Effectiveness of Supported Living in Relation to Shared Accommodation

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Publication details:
Report No. SPRC Report Series 18/08
9780733424434 (ISBN)

Publication Date:
2008

DOI:
https://doi.org/10.26190/unsworks/877

THE UNIVERSITY OF NEW SOUTH WALES

EFFECTIVENESS OF SUPPORTED LIVING IN RELATION TO SHARED ACCOMMODATION

FOR DISABILITY POLICY AND RESEARCH WORKING GROUP

SPRC Report 18/08

University of New South Wales Consortium
Social Policy Research Centre
Disability Studies and Research Institute
City Futures

November 2008

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ISSN 1446 4179
ISBN 978 0 7334 2443 4

Submitted: July 2007

Published: November 2008

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Acknowledgements

Thank you to the people who contributed to this research, particularly the people who participated in the interviews and the Reference Group members.

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Abbreviations and glossary

Accommodation support	Formal service support or informal support provided to the person to fulfil their needs to live in their housing
CACP	Community Aged Care Package
CALD	Culturally and linguistically diverse
Case studies	Six examples of innovative accommodation support for people who require 24-hour support
CO	Community Options
CSTDA	Commonwealth State and Territory Disability Agreement
DADHC	Department of Ageing, Disability and Home Care, NSW
DFC	Department for Families and Communities, South Australia
DHCS	Department of Health and Community Services, Northern Territory
DHHS	Department of Health and Human Services, Tasmania
DHS	Department of Human Services, Victoria
DSC	Disability Services Commission, Western Australia
DSQ	Disability Services Queensland
FACSIA	Australian Department of Families, Community Services and Indigenous Affairs
Group homes	Capital or leased property usually housing 2-6 clients with employed staff up to 24-hours on-site
HACC	Home and Community Care, community-based support to assist people to live in their own home and participate in the community. Provided to older people and a smaller number of younger people with disability
Housing	Physical place where the person lives
Individualised accommodation support	Housing and accommodation support models designed around the person's support needs and preferences
In-home care	Community-based support provided in the person's home. Generic examples include CACP, CO, HACC, accommodation support, semi-independent living
Models	National and international approaches to 24-hour accommodation support
NGO	Nongovernment organisation
OECD	Organisation for Economic Cooperation and Development
People with disability	People with an impairment, where 'disability' refers to their social experience resulting from the way social organisation fails to take account of support needs. The experience of disability is also likely to be intensified when in combination with other social disadvantages based on gender, Indigenous background, culturally and linguistically diverse backgrounds, age, sexuality and economic disadvantages.
Require 24-hour support	Accommodation support needs that require access to 24-hour formal or informal support in person or remotely
Semi-independent living	Housing and accommodation support models designed for individual needs, usually individual or small groups, with less than 24-hour formal support
Supported accommodation	Housing or accommodation support for people with disability who require assistance in a place to live

Executive Summary

The Disability Policy and Research Working Group commissioned the UNSW Consortium to research the effectiveness of supported living in relation to shared accommodation to improve service delivery for people with disability. This research project aims to build on existing knowledge, and increase understanding about accommodation services and housing for people with disabilities. The objective is to improve service delivery to people with disabilities. The project entailed two main parts. Part 1 (Improving Access to Housing for People with Disabilities), aimed to improve understanding of how people with disabilities access housing in Australia, as well as to identify strategies to improve access to housing. Part 2 (Improving Accommodation Models for people with disabilities who require 24-hour care) described innovative models of care for people with disabilities requiring 24-hour support, developed a service framework identifying and describing key components of successful models, and a cost-effectiveness analysis of selected models compared to 24-hour staffed group homes.

The report combines the two Parts and includes an overview of existing national and international approaches to 24-hour supported living, including examples of innovative models; an outline of the primary goals of supported living; an analysis of facilitators and barriers to successful provision of supported living; a framework for assessing the effectiveness of approaches to 24-hour accommodation support based on the goals and facilitators and barriers outlined in previous sections; a detailed analysis of six case studies of innovative Australian approaches to supported accommodation, followed by an application of the assessment framework to the six case studies and a cost effectiveness analysis of the case studies; and a conclusion for policy implications of the research.

The most pervasive trend in current approaches to supported accommodation in Australia and the other countries studied (the U.S and Europe with a focus on the U.K) is deinstitutionalisation. The process is advancing in most countries, including Australia. The most common form of formal residential accommodation support is 24-hour staffed group homes, although there is a trend towards preference of semi-independent living and supporting informal care. An important policy trend is the move towards individualisation of services and many countries have been examining different methods for such provision, including direct funding mechanisms and individualised case management.

The four main goals of supported living identified in the research are (i) human rights concerns for people with disability and the equalisation of their position in society to that of the general population, with a focus on empowerment; (ii) quality of life, including social participation; (iii) independent living with a focus on self-determination and choice; and (iv) cost effectiveness for the person using accommodation support and the most effective use of limited funding.

The main facilitators and barriers to successful provision of accommodation support identified in the research are: effective and supportive legislation and agreements; beneficial and compatible building legislation; effective and streamlined interagency coordination; the nature of the supported living arrangements; funding and demand management; staffing quality including training and management; discrimination,

including the specific interests of Indigenous people and people with cultural and linguistic interests; levels of flexibility and choice in service types and levels; and support for the involvement of informal carers.

The research developed a framework for assessing the effectiveness of approaches to accommodation support based on the goals and facilitators and barriers. The domains include (i) the outcomes and goals of the approach (independent living, quality of life and cultural appropriateness); (ii) administrative systems such as interagency coordination and the policies and practices of the service provider; (iii) service viability in relation to availability, flexibility and mobility of funding for the service user, sustainability of the service, ability to expand and replicability of the service; and (iv) quality of staffing, informal support and coordination between formal and informal support.

Six national case studies of new approaches to support for people who have 24-hour support needs examined in the research are (i) the Lower Great Southern community Living Association in Western Australia; (ii) My Place in Western Australia; (iii) Noarlunga in South Australia; (iv) the Opening Doors Project in South Australia; (v) Tom Karpany House in South Australia; and (vi) Uniting Care Wesley – South East Project in South Australia. All of the approaches are effective when analysed with the effectiveness framework. Despite the wide range of practices and goals in the case studies, all are focused on fostering independence while providing individualised and holistic approaches to service provision. All of the case studies were assessed as being replicable and suitable for people with a range of support needs.

In addition, the cost effectiveness analysis found positive results compared to support provided in group homes. Direct housing costs to the disability government agencies, service provider and person with disability in the case studies seem to be less than some group home models. This is probably because of the range of places that people live and the source of contributions to the housing costs. These included clients contributions, co-resident contributions, subsidised rent through social housing and economic costs to family members through informal care arrangements. The implication is that the other economic housing costs associated with these approaches are incurred by other parts of government (eg. social housing) or families. None of the service providers own the housing in the case studies. Accommodation support and management costs for the case studies also appeared to be lower than or similar to group home costs. The range includes lower costs where people's support needs change following stabilisation of suitable accommodation support and housing. The analysis found that the benefits are likely to be higher for clients in these alternative models of accommodation support than for matched people living in a group home.

1 Introduction

The Disability Policy and Research Working Group commissioned the UNSW Consortium to research the effectiveness of supported living in relation to shared accommodation to improve service delivery for people with disability. This research project aims to build on existing knowledge, and increase understanding about accommodation services and housing for people with disabilities. The objective is to improve service delivery to people with disabilities. The project entailed two main parts. Part 1 (Improving Access to Housing for People with Disabilities), aimed to improve understanding of how people with disabilities access housing in Australia, as well as to identify strategies to improve access to housing. Part 2 (Improving Accommodation Models for people with disabilities who require 24-hour care) described innovative models of care for people with disabilities requiring 24-hour support, developed a service framework identifying and describing key components of successful models, and a cost-effectiveness analysis of selected models compared to 24-hour staffed group homes. For ease of reading, both parts of the research have been compiled into this single report.

The research approach, methods and analytical framework are summarised in Fisher & Parker (2007). The methods included a national and international literature review; interviews with people with disability; interviews with national, state and territory officials; and six case studies using written materials and interviews and questionnaires with service provider managers, clients and families.

1.1 Background

A range of interrelated factors contribute to the need for further evidence-based research into effective supported living arrangements, including trends relating to an ageing population and public and policy recognition of the need for more innovative and flexible models of support. Previously, large institutions were the primary model of accommodation support for people with disability. Support efforts were often underpinned by notions of pity and charity, and embodied a medicalised notion of disability (Oliver, 1990). Since the 1960s, and particularly since the 1980s, conceptions of and policies for disability in the post World-War II period have shifted from a paternalistic welfare approach to an acknowledgment that people with disability have full and equal rights (Parker, 2007). Disability policies and programs were reconceptualised to include, at least in rhetoric, principles of citizenship, equality and rights (Parker, 2006). These shifts spurred a deinstitutionalisation movement across the western world, where large hospital-like institutions were closed, and residents were moved into smaller living arrangements in the community, such as group homes and cluster housing (Young et al, 1998). In addition, policies and service provision have shifted towards home-based care. Such arrangements are considered to offer better personal support and living, as well as provide a greater opportunity for people with disability to participate and integrate with society (Epstein-Frisch et al, 2006).

Evidence abounds demonstrating the positive effects of people with disability living in the community, rather than in institutional care (eg. Stancliffe & Lakin, 2005; Bleasdale, 2006; Bostock et al, 2001; see reference list). The literature reviewed for this report indicates that more recently, governments have also acknowledged that current approaches to supported living are inadequate and insufficient to enable full

and equal participation of people with disability. Key critique centres on a lack of flexibility, non-individualised service provision and cost. People with disability, advocacy groups, key non-government and government stakeholders are all searching for ways to improve supported living arrangements so that they better reflect the preferences of people with disability to live in accommodation settings of their choice, equal to the choices of other members of the public.

1.2 Structure of the Report

Section 2 begins with an overview of current supported living arrangements, in Australia and internationally. It includes a snapshot of policy by state and territory, examples of accommodation support models and a summary of trends in policy direction. In this report, 'supported accommodation' is used as an umbrella term to include housing or accommodation support for people with disability who require assistance in a place to live.

Section 3 outlines the primary goals of supported living: human rights; quality of life; promoting independent living; and cost effectiveness. Section 4 then analyses the key barriers and facilitators to accessing housing and accommodation support in terms of the achievement of these goals. They include: legislative and regulatory systems; building regulations; interagency coordination; current arrangements of supported living; funding and demand; staffing; the impact of discrimination, particularly with regards to people from Indigenous or CALD backgrounds; the importance of flexibility and choice; and the major concerns for carers of a persons with a disability.

Based on the experience of these facilitators and barriers to achieving the policy goals, Section 5 develops a framework for assessing the effectiveness of approaches to 24-hour accommodation support. The dimensions include goals and outcomes for people with disability supported in successful programs; regulatory and administrative systems that enable effective support and accommodation; practical issues affecting the success of supported living arrangements such as building structure and service arrangements; factors affecting the viability of models; levels of demand for such services as well as funding source and structure, and the contribution of formal and informal support to the accommodation support model.

Current innovative approaches to 24-hour accommodation support are presented in six case studies in the next three sections. Section 6 describes the case studies in terms of their characteristics, innovations and challenges. In Section 7, the framework developed in Section 5 is applied to each of the six case studies. The results are summarised to draw implications for informing the future development of similar approaches to 24-hour accommodation support elsewhere in Australia.

A detailed cost effectiveness analysis of the case studies is presented in Section 8. The analysis compares the costs and benefits of the case studies to 24-hour staffed group homes and semi-independent living models. The analysis is conducted in comparison to the findings of Stancliffe and Keane (2000) cost effectiveness analysis of accommodation support for people living in semi-independent services and group homes. Section 9 concludes with a discussion of the implications of the research for policy development. As a final note, the report offers key examples from international and comparative evidence-based studies, which form the basis for much of this research in Appendix A.

