi TeC Program.

Flexible family support is facilitated by a key worker with the aim of maintaining and enhancing the family's capacity to care. The key worker relationship continues overtime, adjusting the package of support as required and ensuring supports remain flexible enough to fit individual and changing needs.

Flexible supports include such things as supporting a parent to learn tube feeding, suctioning or to change a trachea tube, in-home support for bathing and feeding, out of home family-based respite, in-home respite, consultation on sleeping, feeding, positioning or lifting, hiring of a domestic or diaper service, obtaining or borrowing a piece of equipment, day-care or holiday camp inclusion, counselling or any other resources necessary to support a family with a child with a disability including direct funding to families to purchase their own supports.

Shared Care service provides a family-based alternative for children who could not live with their natural family on a full time basis. The alternate family is provided with whatever assistance is needed to enable a child to live successfully and happily with them

including home modifications, access to specialised services, equipment advice and purchase, in-home support and out of home respite.

HiTeC Program assists the family in finding staff to care for their child, arranging staff support schedules to suit the family and organise and supply equipment and supplies.

Internal evaluations have found that the aspects of service provision most valued by families include:

- flexibility and broadness of supports provided;

- positive characteristics of the support staff - professionalism, caring, honesty, good listening;

- ability to design or have input into the supports provided;

- speedy response and availability of support;

- financial assistance to purchase own supports;

- respect for family integrity.

The comparison of the children's quality of life while in the institution and at home found that the children blossomed after moving home and are very happy.
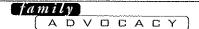

Vermont Options

Similar philosophies and approaches are available in the State of Vermont, USA. The success of their models rests on the composition, training and involvement of highly individualised support teams (Ashe, Martin & Thrall:2004). Over 100 people with complex health needs are currently supported in Vermont and institutional models are not looked to for providing care. The service options for people with complex health needs include:

- a few group homes where medical intervention and oversight is provided by registered nurses and others where the oversight is delegated to non nursing staff;

- at home with family – individualised support teams work with the family to assure the provision of appropriate health care in the home;

- case management model to coordinate these supports.

Key issues include:

- critical importance of collaboration among support members;

- the need to develop a unique set of resources for each individual;

- training for all in making critical judgments in care decisions;

- small caseloads to ensure sufficient time is spent with each individual.

Schriver Medical Clinical Services Corporation, Massachusetts

Based on similar family centred approach and philosophy, Schriver provides:

- coordination of care involving all parties;

- consultation with physicians, specialists, nurses and allied health professionals;

- home visits for assessment and follow-up;

- support and advocacy during hospitalisations;

- development of health care plans and emergency protocols;

- training of people with disability, their families, friends and staff.

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Section 7 Self management of supports

Key messages

Worldwide, a paradigm shift is occurring away from institutional services and professional control, towards an emphasis on self determination and community involvement (Lord & Hutchinson:2003, Nelson et al:2001, Pedler et al:1999, Stainton:2000 in Lord & Hutchinson:2003:71).

Features of self-determination include having an individual budget, exercising control over services and decision making, using person centred planning, having independent support brokerage and having a fiscal intermediary (Mosely:2001, Head & Conroy:2005, Brandon:1991, Community Brokerage Service Society:1996, Laing:1991, O'Brian:2001 in Lord & Hutchinson:2003).

Lord and Hutchinson found that values and principles are an important part of a policy framework and provide coherence and equity for a service (Lord & Hutchins:2003:78).

Stancliffe found that individual budget availability was significantly associated with features of the person's living environment (residence type and residence size) but was not related to the service recipient's characteristics, family contact or guardianship (Stancliffe & Lakin:2005:11)

In the late 1990s, the Robert Wood Johnson Foundation funded 'Self Determination Initiatives' in 19 states of the US. The independent evaluation of the Initiatives in Michigan (the Michigan study) provides new insights into the impact of the self management of funds. The findings are consistent with emerging data from projects in other States of the US (Head & Conroy:2005 in Stancliffe & Lakin:2005:237).

The Michigan study found that:

- individual budgets were distributed equitably, regardless of recipient's personal characteristics such as gender, ethnic background, and levels of intellectual disability, adaptive behaviour and challenging behaviour (Head & Conroy in Stancliffe & Lakin (2005:211);

- control over funds led to improvements in quality of life and increased community membership. This was seen in an increase of power 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 (Head & Conroy:2005 in Stancliffe & Lakin:2005:229-234). These results were replicated in the new Hampshire study (Conroy, Yuskauskas and Spears:in review in Head & Conroy:2005 in Stancliffe & Lakin:2005:220).