2 Existing Supported Living Arrangements

This section is a description of current accommodation support policy in Australia and internationally. It begins with a snapshot of Australian supported living policy by state and territory. In addition, examples of accommodation support models specific to people with disability and more generally designed for other people needing accommodation support are described. Third, the section turns to a brief description of international policy responses in similar policy contexts. The purpose of these discussions is to highlight current developments in disability accommodation support policies and provide a frame of reference for prospective changes in such policies in Australia. It includes examples of innovative models of accommodation support to exemplify the directions in which such policies are advancing and provide possible models that could be used in Australia.

2.1 Snapshot of Australian Supported Living Policy

The following sections include an overview of current accommodation support policy and provision in Australia. First, a summary of national approaches to accommodation support is discussed. Second, a snapshot of Australian policies by state and territory is presented. The information is from interviews with government officials, government websites and reports and secondary literature. It describes the main models, funding, service provision and trends in policy directions.

National

Across Australia, a number of options for people with disability who require accommodation support are available. These include public housing; community housing; crisis accommodation; home purchase assistance; and private rental assistance (Productivity Commission, 2007). The Commonwealth State/Territory Disability Agreement (CSTDA) provides the national framework for the delivery, funding and development of specialist disability services. The specialised disability services covered in the CSTDA include accommodation support, community support, community access, respite, employment, advocacy, information, and print disability.

Analysis of supported living arrangements in Australia has shown a steady growth in CSTDA funded residential services; a slow but consistent decline in the proportion of people housed in large residential settings; a gradual increase in the number of people in community group homes; and a more rapid growth in outreach/drop in services such as semi-independent living (Stancliffe, 2002).

The rights of people with disability have been a central factor in the developments and provision of support services and accommodation in Australia in the past three decades. In accordance with the social model of disability, people with disability are viewed as equal citizens in society whose disadvantage is not necessarily a consequence of their own disability, but rather social, physical and economic factors, which do not enable them to participate in social life as other citizens do. A central aim of Australian federal, state and territory governments in providing disability services is to maximise opportunities for people with disability to participate actively and meaningfully in the community (Productivity Commission, 2007).

Accordingly, one of the major features of current government funded disability services in Australia is the process of deinstitutionalisation – the transfer of many

people with disability, who were until recently segregated from their community in large residential institutions, into the community. This is in keeping with current trends in OECD countries. This process has had a marked effect on disability services and the people receiving them – in 2004-2005, 83.3 per cent of people receiving some sort of accommodation support received community accommodation and care services (PC, 2007).

The following data are sourced from the recent Productivity Commission report (2007). In 2005-2006, Australian governments spent $3.6 billion directly on services for people with disability, 52 per cent of which was spent on accommodation support services, including both community living arrangements and residential institutions. Only a small proportion (12.9 per cent) was spent on community support services providing care and support for people with disability living in both supported accommodation in the community and in private residences (the latter comprising 68 per cent of CSTDA support services in 2004-2005). This includes services such as therapy support (used by 31.4 per cent community support service recipients in 2004-2005), case management and service coordination (used by 46 per cent). A further 12.9 per cent was spent on community access services facilitating better integration of people with disability into the wider community, especially those who have recently been transferred from institutional settings. These services include learning and life skills development (used by 25,111 people) and recreational day and holiday programs (used by 7,822 people) (PC, 2007). CSTDA also funds advocacy services that enable people with a disability to increase their control over their lives by representing their interests and views in the community, including in relation to accessing suitable accommodation support (1.3 per cent of CSTDA funding; PC, 2007). As a consequence of the focus on community living for people with disability, a majority of the 28,355 people in Australia receiving accommodation support services receive them in community settings (2004-2005). The single most common housing arrangement is group homes, which in 2004-2005 housed 31.7 per cent of people, with many others being housed in various different models of accommodation. Other common models of accommodation support include supported accommodation facilities such as long-term institutions both large and small-scale, alternative family placement and in-home accommodation support and personal care (PC, 2007).

Another consequence of the focus on the abilities and rights of people with disability is the government aim at promoting choice and self-determination for people with disability. This is evident in the provision of 'individualised funding'. Under the CSTDA, jurisdictions may, instead of providing or contracting services to provide to people with disability based on administrative decisions, fund service outlets to provide services to a person in need based on their preference. In 2004-2005, 18 per cent of service users reported receiving their services through individualised funding. Relevant examples of state-based individualised funding programs include the Attendant Care Program in NSW and Local Area Coordination in Western Australia (Lord and Hutchinson, 2003).

Most people with disability live with their families (56 per cent of service users in 2004-2005) and rely on informal carers (42 per cent of service users in 2004-2005), mostly family members. Some of these families rely on respite services to sustain their capacity to support informal care. Many people with disability live in

government subsidised social housing (public and community), both in supported accommodation settings funded through the CSHA and in generic housing complexes with external support provided. In 2005-2006, the CSHA provided 341,378 such dwellings in public housing and 29,693 in community housing for generic and specialised use with a total cost of $1.3 billion (including other types of housing funded by the CSHA). People with a disability, in fact, represent a large proportion of public housing tenants – in 2003, when the proportion of people with a disability in Australia was 19 per cent, 40.6 per cent of public housing tenants were people with a disability (PC, 2007).

Due to definitional differences in classification of disability between Productivity Commission Data and that of the Australian Institute of Health and Welfare, statistics from these different sources are not completely interchangeable. In this report, we have mainly relied on Productivity Commission data. In addition, some useful information is provided in AIHW reports. The AIHW estimates that in 2005 there were close to 23,300 people in need of accommodation and respite services who did not receive them or did not receive them at the necessary level (Table 2.1: AIHW, 2007b). Many people using accommodation support receive it from more than one service outlet. Furthermore, many people receive services from more than one service type. Nearly one third (29.1 per cent) of people receiving services, received them from more than one service (AIHW,2007a).

Table 2.1: Estimates of Unmet Demand for Accommodation and Respite services,(a) 2005 ('000)

Age groups (years)	0–4	5–64	0–64
Unmet demand for accommodation & respite services			
(A) No service available, or unable to arrange a service	**1.8	10.6	12.4
(B) Service costs too much or does not provide sufficient hours	*2.7	12.7	15.4
Total (A) & (B)	**4.5*	*23.3*	*27.8*

Source: AIHW 2007b.

Notes: (a) Analysis was restricted to people aged under 65 years with a severe or profound core activity limitation living in households, who reported having an unmet demand for formal assistance with core activities.

* These estimates have an associated relative standard error of between 25% and 50% and should be used with caution.

** These estimates have an associated relative standard error (RSE) of greater than 50% and are considered too unreliable for general use.

The remainder of this section provides a snapshot by state and territory.

Australian Capital Territory

Disability ACT is the division of the ACT Government charged with the portfolio responsibility concerning a range issues relating to people with disabilities, including the planning, funding and delivery of supported accommodation.

Primary Model

The ACT Government does not operate or funds large institutions. Over the past five years the range of supported accommodation models funded in the ACT has increased. In addition to group homes, these include:

- A Link model, in which ten people live in their own dwellings with a support person living nearby. The Link community provides inform social and emotional support to the ten residents who live with a high level of independence and autonomy;
- Family governed models: Disability ACT has provided funding and/or assistance to a small number of family groups who are interested in developing and/or managing supported accommodation arrangements for their adult children. These are generally groups of two or three people sharing to rationalise resources;
- Self managed Individual Support Package (ISP): Disability ACT funds a consumer stakeholders group to establish a consumer enterprise to enable ISP recipients to self-manage packages.

Funding

Under the CSTDA, ACT funded accommodation support for approximately 324 people during 2005-2006 financial year. This included funding for a range of accommodation options.

Service Provision

In 2005-06 the ACT Government delivered accommodation support services to 324 clients. The Government directly delivered accommodation support in group homes to 46 per cent of these people. In 2005-2006 the community sector delivered accommodation services to 172 clients of whom 56 resided in a group home; and 116 people were supported to reside in their own homes or with family in the community.

ACT Government through Disability ACT has Service Funding Agreements with 42 community sector providers to deliver accommodation support services, respite care services, community support access services as well as general advocacy, education and information services. 11 of the organisation also provide services under the HACC program. With the exception of two for profit agencies and one organisation limited by guarantee, all community sector organisations funded to provide disability services are incorporated associations.

Policy Shifts

Over the last decade a fundamental policy shift has been away from a provider-centred approach to an approach that is much more centred on the needs and aspirations of the clients and their families. This paradigm shift was the result of a conscious effort that involved transforming the responsible government agency and the disability sector. Through extensive consultations over the last decade, Disability ACT has developed, adopted, implemented and had evaluated by an international evaluation panel, *Future Directions: A Framework for the ACT 2004 - 08.* This strategic policy, along with *Challenge 2014 - A ten year vision for disability in the ACT,* continues to shape the provision of disability services in the ACT.

New South Wales

(DADHC, 2007)

Primary model

Three main arrangements are offered: (i) large residential; (ii) group homes; and (iii) in home support. In addition to general group home provision, there are also specialised models that are specific to health care, behaviour management (e.g. for 24-hour care), children and people involved in the criminal justice system.

Funding

Funding is available for 5,300 places and the funds go to the services, as the government supports 'funding a system'. Funding for disability services under the CSTDA is nearly $1.1B (from Commonwealth and State), around 45 per cent of which is allocated to out of home support services. Demand exceeds supply. Although an accurate assessment of unmet and 'under-met' need is not available, vacancy management policies and procedures have been used over the past three years, but few vacancies are available.

Service provision

DADHC operates group homes and residential institutions housing 2,544 people and funds 148 community living organisations housing 1,554 people. The Attendant Care program provides individualised support for home living for people with high-level care needs.

Policy shifts

DADHC has closed some of its large residential programs with clients initially moving into group homes. This has now changed to incorporate more flexible options for housing following deinstitutionalisation.

Northern Territory

(DHCS, 2007)

Primary model

Group homes are run by Non Government organisations (NGOs). Set up to provide disability services. These houses provide support for people with various levels of support needs. NGOs also provide several one-bedroom units and apartments, which are used for transitional needs.

Funding

DHCS funds 133 supported accommodation places for older people and people with disability. Low levels of funding create a large waiting list and lack of choice for users when considering location and accommodation style.

Service provision

Supported accommodation is mostly provided by contracted NGOs and funded by DHCS.

Policy shifts

Current policy is shifting to place more weight on user preference in determining accommodation support services, as well as more support and funding for living at home, especially for Indigenous people whose communities are often a long way from the housing offered.

Queensland

(DSQ, 2007)

Primary model

The main models are group homes and providing support for people to live in their own homes. DSQ also has other specialised supported living options including (i) cluster housing; (ii) Innovative Support and Housing (a trial initiative, which seeks to respond to people whose lifestyle support needs are not being met by the disability service system); and (iii) initiatives to provide accommodation support for young people in residential aged care including an Integrated Living Model (two NGOs are funded to provide accommodation, health care and disability support) and Living with Family and Support Networks Model (NGOs are funded to support younger people to live at home).

Funding

Under the CSTDA, DSQ funded accommodation support for approximately 5390 people during 2005-2006 financial year. This included funding for a range of accommodation options.

Service provision

DSQ funds a variety of accommodation support options including those provided by NGOs for people with disability as defined under the *Disability Services Act 2006 (Qld)*. Approximately 4 800 (89 per cent) users receive services provided by NGOs that are funded by DSQ.

Through DSQ's Accommodation Support and Respite Services Directorate, accommodation support was provided to approximately 590 adults with an intellectual disability in government owned housing and in a small amount of private sector owned accommodation. Demand exceeds supply. Disability Services Queensland and the Department of Housing have a Memorandum of Understanding relating to funding and administration of services for users with joint needs.

Policy shifts

DSQ has a person centred approach which is supported by the move towards people pooling support to enable individual support needs to be met.

South Australia

(DFC, 2007)

Primary model

Three main arrangements are offered: (i) institutions (ii) group homes, which remain a significant model and (iii) in home support. Other, more innovative models are being developed as part of the reform in disability services

Funding

Under the CSTDA, funding is provided for 735 places in institutional settings and 897 places in community settings. Funding for support services goes to service providers (mostly NGOs), not to individuals. Approximately sixty per cent of CSTDA funding goes to accommodation support, but there is a waiting list for accommodation services.

Service provision

Since June 2006, the Department for Families and Communities (DFC) has lead significant reform to assist vulnerable clients to access more streamlined and connected services. The State Government's disability agencies are being brought together under DFC to form a single agency- *Disability SA.* A similar process is occurring within housing (*Housing SA).*

Policy shifts

The State Strategic Plan includes a target (T6.10): *Housing for people with disabilities:* double the number of people with disabilities appropriately housed and supported in community-based accommodation by 2014.

The DFC Strategic Agenda 2005-2008 includes deinstitutionalisation as a key direction for people with disabilities. DFC has also recently developed a Supported Accommodation Strategy which seeks to increase the supply of community accommodation as well as consolidate waiting lists and demand management processes in order to better understand and pinpoint growing demand

Tasmania

(DHHS, 2007)

Primary model

Group home (predominantly 4 bedroom) and cluster units are the main models of supported accommodation. Disability Services is in the process of realigning the group home stock to include more unit style accommodation so that greater flexibility exists in meeting the needs of this target group.

Funding

In relation to high-level care, 408 places in 128 units are owned by Housing Tasmania with 24/7 support services funded by the Department of Health and Human Services (DHHS). Several supported accommodation options are owned by the NGO, with the DHHS funded support for the residents. Demand exceeds supply.

Service provision

Tasmania is currently in the process of outsourcing all Government managed group home to Non Government Organisations (NGOs). This process is due for completion by 2008.

Policy shifts

Shifts include greater individualisation of services available to people with various disability, providing more choices and putting more emphasis on the preference of the user in deciding services provided.

Victoria

(DHS, 2007)

Primary model

The main models are (i) Community Residential Units (group homes – a significant number of people using these do not require such intensive support); (ii) a small number of Complex Health needs model accommodation (cluster units); (iii) large residential (two left) and (iv) individual support.

Funding

Disability Services, a division of the Department of Human Services, manages disability support service funding. Demand for support services and housing currently exceeds supply due to lack of funding, so priority is given to urgent cases. All new funding is provided in individualised support packages.

Service provision

Disability support service provision is split equally between the Department of Human Services and NGOs contracted and funded by it, although the DHS is currently moving away from service provision, in favour of funding and administration, and transferring a higher level of service provision on to NGOs.

Policy shifts

There is a strong focus on individualised support and consumer participation. People in group homes with low support needs are moving onto individualised support packages. Service providers are implementing the 'Active Support' framework in group homes to increase user participation. There is a formal commitment to develop plans to close remaining institutions.

Western Australia

(DSC, 2007)

Primary model

Accommodation and support arrangements are decided between the service provider and the family, which offers flexibility. The main models are: shared-care residential; paid host family options; adult foster option (low cost); co-residency; independent living; and support for self managed funding. Details about these models are included in the approaches described in Section 2.2 and the case studies in Section 6.

Funding

Individualised allocations of funding are available to people to make the choice to use the funds in whatever accommodation/service setting they prefer. Funding is capped per person. The DSC is not concerned with the operationalisation of funds, as that is between service providers and individuals. The person has an option to change their funding situation (e.g. change service providers) at any given time. DSC is currently undergoing a 'Sector Health Check', which will re-affirm a policy commitment to individualised funding. DSC avoids service-based funding because it is less flexible in adhering to principles of rights.

Service provision

Around 55 service providers provide accommodation, which range from small (e.g. three people) to large (e.g. 300 people). Service delivery is individualised and organised in conjunction with Local Area Coordinators. Only a small proportion of applications for funding are successful due to limited resources (Bleasdale, 2006).

Policy shifts

The DSC is promoting the 'Developmental Paradigm' policy enabling consistent care through life as a preventative measure against crisis care. It is also furthering its commitment to individualised service provision and funding.

2.2 Australian Approaches to 24-hour Support

The section next explores specific approaches to 24-hour support. Most challenging for accommodation support policy is how to meet the needs of people who require 24-hour support. The following discussion and models present examples of current arrangements used in Australia for this group and people with similar needs. Both disability specific models and general models of accommodation support are presented. These models provide solutions for people who require 24-hour support who would alternatively receive support in formal support settings, such as group homes. Many are focused on reducing the need for 24-hour support while providing a safe environment with as much or as little support as necessary. The examples are in addition to the innovative case studies in Section 6. The case studies are analysed later in the report with a cost effectiveness analysis in contrast to group home models.

Disability specific models for 24-hour supported living

The following innovative models of accommodation support service provision are included to provide examples of models based on current principles of individualisation of support and community living. These models represent recent developments in disability service provision in Australia.

St. Martin's Court, Beaumaris, Victoria

Overview	A community living model providing self contained units for 13 residents, with a common room and courtyard, as well as individual support as necessary, including supervision and personal care. The complex is owned by Supported Housing Limited, a not-for-profit provider of community housing and with the care provided by Australian Home Care, a subsidiary of the Multiple Sclerosis Association.
Innovative dimensions	A focus on resident independence and community living in an alternative to a nursing home with integrated individually tailored support services.
Model of support	24-hour support is available, with an onsite live-in manager providing some direct care support as well as administration and organisation of other care workers as specialist staff as necessary.
Key principles	The model is aimed at providing choice and promoting independence for the residents.
People supported	The model is targeted at people with Acquired Brain Injury and neurological disabilities and each of the 13 self-contained units houses one resident.
Benefits and challenges	Care and supervision available when necessary while maintaining a community living atmosphere. Depending on the level of support, the model may only be suitable for people with low to medium levels of support needs.
Evaluation	N/A
Contact, refs	Supported Housing Ltd, 3/1401 Burke Road Kew, 3101, Phone: 03 9859 8833 Fax: 03 9859 8933, email: shl@shl.org.au

Redevelopment of Kew Residential Services, Kew, Victoria

Overview	A redevelopment of a large residential facility, retaining only 100 residents (out of 480). The new complex provides 20 staffed, mostly detached, group-homes spread out over a 10-hectare development including 380 generic residences. The group homes will be connected through organisation and proximity, but with high levels of independence, especially in relation to levels, types and roster of care services provided in each one.
Innovative dimensions	Providing smaller scale residences in accordance with the process of deinstitutionalisation, while maintaining high levels of support and supervision.
Model of support	House-based support rosters providing necessary support staff for all residents of each house. Support services include personal care and supervision as well as on-site medical and dental services.
Key principles	The program is aimed at promoting a more personal, home like atmosphere for residents in need of high levels of support.
People supported	100 residents with high support needs will live in houses with an average of 3-5 residents.
Benefits and challenges	High levels of services available in close proximity and small family style housing in the community. Cost effective model. House-based rostering may not be completely individualised.
Evaluation and research	Although the homes on the site of the old complex have not been occupied yet, a review of outcomes for residents of the institution who have been moved to other group homes in the community has shown an improvement in adaptive behaviour and general quality of life. (Radler, 2007)
Contact	Alma Adams, Phone: (03) 9854 1389, Email: Alma.Adams@dhs.vic.gov.au

Tenant Managed Cooperatives , South-western and Inner-western Sydney, NSW

Overview	Housing cooperatives purpose built for people with disability who choose to live in a self managed environment (either alone or with their carers). Funded by the NSW Department of Housing and designed with the input of prospective tenants, they offer 1-2 bedroom units within a complex of 7 and 9 units (respectively) in a community setting. Support services are individually planned and tenancy management services are also provided, while involving tenants in the decision making process.
Innovative dimensions	Enables high levels of independence and community living, as well as maintaining informal carers in supported accommodation.
Model of support	Support services are individually planned and provided by HACC or the NSW Attendant care program.
Key principles	The cooperatives are aimed at fostering a well- supported community of peers while normalising lifestyle and enabling self-determination.
People supported	Most of the people currently in the cooperatives have physical disabilities and Multiple Sclerosis, some live in a unit together with their carers.
Benefits and challenges	Highly individualised and resident-determined support and physical environment. Ability to house residents with their carers. HACC services may not provide sufficient support for people with high needs.
Evaluation	N/A
Contact	N/A

Floating Care – Supported Accommodation Initiative for People with HIV/AIDS, State-wide, NSW

Overview	Independent accommodation for people with HIV/AIDS needing an extra level of personal and accommodation support. Clients rent accommodation leased by housing associations from the private rental market. Support is individually organised by a case-manager from the Bobby Goldsmith Foundation, and provided as a complete package in the client's home.
Innovative dimensions	Recognition of the unique challenges faced by people with HIV/AIDS living in the community.
Model of support	Personal support and care funded by DADHC and NSW Health and organised by a non-government case manager.
Key principles	Enabling people with HIV/AIDS to maintain independent life while providing them with necessary care and support.
People supported	People in NSW with HIV/AIDS who have challenging behaviours such as mental illness (either associated with HIV/AIDS or not), addictions and are homeless or are at risk of homelessness. The program currently provides up to 20 living units for clients in metropolitan Sydney. Excluding their HIV diagnoses, 43 per cent of clients have dual diagnoses and 33 per cent have triple diagnoses.
Benefits and challenges	Good flexibility and individualised planning. Separation of housing and support provides better choice. Privately owned housing could be unstable as tenancy could be terminated by the landlord at any time.
Evaluation	N/A
Contact	James Fraser - james.fraser@bgf.org.au , Leila Barreto - leila.barreto@bgf.org.au

Good Neighbour Program, Western Australia

Overview	A community living model providing individuals with disabilities with subsidised, independent housing, leased by a community housing organisation from HomesWest, as well as low levels of support and supervision, as necessary, from other tenants who received subsidised rent in return for their support.
Innovative dimensions	Quasi-informal support and good community integration for people with disability.
Model of support	A tenant without a disability living in the housing complex provides assistance to tenants with disabilities in pre-negotiated areas and basic supervision.
Key principles	The program aims to facilitate community integration and social ties while providing necessary support.
People supported	The program supports people with low levels of support needs in several different areas across Western Australia.
Benefits and challenges	Facilitating higher levels of independence and preventing institutionalisation for people for people whose personal support needs are low. Encouraging community integration. Not suitable for people with high personal support needs.
Evaluation and research	Bleasdale (2006) mentions that program users and service providers he interviewed mentioned the program as highly successful and helpful in maintaining independence and fostering community ties. Bleasdale also mentions, however, that the program is in a process of change with the service component becoming more formalised.
Contact, refs	N/A

Generic models for 24-hour supported living

In addition to accommodation models designed specifically for people with disability, policy lessons are also available from innovative models of for other people with complex needs, including some people with disability. They are generic alternatives to disability specific services. Some of the services are not suitable for people with high support needs, but experience of these models can be generalised to the development of disability specific accommodation support. Disability policy can also learn from the experiences of accommodation support to address the additional support needs for people previously institutionalised for other reasons, such as people formerly in corrective services (Willis, 2004) or mental health facilities (Muir et al, 2007). These groups of people are included in the examples below.