- individualised funding led to an overall cost reduction (Head & Conroy:2005 in Stancliffe & Lakin:2005:232-233), replicating the conclusions of Stancliffe in relation to semi-independent living (Stancliffe & Lakin:2005:144) and findings from demonstration projects in nine states of the US (Conroy, Fullerton, Brown & Garrow:2002 in Head & Conroy:2005 in Stancliffe & Lakin:2005:237).

Increased control by families of respite and personal assistance services was 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 (Caldwell & Heller:2003 in Stancliffe & Lakin:2005:8).

Policy implications

- 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.

Background

Worldwide, a paradigm shift is occurring in the disability field, reflecting a move away from institutional services and professional control towards an emphasis on self determination and community involvement (Nelson et al:2001, Pedler et al:1999, Stainton:2000 in Lord & Hutchinson:2003:71).

Lord and Hutchinson's review of the literature (Mosely:2001, Head & Conroy:2005, Brandon:1991, Community Brokerage Service Society:1996, Laing:1991, O'Brian:2001) documents key features of self-determination as having an individual budget, exercising control over services and decision making, using person centred planning, having independent support brokerage and having a fiscal intermediary. In addition, Lord and Hutchinson emphasise that in individualised funding arrangements, infrastructure supports for individuals are separate from the service system and the facilitator-broker role is differentiated from case management with the facilitator being focused on the individual and their participation in the community (Lord & Hutchinson:2003:79-81).

Self-determination emphasises community participation (DeJong:1993, Hutchinson et al:2001 in Stancliffe & Lakin:205:204), and arose in response to documented low levels of control experienced by people with disability (Kishi et al:1988, Parsons, McCarn & Reid:1993, Sands & Kozleski:1994, Wehmeyer & Metzler:1995 in Stancliffe & Lakin:205:204).

Clearly, self-management is underpinned by values and principles. Lord and Hutchinson (2003) studied self-determination initiatives and found that values and principles mattered as a policy framework to provide coherence and equity for the service (Lord & Hutchinson:2003:78-79). Flexibility is also important, as a 'learn as you go' philosophy was found to maximize outcomes in a service (Lord & Hutchinson:2003:71). Flexibility is inherent in the person centred approach.
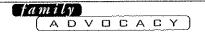
Head and Conroy (2005:220) distilled the self-determination concept into a testable form as three propositions: a) if people gain control, b) their lives will improve and c) costs (public money required to support an individual) will not increase. Self-determination promotes a holistic view of quality of life, looking at employment supports, community living, leisure activities and relationship building (Lord & Hutchinson:2003, Roeher Institute:1997).

This report draws on data from the independent evaluation of 'Self Determination Initiatives' in Michigan. These findings are consistent with emerging data from Projects in 18 other States of the US (Head & Conroy:2005 in Stancliffe & Lakin:2005:237).

Who has an individual budget?

Evaluation of the 'Self Determination Initiative' in Michigan (Stancliffe & Lakin:2005:211) found that individual budgets were distributed equitably, regardless of a recipient's personal characteristics such as gender, ethic background, and levels of intellectual disability, adaptive behaviour and challenging behaviour.

Using case studies from Canada, the US and Australia, Lord and Hutchinson (2003:81-82) support the finding that the allocation of individualised funds was designed to be equitable and accountable to both the funder and the individual. However, the size and type of an individual's residence affected whether they received an individual budget.

Stancliffe & Lakin (2005:212) found that for each additional resident with disability living in a setting, the odds of a person having an individual budget decreased by 18%. In addition, people living in their own homes were more likely to have individual budgets than people living in group homes (Stanclife & Lakin:2005:211). Stancliffe and Lakin hypothesised that the strong link between individual budgets and people living at home may be explained by people using their individual budgets to move out of home, (showing how individual budgets allow for greater independence), by administrative convenience in accounting or by a tendency to select individual budgeting to support a more individualised approach to services.