Matavai Ageing in Place Initiative, Waterloo, NSW

Overview	A program aimed at existing residents of a public housing complex whose support needs have grown, mostly due to ageing. Clients were moved into the top floor of their existing public housing complex, which was converted into 7 one-bedroom self-contained units, with a communal area between them. Support is provided by pooling together the services residents are entitled to through their individually assessed Commonwealth Aged Care Package into one communal support package.
Innovative dimensions	Maintaining almost the same residence while receiving more comprehensive support.
Model of support	Support is provided by contracted carers through the CACP and the communal package offers 12 hours of care a day, with meals and social activities included.
Key principles	Ageing in place is important in order to maintain independence. The program also focuses on community living and peer connections.
People supported	Seven people are currently supported on the top floor of one of the Matavai public housing towers in Waterloo. The program is currently aimed at elderly people.
Benefits and challenges	Higher levels of care and supervision than would be available with an individual CACP. Ageing in place diminishes the need to adapt to new surroundings. Cost effective method of service provision. Not appropriate for people with high support needs due to possible behavioural problems affecting other residents and neighbours.
Evaluation	N/A
Contact, refs	The Mercy Arms – Ms. Kay Kavanagh, Manager, Cnr Elizabeth & Raglan Streets, Waterloo, (PO Box 63 Waterloo), Ph: 02 9310 1201, Fax: 02 9310 3123

Port Jackson Supported Housing Program, Sydney, NSW

Overview	An initiative of the NSW Department of Housing, the program offers affordable, stable housing and tailored support packages for people in need of both. The project assists people in such need to attain subsidised housing from social housing and market sources and provides necessary support through one of 23 registered support partners.
Innovative dimensions	Connecting the housing and support needs of people with special needs in a community setting, promoting independent living.
Model of support	Admission into the program is restricted to people who have been approved for a support package from an external provider and they continue to receive case management as well as individualised services such as personal care, counselling and employment services.
Key principles	The program is focused on facilitating and encouraging independent community living for people with special needs. The program ensures that housing is an integral component of the overall assistance package provided for each client.
People supported	The program is targeted at people with special needs such as homeless people, people with mental health issues, people with drug and alcohol issues and people with disability. The managing authority, St. George Community Housing currently administers 80 properties, planning to increase to 211 over time.
Benefits and challenges	Promotes independence while maintaining support services to facilitate social inclusion and rehabilitation where possible. Limited places are offered, restricted by availability of suitable housing. Not suitable for people with high levels of needs and generic housing may be unsuitable for people with physical disabilities.
Evaluation and research	NCOSS (2006) argue that without increased funding for public and community housing, such a program could affect availability of housing for other people needing social housing.
Contact, refs	Liza Sloan, Senior Housing Manager, St. George Community Housing: 9585 1499

Crisis Accommodation Program Innovation Initiative, State-wide, NSW

Overview	A transitional service helping people who have been through crisis accommodation (The Supported Accommodation Assistance Program) make a successful move into long-term housing. The program provides subsidised medium-term housing from a community housing provider and in-home support through SAAP outreach services for a period of 6-9 months. Rent is subsidised by DoCS for the duration of the program and the client may stay in the property as a resident of the community housing association.
Innovative dimensions	Helping people back into stable long-term housing, as a smooth transition from crisis accommodation.
Model of support	In-home support and living skills training is provided based on an individual support plan, mostly provided by contracted non-governmental organisations.
Key principles	The program aims at encouraging and facilitating independence and transition into stable community living.
People supported	The program is available to people who have used crisis accommodation - People who are homeless, escaping domestic violence, or have other special needs.
Benefits and challenges	Facilitating a smooth transition from short-term to long-term accommodation. Less moving is necessary due to the possibility for maintaining residency after the conclusion of the program. Helpful linkages between support services and accommodation with a support plan. Not suitable for people with high levels of support needs and generic housing may not be suitable for people with physical disabilities.
Evaluation and research	NCOSS (2002) mention a 2000 evaluation of the program which supported its continuation. The evaluation noted, however, the lack of community housing stock as a factor limiting the size of the program and affecting other people in need of community housing.
Contact, refs	N/A

Housing and Accommodation Support Initiative, State-wide, NSW

Overview	A program funded through the NSW departments of Housing and Health, providing individualised support and long-term accommodation packages for people with mental health issues. The program provides housing through social housing and accommodation support through a case management model from contracted non-governmental organisations.
Innovative dimensions	Providing long-term community housing and support services in order to help maintain stability despite changing needs. The program varies in the level of support to match different levels of need.
Model of support	Case managers tailor individual support packages providing services such as psychiatric assistance and personal care where necessary.
Key principles	The program is aimed at facilitating long-term stable community accommodation in generic settings and reducing hospitalisation.
People supported	The program supports 686 people in the three different ‘stages’. The program is targeted at people with mental health issues with different levels of support needs.
Benefits and challenges	Promoting independence and facilitating stability through recognition of changing needs. Possible lack of meaningful community integration and peer relationships.
Evaluation and research	An SPRC evaluation Report (Muir et al 2007) showed high levels of housing stability and decreased hospitalisations, as well as high levels of satisfaction among clients, at a low per client cost compared to institutionalised care.
Contact	NSW Health, ph (02) 9391 9830, Fax (02) 9391 9041

Private Rental Brokerage Service, State-wide, NSW

Overview	A NSW Department of Housing program aimed at helping people with complex needs secure private market-based housing (or community housing) and facilitating stable tenancy through support services. The program provides coaching and advocacy for attaining and maintaining private tenancy as well as individualised support packages.
Innovative dimensions	Providing accommodation support in generic housing solutions.
Model of support	Support is provided and managed by a contracted provider. Support services include personal assistance and other services as necessary.
Key principles	Fostering independence and community living as well as rehabilitation and long-term stability.
People supported	The program is aimed at all people needing some level of assistance in order to maintain stable residency, such as people with substance abuse issues, mental health issues and people with a disability that requires low levels of care. In April 2006, 433 clients were being supported in the private rental market and 48 in community housing. An additional 91 were receiving assistance for finding suitable accommodation.
Benefits and challenges	Reducing the stress from the social housing system and widening the pool of available housing. Not suitable for people with high levels of support needs.
Evaluation	N/A
Contact, refs	NSW Department of Housing General Enquiry Line 1800 629 212 www.housing.nsw.gov.au

Housing Support for the Aged Program, Statewide, Victoria

Overview	A state-based program providing support for maintaining public housing tenancy and improving overall health and wellbeing for people aged 50 year and over with complex needs and history of homelessness. The program provides ongoing case management to people entering or already living in public and community housing, planning and organising support services, supervision and counselling.
Innovative dimensions	Support and case management for maintaining successful long-term tenancy, available in current housing if at risk of homelessness.
Model of support	The program offers low level monitoring, case management for planning and organising access to necessary specialist support services, help setting up appointments for health care services and crisis assistance including short term funding.
Key principles	Maintaining independence, health and wellbeing as well as tenancy stability.
People supported	13 HSAP services in different regions support between 20-25 people each. Clients are all aged 50 and over and typically have a history of homelessness and/or complex support needs associated with the conditions such mental health issues, drug and alcohol dependence, age-related frailty or disability.
Benefits and challenges	Preventing residential placement or homelessness for people with complex support needs. Low levels of supervision would not be suitable for some people with disability with high levels of support needs.
Evaluation	N/A
Contact	Page with contact details of all HSAP service managers: www.health.vic.gov.au/agedcare/services/lowcost/housing.htm

Sandridge Program, Melbourne, Victoria

Overview	A temporary accommodation support service for young people with a history of homelessness aiming to develop stable, long-term tenancies through a specialised support and accommodation program. The program is funded through the SAAP and provided by Richmond Fellowship Victoria.
Innovative dimensions	Temporary accommodation support while providing life skills and support services to facilitate future independent accommodation stability. Focus on young people. Different streams of support for different needs.
Model of support	Accommodation support is provided in two residential settings – one a 24-hour staffed residential facility and the other a block of ten single bedroom flats. Support is provided in a holistic program including life-skills and crisis education as well as counselling and necessary specialist support.
Key principles	Breaking the 'cycle of homelessness' and providing homeless young people with the skills to maintain independent living.
People supported	The program is aimed at homeless people between the ages of 18 and 25 who have experienced significant trauma, abuse or neglect.
Benefits and challenges	Holistic life skills education may prevent future occurrences of homelessness in clients and accommodation takes homeless people away from their current situation. A focus on homelessness means the program is only suitable for people in particular situations.
Evaluation	N/A
Contact, refs	Sandridge Program, 71 Heidelberg Road, CLIFTON HILL VIC 3068, PH: (03) 9489 3378, FAX: (03) 9482 3357, EMAIL: sandridge@rfv.org.au

Summary

Current approaches to disability accommodation support in Australia focus on both small residential settings, most commonly staffed group homes, and home-based support service provision. In relation to support services, the trend is towards individualised funding and service provision, as evident in many of the models above. Many innovative models, both residential and home-based, provide case management and individually planned support services that provide the services necessary for the person and changing needs of the person supported.

In relation to accommodation settings, the trend is towards minimisation of size of setting, both physically and in relation to the number of people accommodated in each setting. This, in conjunction with the emphasis on community integration in disability policy, has promoted the trend towards independent community living and generic housing where possible.

2.3 Comparative Research and International Arrangements

In a comparative analysis of supported accommodation arrangement for people with an intellectual disability, Braddock et al (2001:115) found Australia, the US, Canada and the UK have all seen a general shift towards smaller community-based settings with a similar number of people with an intellectual disability residing in group homes across each country (43–47 per cent of all people with disability). When Australia is compared with the UK or USA, these latter countries have between 22 per cent and 71 per cent more places per person than Australia, signalling that the current rate of growth for accommodation support in Australia seems unlikely to meet the increasing demand (Stancliffe, 2002).

Mansell (2006: 65) found that while there has been substantial progress in people living in the community in liberal welfare states, it is the Scandinavian countries (e.g. Norway and Sweden) that are deemed to be the leaders in the deinstitutionalisation process. In these countries, all institutional provision has now been replaced. In other European countries (e.g. Belgium, Germany, Spain, Greece and the Netherlands), existing institutional care still dominates despite some alternative community living arrangements (Mansell, 2006).

Even in countries where large institutions have been replaced with group homes, it is now widely recognised that there remains a considerable problem with any 'one size fits all' policy founded on the provision of group homes. Developments in the UK, Ireland, US, Canada and elsewhere suggest possible solutions to this problem lie in a combination of increasing the individualisation of funding allocations, increasing the flexibility of potential living arrangements in ordinary housing dispersed within the community and having a more rigorous performance management of services based on the actual outcomes to be achieved for people with disability (Emerson, 2006). These issues are discussed in relation to Australia in more detail throughout this report.

Approaches to 24-hour support – United States

The provision of services to people with disability in the United States is a complex interplay between historical and contemporary forces, including competing interests of people with disability, their families, unions, service providers and professionals as well as politicians, officials and the dynamic economies of the states and nation.

The bulk of the nation's $109 billion commitment to long-term residential care for people with disability supports institutional care, including nursing facilities (Braddock, 2002). However, overall spending on services for people with intellectual disabilities focuses on community services (65 per cent of the total $38.55 billion in 2004), with only 20 per cent going towards institutional services (Braddock et al., 2005).

The majority of people with disability live at home and receive personal assistance, close to 75 per cent of which is provided by unpaid, informal carers (US census, 2006). Many of those who do receive paid assistance do so in conjunction with some form (and level) of unpaid care (Freedman et al., 2004). As of 2004, only 11 per cent of the estimated 4.6 million people with intellectual disabilities in the United States live in supervised residential settings (Braddock et al., 2005).

Nursing homes are commonly used as an option for supported living, although 90 per cent of residents (as of 1999) are over the age of 65 and have disabilities that are age-related. In 2004, 30,987 people with intellectual disabilities were housed in nursing facilities, representing 6 per cent of the total number of people with intellectual disabilities housed in residential settings. In 2004, 68 per cent of the 494,277 people with intellectual disabilities in residential settings were housed in settings with 6 or fewer residents, most commonly group homes, but also supported and supervised community living arrangements (Braddock et. al., 2005). The primary response to people requiring high levels of care (and without access to informal care) is relocation to staffed accommodation settings (Bridge et al, 2002).

A current trend in disability support is the shift towards 'consumer directed' support programs, involving mainly individually negotiated and/or directly purchased personal assistance services tailored to the needs and preferences of the person with a disability. Most such services are funded through Medicaid, which is a limited medical insurance program aimed at low-income earners, and is means-tested. Doty and Flanagan (2002) argue that although the philosophy of 'consumer-directed' support has gained acceptance, and almost all states offer at least one such program, program users make up a small minority of people with disability who receive assistance. They estimate the number at 486,000 people using 139 programs.

Support programs for people with disability in the United States are generally means-tested and aimed at low-wage earners who would not be able to maintain basic levels of quality of life without government help and are viewed as part of the welfare system. Viewed as a safety net against poverty caused (and/or furthered) by the disability, disability support programs are also focused on retaining employment when possible, for economic as well as empowerment and integration purposes, rather than continued income-transfer (Burkhauser & Daly, 2001). Despite the high levels of people with intellectual disabilities being supported at home by family carers, only 6 per cent of spending on services for people with intellectual disabilities is directed towards family support, supporting a total of 399,337 families (Braddock et al., 2005).

Three examples of models for accommodation support in the United States are described below. They illustrate current directions in US accommodation support policy towards community integration and semi-independent living.

Department of Housing and Urban Development Multifamily Housing program, Federal, U.S.A

Overview	A federally funded program established in 1988, administered by nongovernment organisations, for providing affordable public/private housing for people with disability and their families in an environment that includes formal support services contracted by state or local authorities. The DHUD (US Federal Department of Housing and Urban Development) provides interest-free capital advances to NGOs seeking to build low-cost housing with available support services. The DHUD also provides rent assistance to residents in order to further subsidise the housing.
Innovative dimensions	Enabling and encouraging people with disability to live as independently as possible and to remain with their families in affordable housing.
Model of support	24-hour supervision and support services including case management and healthcare available to people with disability, in addition to ensuring their retention of affordable, long-term accommodation.
Key principles	Enabling and encouraging independence and community living. Preventing unnecessary and unsuitable institutionalisation for the purposes of personal rights as well as cost effectiveness.
People supported	Housing is available to adults with disabilities or aged people defined as 'very low income earners' and their families. 365,000 such people are currently accommodated in multi-family housing.
Benefits and challenges	The program provides a good long-term solution for people needing accommodation support, ensuring stability and affordability as well as supervision. Only very low income earners are eligible for the program and service and supervision is not required to be comprehensive or professional.
Evaluation	N/A
Contact, refs	www.hud.gov/offices/hsg/mfh/mfbroch/hubs_pcs.cfm www.hud.gov/offices/hsg/mfh/progdesc/disab811.cfm www.udeducation.org/resources/readings/welch.asp

New Hampshire Self Determination Project, New Hampshire, U.S.A

Overview	A state-based program focused on the administrative side of the client-government relationship. Working to affect a shift in administrative practices towards more individualised and person-centred planning and service provision including both formal and informal care. Enabled by a grant from a health-care foundation and continued with the support of the state government, 'Learning stakeholder' workgroups were established with participants including people with disability, family members, carers and administration professionals in order to develop administration and planning practices based on the principle of self-determination.
Innovative dimensions	Including all levels of stakeholders in the development of administration practices and a focus on best-practice standards in person-centred planning.
Model of support	Services administered include all levels and types of support necessary for the person, including personal assistance and community integration.
Key principles	Focusing on the principles of self-determination and empowerment through cooperation and integration. Encouraging a shift from 'program-driven services' to 'consumer-directed supports'
People supported	Both adults and children (and their guardians) with disabilities necessitating all levels of support.
Benefits and challenges	Constant cooperation and revision of practices ensures constantly evolving standards and an ability to maintain the person-centred focus of the program and administration practices. Systemic change is difficult to establish and can be costly to update. Not all stakeholders involved are equal participants in the process due to lack of access to necessary information and technology.
Evaluation and research	Lord and Hutchinson (2003) mention the constant evaluative nature of the program as well as the annual program-wide evaluations, which have found the program to be successful in increasing the level of satisfaction and control for people with disability. The evaluations were conducted using specially formulated tools also created in the process.
Contact, refs	www.unh.edu/rwj/index.html Lord & Hutchinson (2003) www.unh.edu/rwj/states/nh.html www.rwjf.org/programareas/resources/grantsreport.jsp?filename=027576.htm&pid=1144

Home Based Support Services Program, Illinois, USA

Overview	A state-based program providing individualised budgets for adults with intellectual disabilities living at home and their parents. The program is intended to prevent out-of-home placement for people with intellectual disabilities by enabling them and their carers to access services that will remove strain from informal carers (generally parents) and encourage community integration.
Innovative dimensions	People and their families receive cash payments in lieu of services and purchase preferred services based on their own needs.
Model of support	Services are purchased directly by guardians of people as necessary from a stipend paid by the state. Frequently purchased services include respite care, personal assistance, home modifications, employment services and transportation.
Key principles	The program is aimed at normalising the life-course of people with intellectual disabilities and encourages community living and family participation.
People supported	The program provides means-tested funding for people with intellectual disabilities living with their guardians and receiving a mixture of formal and informal care. As of 2004, 1,436 families were receiving the benefit, with 1,632 on the waiting list (Caldwell, 2006).
Benefits and challenges	Individualised funding and needs-based service purchasing facilitates community living and helps alleviate the hardships faced by guardians of people with disability. Very long waiting lists due to high demand for the program and lack of funding have made it hard to access for many people.
Evaluation and research	Caldwell (2006) evaluated the effect of the program on levels of out-of-home placement as well as satisfaction of both people with intellectual disability and their families. In a 10-year study he found that the program indeed decreased instances of out-of-home placement (as compared with families on the waiting list) and resulted in increased levels of satisfaction among the people and their families.
Contact, refs	Family Assistance/Home-Based Support, 405 William G. Stratton Building, Springfield, IL 62765-000, (800) 843-6154, ext. 3, option 1, Fax: (217) 782-9535, Dhsdb09@dhs.state.il.us, www.he.net/~altonweb/cs/downsyndrome/index.htm?page=ilresources.html

Summary

Although still heavily reliant on medium and large-scale residential living arrangements, especially for people with intellectual disabilities, disability accommodation support in the United States is moving towards deinstitutionalisation. The current direction of disability service provision in the United States, as evident in the above models, is consistent with international trends towards increased in-home support and community support. The most common models of formal support are still residential solutions, both small and large scale.

All of the models mentioned above are aimed at increasing self-determination and community living by providing sufficient levels and type of support needed in a community setting – either promoting living at home with parents or other carers or in suitable community housing. The USA trend is away from generic disability support services. This is evident in the fact that all of the models feature individualisation of support services and planning in order to provide support that is best tailored to the person's needs.

Approaches to 24-hour support – United Kingdom and Europe

In the United Kingdom, old and new models of supported living arrangements co-exist. The vast majority of children with learning disability live with their own families, although a small percentage live in residential services, including educational establishments. Just under two-thirds of adults with learning disabilities

live in private households, most of them with their families, with the remainder living in some form of communal residential establishment. The deinstitutionalisation of people with intellectual disabilities has been a central tenet in the process of reforming disability support services in Britain, with the number of people living in 'mental handicap hospitals' in the UK dropping to just over 1,500 people by the end of 2000. More people with intellectual disability, however, still live in conventional nursing homes (3,837 as of 1999) (Braddock et al., 2001).

The availability of different housing options varies geographically, but includes: registered care homes; shared housing; cluster housing or bed-sitters (self-contained units usually on a single site but occasionally dispersed across a neighbourhood); adult placements or adult fostering schemes; rental and home ownership (Hanneman and Blacher, 1998; UK Foundation for People with Learning Disabilities, 2001; UK Department of Health, 2005). These housing options are sometimes supplemented by accommodation support, variously available through specialist disability services; mainstream accommodation and personal support; and contracted services, which are increasingly available through the flexibility of budget holding. People with the greatest need for assistance usually receive care in the poorest setting, such as institutions. However, the trend to individualisation in supported living has translated into better services and offers a means of re-structuring past models.

In 2004, 80 per cent of people with learning disabilities in England were living in the community. Group homes have been identified as the most common solution for housing and 24-hour support, housing 62 per cent of people with learning disabilities who were living in supported accommodation. Only 3 per cent were living in National Health Service Hospitals (Emerson, 2004; UK DoH, 2005). Support services for people with learning disabilities are mostly provided by a family member (59 per cent) or other informal carer (4 per cent), with the rest being provided by paid workers, mostly contracted and/or funded by the government (UK DoH, 2005).

Since 1997, a central feature of the British model for the provision of support services for people with a disability has been direct payments. An outcome of disability advocacy groups' calls for empowerment and consecutive British governments' commitment to the transfer of social services into the private sector, local authorities have, since 2001, been required to offer, and encourage the take-up of, direct payments in lieu of services. Such services are instead purchased directly by the recipient with the payments. Direct payments recipients are still, however, a small minority (less than 2 per cent as of 2003) among recipients of disability support services (Riddell et al, 2005). Direct payment programs are also available in several European countries including The Netherlands, Italy and Austria, with varying levels of universality, funding and restrictions (Ungerson, 2004). The welfare states of central and southern Europe such as Germany and Italy remain focused on informal and community-based care, many times merging the two. Direct Payment programs in Italy have been noted as encouraging a formalisation of family and community care arrangements due to the lack of restrictions on the use of the direct payments (Ungerson, 2004).

Current spending (as of 2004) on disability benefits, both in cash transfers and in services, among European Union member states is Euro 220,753,000,000, making up 8.1 per cent of total expenditure on social services. 41 per cent of this funding goes to disability services – 65.3 per cent to accommodation services and the rest going to

support services (10.3 per cent), rehabilitation and other disability services (Eurostat, 2007).

In Sweden and Norway, all institutional provision of care and accommodation has been abolished in favour of community living, which has been enshrined as a right in law. The most widely utilised method of support in these is small-scale staffed residential accommodation (e.g. group homes, cluster-housing) with 0.4 per cent of the population under the age of 65 in Nordic countries (Sweden, Denmark, Finland and Norway) being supported in such settings (Emerson, 2004; Hvinden, 2004).

Examples of innovative models of accommodation support in Europe, particularly the UK, are described below. They illustrate the policy preference for consumer-directed and individualised services among European governments.

Sheltered Housing project, National, UK (example used: Leicester City Council Supported and Sheltered Housing)

Overview	A national initiative, administered by local authorities, for housing people with disability (mostly those over 50) as well as frail aged people in small scale housing community cooperatives with small living units (mostly 1 bedroom) based around a communal area offering amenities such as kitchen and lounge room. Sheltered housing offers supervision and personal assistance at different levels (in different housing complexes) based on the needs of the person, while helping them maintain independence and a normalised lifestyle.
Innovative dimensions	Balances the dual needs of people with disability for independent living and support. The program offers an individual living space and community integration while ensuring the health and safety of people with disability.
Model of support	The support dimension of the program differs widely from one housing complex to another. Leicester City Council, for example, offers 20 ‘sheltered and supported’ housing complexes, some of which only provide daily contact with a supervisor while others provide personal assistance for people with medium to high needs.
Key principles	Independence and peer community integration are important principles, backed up by individual needs-based planning and a focus on protection and assistance when necessary.
People supported	Most sheltered and supported housing complexes offered through Leicester City Council are open to people over 65 (or those over 50 with a disability) although some support people of different ages and families.
Benefits and challenges	Encouraging high levels of independence and community integration while maintaining peer solidarity and support as well as professional supervision.
Evaluation and research	Most research regarding sheltered housing does not mention people with disability directly, but rather focuses on aged residents in general and has found high levels of satisfaction and independence.
Contact, refs	www.leicester.gov.uk/your-council--services/housing/supported-and-sheltered-housing, www.direct.gov.uk/en/DisabledPeople/HomeAndHousingOptions/SupportedHousingSchemes/DG_4000295

Direct Payments program, National, UK

Overview	Currently being promoted as a central method of individualised service funding for people with disability in the UK, direct payments offer cash payments transfers to people with disability or their guardians in lieu of directly provided or contracted services. Recipients' needs are assessed and a corresponding level of funding is decided upon, with which the recipient purchases any services they prefer. Recipients decide the level, type and provider of the services and take on the responsibility of administration of the services.
Innovative dimensions	Transferring almost complete control of support services from administration professionals onto the person in order to provide them with exactly the help they need and prefer is seen as very empowering for people with disability.
Model of support	The recipient purchases the support they prefer and may choose from any model available on the market (apart from paying a relative living with them). A common model is support from one-on-one personal assistants providing personal care as well as general assistance (e.g. housekeeping, transport), in a quasi-informal care arrangement
Key principles	Empowerment and equalisation of the social position of people with a disability with that of the general populace. Completely individualised support planning.
People supported	Less than 2 per cent of people receiving some type of disability support purchase it through direct payments, although raising this to a more substantial proportion is a central objective of the Department of Health. Since 1999, the program has been open to any person in the UK with disability support needs.
Benefits and challenges	Empowerment for people with disability and better satisfaction due to individually tailored care models as well as a more cost-efficient way of deliver services. Possible far reaching effects on the welfare state due to complete privatisation of welfare services. Complex high-level administration changes. Transferring responsibility onto the person may also transfer risk if mistakes are made or plans fail, possibly due to complex administration requirements.
Evaluation and research	The concept of direct payments in general, and the British model in particular, are a focus of much social research and researchers have found both higher levels of satisfaction and quality of life for direct payment recipients, but also reasons for concern for future equity of service provision.
Contact	www.direct.gov.uk/en/Hl1/Help/ContactUs/ContactUsForm/index.htm