Self-determination increases control

The extent of self-determination experienced by a person with intellectual disability is often measured by the Decision Control Index (DCI), an instrument which evaluates who makes choices and exercises control in relation to items in people's everyday lives, such as use of personal money, choice of food and choice of home (Conroy:1997, Head & Conroy:2005 in Stancliffe & Lakin:2005).
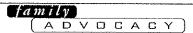
In a study of a sample of 70 people from the Michigan 'Self-Determination Initiative', Head and Conroy (2005) found that control over funds led to improvements in quality of life and a decrease in costs. This was seen in an increase of power in terms of hiring and firing direct support staff, choice of agency support person, choice of people to live with, choice of house or apartment and choice of case manager. These are areas in which people with intellectual disability have previously been found to have the least control (Heller, Miller & Factor:1999, Wehmeyer & Metzler:1995 in Head & Conroy:2005 in Stancliffe & Lakin:2005).

The Michigan study replicated an earlier study from New Hampshire, which had also found that self managed funding led to individuals having greater control over their lives (Conroy, Yuskauskas & Spears in review in Head & Conroy:2005:220). Similarly, Stancliffe et al (2000) found that an individual's personal control was positively related to the amount they had available for discretionary spending. Stancliffe (2005:132) found that people living independently exercised more choice and control than people in group homes.

Head and Conroy (2005 in Stancliffe & Lakin:2005:235) argue that individualised funding led to greater control because friends and allies were incorporated. With the support of allies, individuals are **expected** to make decisions about the aspects of their lives that mattered to them most including their jobs and other day activities and their accommodation, where they moved from settings that were licensed and regulated to supported independence. This was supported by Stancliffe who noted that the semi-independent living environment not only provided opportunities for independent participation, but also **demanded** such participation due to lack of staff presence (Stancliffe:1997, Stancliffe & Keane:2000 in Stancliffe & Lakin:2005:138).

Self-determination improves quality of life

Stancliffe and Lakin (2005:216-7) emphasise that self-determination has more wide ranging benefits than freedom from staff control. Other benefits include improved quality of life, increased community membership and cost reduction (Conroy:2000, Conroy & Yuskaukas:1996, Conroy, Yuskaukas & Spear:2001 in Stancliffe & Lakin:2005:216).

In their study of the effects of individualised funding, Head and Conroy (2005 in Stancliffe & Lakin:2005:231-232) found that individualised funding led an individual to report a higher quality of life and participate in an increased number of integrative activities. The biggest increases were reported in levels of happiness, getting out and general quality of life, which confirms the all-round/holistic benefits of self-determination/self-management.

Further, Caldwell and Heller (2003 in Stancliffe & Lakin:2005:8) reported that consumer-directed family support was shown to have benefits for both family and people with intellectual disability. They examined outcomes for both the family and the person with disability associated with a consumer directed family support program in Illinois. They found that more control by families over respite and personal assistance services was linked to increased satisfaction with services, more community participation by the person with developmental disability, less staff turnover and more hours per week of employment for mothers.

Self-determination decreases cost

Head and Conroy (2005) offer a recent finding that individualised funding leads to an overall cost reduction, replicating the conclusions of the study of people in semi-independent living (Stancliffe & Lakin:2005:129-150). The Head and Conroy study provides a detailed examination of the cost issue, by comparing baseline costs from 1998 with costs from 2001 after individualised funding had been implemented. Among the 70 participants, costs decreased by an average of 16% when adjusted for inflation (Head & Conroy:2005 in Stancliffe & Lakin:2005:232-233).

Head and Conroy argue that the reduction in service costs is attributable to the fact that:

- individuals were no longer required to accept unwanted services;

- as individuals chose the method of service delivery, support arrangements more exactly fitted their needs and preferences;

- individuals could negotiate prices with providers and shop for lower rates;

- there was no middleman element of using a provider agency. This led to a reduced cost per hour;

- use of budget target in planning processes created incentives for a more creative approach to providing support.

Similar findings have been reported from demonstration projects in nine other states of the US (Conroy, Fullerton, Brown & Garrow, 2002 reported in Head & Conroy: 2005 in Stancliffe & Lakin:2005:237).

In summary, self-determination provides a 'win-win' for public policy. The results from Michigan show that not only is self determination a fiscally conservative approach to service delivery but also that participants in self determination perceive themselves as having greater choice, less professional domination and a higher quality of life.

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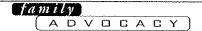
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