Persoonsgebondenbudget (PGB) – Person Centred Budget, National, Netherlands

Overview	A national direct payment system providing cash payments to people with disability in lieu of the services as necessary. Recipients receive an individually calculated monthly allowance to purchase services on the open market or from an informal carer. Recipients decide the type, level and provider of care that they prefer and take responsibility for administration of the funds and accountability to the government.
Innovative dimensions	Empowerment and individualised services for people with disability with an opportunity to recognise and enable the continuation of informal care, thus maintain stability for the recipient.
Model of support	Users create their own model by purchasing any service covered by the program (ADL and IADL support). The most common type of service purchased by recipients is personal assistance either from an existing informal carer or an unprofessional private carer.
Key principles	Independence and individualised support services in order to empower people with disability.
People supported	The program is currently available to all people with a disability and has grown since the removal of a cap on the proportion of funding that was available to it from the disability services budget. In 2004, nearly 70,000 people received at least some services through direct payments.
Benefits and challenges	Higher levels of independence and individualisation of services promote greater satisfaction with support. Low administration costs and enterprising recipients make the program a cost-efficient way of providing services. Possible wide-reaching consequences for welfare provision equity due to privatisation of services. Complex administration requirements may discourage innovative support models.
Evaluation and research	Several studies evaluating the program have found higher levels of satisfaction, quality of life and independence among recipients. Research has also shown, however, that the private small-scale care market that is necessary for recipients to purchase care services has not developed as expected and this heavily constricts the level of choice in services that is available to recipients.
Contact	

Summary

Most European countries are committed to encouraging independent living and reducing the size and clinical nature of residential facilities. This is done with the goal of safeguarding the civil and social rights of people with disability and encouraging normalisation through support. A central method of achieving this in several countries, as evidenced by two of the models mentioned above, is direct payment programs, which are aimed at providing people with disability with the tools to take complete control over their lives and live like the wider community with exactly the support they need and prefer in order to participate in society. UK accommodation support models are focused on fostering stable and sustainable community living, especially for those with lower levels of support needs, in order to prevent readmission into residential settings. Current common models of provision in the U.K focus on small residential settings and individualised in-home support. The British Direct Payment program is currently viewed as an innovative way to provide support services. The government is encouraging the take-up of direct payments and making them a more prominent feature of the disability support system.

The lack of uniformity in policy, practice and terminology, especially among European countries, makes comparative analysis difficult, though general trends are discernable. The most recognisable trend in all of the regions reviewed is that of deinstitutionalisation and the rights-based notion of disability support. All countries in these regions have made a commitment to smaller and less institutional residential

facilities and a focus of many countries is promoting the participation of people with disability through encouraging independent community-based living arrangements.

Several European countries, most notably the United Kingdom and the Netherlands, have identified the notion of direct payments as a central method of support provision in the future and have taken steps to encourage its growth and take-up. In Australia and the United States, case-managed, individualised funding is being promoted as an important method of tailoring support to the needs of the person, especially when provided in conjunction with affordable and suitable accommodation. This is seen as a central method of preventing admission (or readmission) into residential facilities, especially for people with low levels of support needs.

Stability and sustainability of tenancy are also seen as important for the wellbeing of the person, and cost effective funding. The notion of individualised, home-based care being revised and tailored to suit the changing needs of people rather than the person moving to a facility where their needs can be better met, has become a focus of many different support methods and aids in creating such stability.

2.4 Summary of Existing Supported Living Policies

Current supported living arrangements can be summarised in two ways: types of housing, that is, where people live (Table 2.2); and accommodation support (Table.2.3). For the purpose of this summary, housing types are categorised by who owns or provides the housing. Accommodation support is categorised by type of support and who organises, provides, funds, manages the funds and provides the support. They include both generic and specialist services and market arrangements.

These tables include the common current arrangements. They include arrangements that do not address the goals of supported living policy discussed in the following Section 3. An example is types of congregate housing, which are not pursued in current policy directions, but which still house a significant number of people with disability.

Table 2.2: Housing Types by Owner or Provider

Owner or provider	Place where people with disability live
Person with disability	Own property
	Shared equity
Family or friends	Live with family or friends
	Live in family or friends property
Private	Rental property alone or shared
	Licensed residential facilities
	Unlicensed boarding houses
Housing departments and community housing	Public or community housing
	Disability housing
Disability departments	Individual homes
	Group homes
	Clustered accommodation
	Institutions
Disability NGOs	Individual homes
	Group homes
	Clustered accommodation
	Institutions
Other NGOs	Licensed residential facilities
Health departments	Residential mental health services
Other state departments	Out of home care (child protection, shared care, foster care)
	Corrective services
Federal departments	Residential aged care
Other	Homeless and refuge housing

Table.2.3: Source of Accommodation Support by Function in Support (Organiser, Funder, Funds-holder or Provider)

Source of accommodation support (person or agency)	Function of source of support			
	Organise support eg. case management	Provide funding	Funds-holder	Provide support
Person with disability	self-managed	self-funding	direct payment	-
Family or friends	informal	informal	direct payment on behalf of PWD	informal
Private	yes	-	-	private market
Housing departments and community housing	yes	yes	yes	yes
Disability departments	yes	yes	yes	yes
Disability NGOs	yes	-	yes	yes
Other NGOs	yes	-	yes	eg. SAAP
Home and Community Care (HACC) – federal/state/NGO	yes	yes	yes	yes
Health departments	mental health	yes	yes	mental health
Corrective services departments	yes	yes	yes	yes
Federal departments	-	eg. Disability Support Pension; rental assistance; aged care; care packages eg. CO, CACP	-	aged care

Note: Accommodation support to meet support functions as needed: e.g. financial; skills development; safety, medical, personal, home and community care; transport; participation; transition support.

3 Goals of Supported Living Policy

The goals of supported living policies are based on three principles that inform the current development of disability policy. First, like other citizens, people with disability want equal choice, freedom and control over their living arrangements, including where they live, who they live with and who provides support to them. For most people with disability this means informal support from family and friends while living in the community, supplemented with formal support or housing where necessary.

Second, governments are reorienting disability accommodation support policy towards prevention and early intervention and away from crisis responses or relative need. The implication is that policies aim to be responsive to people's changing support needs and preferences in the community context in which they live or in which they would prefer to live. The benefits of this principle are both to improve quality of life outcomes for people with disability and the people who support them and also to improve resource efficiency for government.

Third, governments are moving towards individualised service provision, consistent with the other two principles. This approach has implications for provision of all forms of accommodation support, including access to generic and disability specialist housing and support services. Service planning becomes based on what is most appropriate for a particular person's changing support needs and personal preferences.

In the context of these principles, for most people with disability, many past accommodation models do not meet either people's preferences or government principles of service provision. This includes most group care models. This section introduces the four goals of achieving human rights, improvements to quality of life, independent living and cost effectiveness as the context for evaluating the facilitators and barriers to positive experiences of supported living in the next section.

3.1 Human Rights

Under the binding International Convention on Social, Economic and Cultural rights (ICESCR) (United Nations, 1966), people with disability have the right to an adequate standard of living, which entails the fulfilment of basic material needs. Article 11 in the ICESCR affirms:

> the rights of everyone to an adequate standard of living for himself and his [sic] family, including adequate food, clothing and housing, and to the continuous improvement of living (UN, 1966a).

The right to housing and accommodation support is of particular importance to people with disability as it facilitates participation in wider political, social, economic and cultural spheres of society (Parker, 2007a). One of the barriers to achieving housing rights has been the absence of a universally recognised definition of the set of entitlements comprising this norm. General Comment No. 4, of the Committee on Economic, Social and Cultural Rights (CESCR), on the Right to Adequate Housing defines this right as being comprised of a variety of specific concerns. These include: (i) legal security of tenure; (ii) availability of services, materials and infrastructure; (iii) affordable housing; (iv) habitable housing; (v) accessible housing (vi) location; and (vii) culturally adequate housing. CESCR (1991) argue that these extensive entitlements reveal some of the complexities associated with the right to adequate

housing. They also show the many areas that must be fully considered at the national level. Any person, family, household, group or community living in conditions in which these entitlements are not fully satisfied, could reasonably claim that they do not enjoy the right to adequate housing as enshrined in international human rights law.

While history has demonstrated a clear shift in attitudes about and policies for people with disability, poor access to accommodation support remains a barrier to fulfilling basic citizenship rights for some people with disability (Parker, 2006). Internationally, people with disability have called for a focus on getting community living 'right', and implementing strategies so that people with disability can lead full and independent lives (Bigby, 2004; DRC, 2006). Some positive shifts have been made, with a paradigm shift away from professional control towards an emphasis on self-determination and community involvement. In some countries, the availability of an individual budget, control over services and decision making, using a person-centred planning and independent support brokerage are measures which have increased self determination for people with disability (Epstein-Frisch et al, 2006).

However, large gaps between policy principles and policy practices remain when it comes to ensuring full and equal participation for persons with a disability. In Ireland for example, although official rhetoric promotes human rights principles, there is a pervasive and fundamental marginalising and disempowerment of people with an intellectual disability (Burton, 2002). Similarly in Australia, human rights are not met for people unable to access the support they need. Examples include the high numbers of young people with disability still living in aged care facilities (FaCSIA, 2007) and the large unmet demand for accommodation support (AIHW, 2003; AIID, 2006). Access to support is aggravated for Australians due to the federal system that restricts portability of disability accommodation support between states and territories (WWDA, 2005). This creates further barriers to equality for people with disability.

Human rights form the conceptual framework for the other three goals of supported living, which cannot be read independently of this first goal.

3.2 Quality of Life

Improving quality of life is considered to be one of the most important goals of disability policy, particularly in the area of service provision. In Australia, quality of life is recognised as an important goal under the Disability Services Act (DSA) (1986). The DSA was introduced in response to community calls for urgent and fundamental reforms in the area of service provision for people with disability. The Government of the day argued that it enables a more flexible range of support services to be provided to people with disability, for example, in the areas of accommodation, employment and community participation (Commonwealth Government of Australia, 1998). The DSA promotes the notion that people with disability had a right to enjoy the same rights that all members of Australian society enjoy, for example, the right to respect, dignity, development, quality of life, choice, the least restrictive alternative and the pursuit of grievances. The principles also promote the achievement of outcomes such as competence, self-reliance and participation in the community (Commonwealth Government of Australia, 1998). In addition, the Act combines with existing systems to improve the quality of services received (DSQ, 2007). Felce (2000) argues it is important that policy principles and practice pertaining to

supported accommodation and services are measured in terms of the quality of life of the individual service user.

In terms of supported living arrangements, when compared to institutions, community-based living offers better possibilities for good quality of life of people with disability (Young, 2006). Community-based living has been found to offer improved community access, self-determination and wellbeing, and offer more opportunities for interaction and increased input into house decision, which contributes to increased improvements in self-care and domestic skills. In addition, people using semi-independent living options experience greater benefits that people in group homes, for the reasons described below and in Section 8 (Stancliffe & Keane 2000).

Community-based living offers better opportunities than institutional care to increase social networks and interaction with family and friends (Howe et al, 1998; Emerson et al, 2001; Kim et al, 2001; Young, 2006). For most people family is very important, and keeping close to them is considered to be a primary goal in type and location of supported living arrangements. Although family connection is an important goal for people, the level of satisfaction with the way in which services assist people to maintain ties with family varies. Some participants view services as being in place to provide practical support, and importantly, to resource contact and maintenance of relationships between people and their families or other people who are important to them (Stakeholder Interviews, 2007).[1]

Brian receives 24-hour support in a group home. Asked what the best thing about the support he receives is, he nominated the taxi home to see his Mum. (Stakeholder Interviews, 2007).

During interviews, it become clear that different people in the service relationship had differing ideas of how this principle is applied. In Brian's case, his service provider, when interviewed, stated that Brian's mum had to be 'assisted' to develop boundaries, as she was 'too involved'.

Numerous studies undertaken in the UK show that village communities and dispersed housing were found to be more beneficial than residential campuses in relation to quality of life and satisfaction (Emerson et al, 2000). Longitudinal studies mostly showed significant increases in overall adaptive behaviour for people moving into the community (Kim et al, 2001). In relation to funding arrangements from a quality of life perspective, direct support payments are considered to enable the person to be at the centre of their own care arrangements and minimise the reliance on a formal support system where the rosters of staff often end up dictating the opportunities for the person. Similarly, people seem to be better linked to their community when such arrangements exist (DSQ, 2007). However, many people with disability continue to have inadequate levels of support and describe themselves as 'existing' rather than living a quality life (McNamara, 2001). In numerous areas of daily living, people with

[1] Stakeholder Interviews (2007) refer to interviews conducted with individuals with a disability and/or their family members utilising supported accommodation services, as well as the service providers. All names (of individuals and services) have been changed. Summaries of the findings are presented in boxes. Quotes are indented.

disability continue to face marginalisation (Parker, 2007a), such as having a higher vulnerability to abuse and neglect in community and/or institutional accommodation settings. This is particularly prevalent for women with disability (Ticoll, 1994; Frohmader 2002; Dowse 2004).

3.3 Independent Living

Under the UN Convention on the Rights of Persons with a Disability, independent living is defined as the equal right of all persons with disabilities to live in the community. People with disability should have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others, and are not obliged to live in a particular living arrangement. Furthermore, people with disability should have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community (UN, 2006).

Some people with disability are active members of their local communities (Stakeholder Interviews, 2007). In some cases, their comments reflect their use of community facilities, and in other cases, reflect their relationships with people in their community. Interestingly, people with disability using more innovative supports tended to focus primarily on citizenship concepts (e.g. such as relationships and belonging), whereas people with disability living in more traditional support services, such as group homes, talked more about the use of community facilities.

> Anna talks about the importance of the community aspect of the service her daughter uses. There are a lot of social functions, such a pot luck dinners, which are open to all living in the units, and also other people in the broader community. There appears to be an explicit effort to connect with broader community members and family members of people living in the units through these activities.
>
> Zach is very comfortable in his neighbourhood. He has friendly neighbours, and there are no complaints about noise from them. His family try hard to encourage him to be helpful to older neighbours. Sarah has seen an increase in Zach's embeddedness in the community in the last year, which she puts down to his increasing maturity.
>
> Liam goes to the local library, pub and is part of a local basketball team (that has some members with a disability). He also likes going to the beach. (Stakeholder Interviews, 2007)

Burchard (1991) in analysing social integration, found that despite it being a clear policy goal, it was not being achieved in any of the residential settings under analysis (family home, a group home or a supervised apartment). In addition, social activities with non-disabled peers or friends were very infrequent and even non-existent for many people. The prevailing assumption is that any integration has a positive influence of the quality of life of people with an intellectual disability, however Cummins and Lau (2003) argue this assumption is misleading because successful integration is hard to achieve and unsuccessful integration can be more stressful than beneficial. They suggest that the goal of integration should be to create a sense of community and connectedness rather than just immediate physical integration. In addition, Cummins and Lau note that use of objective indicators are problematic in

researching integration, as experiences are subjective. Objective indicators often only record the level of integration, rather than the effects of such exposure. For example, having a sense of 'community' for people with an intellectual disability may be more likely to be found in families or groups of equals, rather than with the wider community.

Achieving community inclusion in spite of challenges requires a holistic solution incorporating housing arrangements, community development, access to mainstream services and facilities, protection of rights and micro-management of support staff to provide the level and kind of support (Bigby, 2004). A number of commentators have noted the benefits of services that move away from options that are linked with a diagnostic category (Ozanne, 2001; Bleasdale, 2006; DFC, 2007). They discuss the benefits of support services that are based on specific support needs, taking into account the whole-of-life of the person, where support is not be based solely by the disability categorisation, but rather according to specific support need. Their research shows this approach to support need contributes to greater independence and self-determination.

Howe et al (1998) note the key criteria for self-determination include the person being able to choose direct house ownership or rental; choice of housemates; having preferences taken into consideration in the development of the support; and making decisions on daily activities. Similarly, McKonkey et al (1994) in their research identified four priorities regarding the preferred living arrangements of people with an intellectual disability: (i) contact with family members, as well as with friends and other relations; (ii) participation in household activities; (iii) access to local amenities; and (iv) having one's own room. Respondents living in group homes and residential home situations commonly mentioned issues of comfort and security afforded to them by the home, and the importance of having activities outside the home. Group homes in the community with up to three people were considered to be the most desirable mostly due to opportunity for independence with the security of staff support.

A number of non-randomised controlled studies report the importance attached to independent living with less restrictive housing and high feelings of 'self-efficacy' being associated with high housing satisfaction levels (Fakhoury, 2002). Burchard et al (1991) found that supervised apartments provided the most autonomy and choice-making opportunities over group homes and family homes. In a comparison between community living and cluster housing, Young (2006) found that while choice-making skills improved for both groups, due to increased opportunities to actually make decisions in community living situations, this group developed significantly better skills in this area. Furthermore, the community group also developed better domestic skills dues to increased participation in household routines, and better social skills dues to more opportunities for interaction with the wider community (Young, 2006). Stancliffe (1997) found that household size (including number of staff) also influenced decision making levels, with smaller groups having more choices.

3.4 Cost Effectiveness

A fourth goal of supported living is cost effectiveness from the perspective of the person using the supported living and the agencies organising it. Researchers disagree about which approaches to supported living are the most cost effective. Some studies have found some correlation between cost levels and outcome benefits in relation to

type of living arrangement (Emerson et al, 2004), whereas other studies have found no significant difference in the cost of the different methods of support (i.e. supported living and traditional residential services) (Howe et al, 1998). Extensive US studies of costs and outcomes of deinstitutionalisation (e.g. Eidelman et al, 2003) reveal a consistent pattern across states and over time of better outcomes and lower costs in the community. However UK cost studies indicate that community services are more expensive than institutional services. The contrast between US and UK research demonstrates a stark difference in the nature of support provided to and outcome achieved by people with intellectual disability who live in campuses, villages and dispersed housing schemes (Epstein-Frisch et al, 2006:6; Stancliffe & Lakin, 2005).

Various government departments across Australia note that individualised packaging of supported accommodation (particularly for high needs clients) is expensive, and when compared to group homes, the latter is considered to be far more cost efficient. Depending on how the group home is operated, it can facilitate people having input into their own lives, within a reasonably resource efficient environment (Stancliffe, 1997). Equally, having a combination of supports can also be far more cost effective than formal funding requirements for traditional group home and institutional supported arrangements (Government Interviews, 2007).[2] In contrast to the experience of some Australian officials with the costs of group homes, Stancliffe and Keane (2000) found staff support costs were substantially higher in group homes (compared with semi-independent arrangements), not just in terms of financial cost but also in achieving positive outcomes for people. As well as the immediate quality of life benefits, the Australian Institute on Intellectual Disability (AIID) (2006) argue that achieving positive outcomes for people with disability can be seen as beneficial from a cost perspective as over time because it lowers community costs.

Heywood (2001) found that adaptations to housing structures were the most cost efficient, but only if undertaken correctly. Some of the key reasons why major adaptations had not been successful include: professional failing (e.g. not listening to needs); institutional and structural barriers (e.g. inadequate funding and staffing levels); confusing legislation; focusing on outputs rather than outcomes; and philosophical issues including the persistence of the medical model of disability. In the UK it has been noted that there is insufficient research into the relationship between resource input and either the quality of support or outcomes for people with an intellectual disability. Quality is often determined by how resources are used (UK Department of Health, 2003), rather than being measured according to principles of citizenship and rights. Similarly in Australia, there is insufficient evaluation or research. Epstein-Frisch et al (2006:4) suggests that one of the reasons for the lack of cost effectiveness research is that most grassroots programs do not have the time or funding to commission independent evaluative research.

These four goals of disability supported living policy are applied in the next section on facilitators and barriers to understand the effectiveness of current policy.

[2] Government Interviews (2007) refer to the interviews conducted with government officials from six states, one territory and one federal agency in Australia. The are also referred to and referenced individually throughout .

4 Facilitators and Barriers

The research revealed nine key areas in which facilitators and barriers impact on the achievement of the goals of supported living policy described in the previous section. They are legislation and agreements, building regulations, interagency coordination, the supported living arrangements, funding and demand, staffing, discrimination, flexibility and choice and informal carers. This section discusses the evidence in relation to these facilitators and barriers, with the purpose of informing policy development that can respond to these experiences of the current system. The findings are applied in the development of a framework for assessing the effectiveness of accommodation support models in Section 5.

4.1 Legislation and Agreements

The first key area is the financial and legislative arrangements between governments, which determine the conditions and pool of funding available for supported living policy planning and implementation. The Disability Services Act (1986) provides standards and key performance indicators for organisations receiving government funding for providing disability services. No national or compatible state-wide outcomes frameworks are operational to measure the effectiveness of supported living policies.

Commonwealth State and Territory Disability Agreement

The CSTDA was described in Section 2.1. It encompasses the principles and objectives outlined in the Disability Services Act 1986 and the Disability Discrimination Act 1992, therefore playing a potential role in demonstrating Australia's commitment to human rights for people with disability. The availability of support services is critical to achieving equalisation of opportunities for people with disability.

Since the introduction of the CSTDA bilateral agreements, the coordination between different levels of government and service provision has significantly improved. However, the regulation of supported living arrangements continues to have some problems. They include questions about the success and equity of joint funding arrangements. The agreements are made in a context of multiple services, programs, models and funding arrangements, which has led to inefficiencies and gaps in service delivery (DHS, 2007; Senate SCCA, 2007). Some governments have called for a renewed strategy (e.g. Victoria's State Disability Plan), which could enable planned responses to the key issues facing supported accommodation and specialist disability services (Senate SCCA, 2007).

The lack of a national framework for the coordinated and flexible delivery of housing and support services for adults with disability is problematic (Bridge et al, 2002; AHURI, 2002). Linkages are often informal cooperation between service providers, rather than formalised arrangements. This is contrasted to the United Kingdom, which has national regulations in place to address accessible design of new houses (Innes, 2006). In addition, a UK Independent Living Bill introduced in June 2006 promotes freedom, choice, control and participation. The Bill ensures that local authorities promote and support independent living, and establishes a duty on housing authorise set up a disability housing register, and allocate suitable housing in the community (UK NCIL, July 2006).

Commonwealth State Housing Agreement

In Australia some supported living arrangements are also affected by the Commonwealth State Housing Agreement (CSHA) 2003, which provides funding to assist people whose needs for appropriate housing that cannot be met in the private market. Steps to reform the housing assistance system have occurred under the current CSHA (AHURI, 2002a). Concerns centre around a growth in housing need; the impact of targeting on a social housing system; increases in demand where people are missing out; and ageing and inappropriate stock (AHURI, 2002a).

While several jurisdictions have argued that supported living requires an expanded range of available options across a continuum, concerns have been expressed that such an expansion will actually increase pressure on legislative definitions, such as those contained within the CSTDA (e.g. number of service users, ownership of dwelling, hours of support) (Government Interviews, 2007). There is strong support for the development of a national housing policy framework that would integrate and coordinate housing policy and other social policy objectives across all levels of government (AHURI, 2002).

Outcome information for policy planning

Most government officials commented on the lack of outcome information available across Australia to inform policy planning and had differing ideas about what the outcome dimensions would be (Government Interviews, 2007). No outcomes framework operates nationally or state wide to measure the effectiveness of supported living. Some states are taking action to address this gap. South Australia for example, is reviewing the assessment and registration of people with disability requiring supported accommodation to understand the issue of growing demand.

Western Australia has also begun to look at developing a framework of outcomes that can be used to measure not only simple housing and service outcomes, but also quality of life and citizenship. They acknowledged that an outcomes framework must move beyond just a quantitative cost-benefit analysis, to include qualitative experiences (DSC, 2007). Developing outcomes frameworks is an area that requires further evidence-based research to prioritise service funding and respond to demand (DFC, 2007).

While there are some mechanisms in which to measure unmet demand for services (e.g. SAAP), these remain insufficient. Clear indications have been given through interviews with government officials, research papers and disability advocacy reports that demand exceeds supply. However, the lack of registers or measurement frameworks to map unmet need for services hampers the planning for supported accommodation options now and into the future.

4.2 Building Regulations

Second, some state departments noted that while building regulations protect standards, they can also act as a barrier to accessible and affordable housing stock. This is particularly the case for large residential centres, which have complex codes. Statutory regulations can adversely impact on accommodation arrangements in a number of ways, including development of new housing or maintaining current housing arrangements for ageing residents (Innes, 2006; Government Interviews, 2007). For example, Buildings Codes Queensland has adopted a new standard relating

to Fire Safety in Residential Care Buildings (regulation 14.1 Building Act 1975 was implemented from 1 June 2007), requiring sprinkler protection in all new buildings constructed to provide residential care. This standard relates to any residential care building where two or more residents have an evacuation impairment (requiring physical assistance in conducting their daily activities and to evacuate the building during an emergency). The Standard has significant implications for people with an evacuation impairment, including: reduced availability and choice of housing stock, and increased expenses for properties owned by the Department of Housing, non-Government-organisations and private landlords (DSQ, 2007). This requirement, and these concerns have existed in Victoria for some years. In addition, in Victoria it has been noted that this requirement can unintentionally impact on people with disability living in their own homes with staffed support and that the Fire safety equipment (e.g. sprinklers) in staffed accommodation contributes to an 'institutionalised' look, which could stigmatise people living there (DHS, 2007).

A study by AHURI (2002) into the housing and accommodation support for adults with intellectual disability found that a whole-of-government approach to building regulation is critical – including better zoning, land use and building regulations – as these are necessary to provide greater choice of accessible and affordable housing. Further research into the impact of statutory regulations on supported living arrangements is warranted.

4.3 Interagency Coordination

The third systemic facilitator and barrier is the effectiveness of interagency coordination between government agencies and with the numerous service providers involved in the sector, either through case management, service system or policy coordination mechanisms.

Reasons for coordination

People with disability, like other citizens, have needs that are not neatly packaged into the systems and supports associated with or offered by only one government agency or service provider. As a result they often have involvement with a number of agencies, posing a number of challenges both for the person and for the agencies. In shifting away from provision of generic services that embody a 'one-size-fits-all' approach, towards a more individualised and flexible system of service provision, agencies must also change their interagency coordination to ensure effective delivery of support. In a study undertaken by Bigby (2006), housing providers and support service providers did not adequately share information about their service provision to people with disability, which impacted upon the suitability of the accommodation. Sachs and Associates (1991) note the weak program coordination between public housing programs and accommodation support programs, which are often not formally linked.

Government departments themselves are cognisant of a general lack of understanding of the roles, responsibilities and programs within and between government departments (Government Interviews, 2007). In addition, agencies have difficulties assigning responsibility for people with a dual diagnosis (e.g. mental health/disability; drug or alcohol/disability) (DSQ, 2007). Bridge et al (2002) argue that linkages are still primarily based on informal cooperative efforts that vary in their effectiveness. This can be problematic as such informal links often result in cost-shifting and

inefficiency due to a lack of attention to cross-policy integration strategies. Bostock and Gleeson (2004) suggest that the lack of coordination between housing and support often results in disability agencies focusing more on support requirements of clients to the detriment of housing requirements. In addition, Bleasdale (2006) believes that the inability to disconnect housing and accommodation support can lead to narrow thinking about available options and suitable support.

The development of different (and innovative) models of accommodation support is largely dependent on which agency is primary policy driver – housing or disability. For example, if the starting point is housing, then support packages can be designed to take into account housing requirements (e.g. through modification, redesign, relocation and rent assistance). However, if support services are the policy driver, then more often than not people share support packages (e.g. through living in a group home or similar) (Bostock et al, 2001). To operationalise effective, flexible and well coordinated supported living arrangements, it is critical to have strong coordination between housing and support.

Housing and accommodation support separation or integration

A long standing issue debated by policy officials and researchers is whether the separation or integration of housing and support is more effective. Historically, residential care was a single package of housing and accommodation support. In contrast, community care typically separates them (Oldman, 2000). Reynolds et al (2002) suggests that a range and diversity in approaches must be available to link housing and support services, including: housing being formally linked to off-site support services; interdepartmental agreements/protocols; support packages or programs specifically linked to low cost housing tenants; coordination through general case management or care coordination support programs; provision of on-site support; and service coordination in local service networks. Bigby (2006) notes that the separation of day programs from accommodation is only successful where organisations coordinate and communicate. When these factors are not practised, it results in a rigid and inflexible environment.

The preferences of people with disability for having integrated or separation housing and accommodation support services are not clear from the research for this project. Some people want housing and accommodation support packaged. For others, separation of housing and accommodation support is more desirable. Family members who are heavily involved in putting together flexible and innovative support options for their family member are more likely to be comfortable with managing support hours, and prefer separable funding. Conversely, people who have a minimum of family involvement or who have ageing families, appear to benefit from a structure that does not rely on the management or coordination by family or another supporter (Stakeholder Interviews, 2007). Funded coordination can be a bridging factor between the two approaches. The inconclusive preferences suggest policy that separates support and housing meets both preferences. Separate support and housing can be packaged if it suits the person's needs, but fixed packages cannot be separated.

Memoranda of Understanding

Having well-coordinated agencies is an important policy goal for Australian governments, and government officials are well aware of the improvement needed to reach that goal (DSQ, 2007; DHS, 2007). Only a few states have formal Memoranda

of Understanding (MoU) between departments, which have been shown to be successful in facilitating and maintaining interagency- coordination. Western Australia has an MoU between the Disability Services Commission and housing so that clients are prioritised (DSC, 2007). In NSW, a Housing and Human Services Accord between the Department of Housing and NSW Human Service agencies (including DADHC) has been signed providing a framework for cooperation between agencies to assist social housing clients with support needs and to assist clients of human services agencies with housing needs (including people with a disability). In addition, DADHC has a MoU between Department of Community Services (with children with disability) and Departments of Housing and Education (DADHC, 2007). While South Australia has no formal MoUs, they have a strong emphasis on whole-of-government initiatives, with a good interface between disability and community housing sectors. South Australia has both disability and housing within the one department, which allows for increased opportunities for obtaining affordable housing for people receiving disability support (DFC, 2007). In Queensland, Disability Services Queensland and the state Department of Housing have an MoU which includes a schedule for shared living arrangements. Conversely, in Victoria the siting of Disability and Housing within the one department (DHS) does not appear to result in better housing outcomes for people with disability.

For people with disability using services, having well coordinated support is considered extremely important – in both arranging of daily activities, and in the longer term goals and operation of people's lives. Support which is coordinated was of particular importance for people who did not have other people in their lives to organise a range of supports on their behalf (Stakeholder Interviews, 2007).

Human service sectors

A key issue pertaining to interagency coordination is that clients who access other support systems (e.g. mental health, health or criminal justice) have often received types of support not traditionally offered by the disability service system. This can have a negative impact on transition, as services offered via the disability service system may be inappropriate or inadequate in addressing the priority needs of the person (DSQ, 2007). FaCSIA (2007) noted the gaps in coordination between departments, for example juvenile justice, which results in a lack of proper rehabilitation and posing the risk that the young person ends up with higher, more complex needs. NSW has a policy focus on improving coordination between disability and the criminal justice system to ensure that appropriate supports are in place prior to young people being released, so that needs do not escalate or become more complex (DADHC, 2007).

The intersection between service streams can also have consequences for people living in accommodation support services. One example is in accommodation support packages that do not include funding for travel support to and from a day program. Such contradictions impact on the choices available to people using services (e.g. moving from supported employment to open employment) and can create an unnecessary dependency (Stakeholder Interviews, 2007).

Dependency on accommodation support for other support needs (eg. employment, training, transport, day activities and therapy) arises for several reasons. People using accommodation support might not have access to additional support services (unmet

or under-met need). The accommodation support model might be one that does not engage with other service providers. Other service providers might prioritise people who do not have accommodation support. These examples of poor coordination or poor access to other support services shift the cost to the accommodation support service.

Another important identified barrier is poor coordination between different departments during transitions, , such as transitions from institutional care and age-related services (18 and 65 years). In contrast, good transitions require coordination between the formal and informal support services, at least temporary case management and the associated costs of temporary additional support to manage the change.

Liam's mother said that Disability Service [a large non government service provider] gave her about six months warning that when Liam was 18 years, he would have to leave. At the same time, DADHC also told her that he was not eligible for their services and closed their file. As a result, Liam's mother tried to find alternate accommodation, even contacting services in New Zealand. She said that Liam was 'literally dumped on me'. The impact for her was significant, as she had to move her family from another city to Sydney, and gave up work to care for Liam. She said that she received no help from services, even though Liam was at times violent, and that she believes that she has experienced some permanent damage from frequently being concussed. She does not blame Liam, saying that he was 'very frightened', and that the experience was 'traumatic' for everyone. Eventually, Liam's mother was able to find a DADHC worker who agreed to arrange a new psychological assessment for Liam, resulting in DADHC agreeing to assist in finding the current accommodation and support. Even now, she said that she cries about what happened to their family at that time (Stakeholder Interviews, 2007).

4.4 Supported Living Arrangements

The fourth facilitator and barrier is the funding arrangements of where people live. This includes the type of housing, the location and co-location, who they live with, the condition and quality of the housing, the appropriateness to the person's support needs; and direct payments and individualised service provision.

Considerations in housing arrangements

Government officials commonly agreed that of utmost importance in any housing arrangement is availability, flexibility and diversity of affordable and purpose appropriate housing options (Government Interviews, 2007). A critical issue is having considered, well planned transition processes to support people to live happily and safely, more independently. Slow, purposeful transition which builds on gains made, rather than quick, crisis-driven moves into services is seen as crucial for people with disability to develop confidence and security in their new living arrangements.

Anna says her daughter, Reba's, move into her unit was carefully managed, with a gradual transition and careful observation to check that Reba, and the woman she lives with, were both managing and happy there (Stakeholder Interviews, 2007).

The number of people in any housing arrangement (particularly in group homes) is an important contributing factor to quality and satisfaction. Stancliffe and Keane (2000)

in a study of semi-independent living arrangements found that participants in smaller (staff-to-user ratio) arrangements experienced more social satisfaction, more frequent and independent use of community facilities, more participation in domestic tasks and greater empowerment. In addition, when assessing issues such as loneliness, health care and money management – where it would seem that lower support-staff levels would provide lower results –little difference was found.

Commentators have summarised the key principles of good housing for people with disability (see for example, DHCS, 2007; Ward, 2005). Bigby (2000) describes quality housing and support as including: a house which is appropriate in its design; affordable and where tenure is secure; has access to required supported services (formal or informal) that are available when needed, and provided in a way that meets individual needs and circumstances. AMIDA (1997) outline the key criteria of what people with disability see as making a house a 'home': homes have a real address rather than the names of facilities or group; leaving is by choice; the people who live there have expectations of permanence; tenure is by a lease or ownership; people have control over who can visit or stay; and people have control over their physical environment. These features are important in developing community and independent living options for people with disability.

Cluster housing

Although most people with disability prefer community living that is, living within community rather than an institutional setting, researchers have made a number of critiques of this type of housing, particularly if it is organised as clustered (rather than dispersed) community living. Researchers cite cluster housing as providing an overall poorer quality of life when compared with dispersed housing.

EIDRN (2003) argue that family and community ties continue to be disrupted even with more progressive cluster community living arrangements, which are reminiscent of institutional services. Some advocacy/parent groups agree that some current community arrangements remain similar to institutional living in their approach to housing and support services (Bostock & Gleeson, 2004). Mansell (2006) argues that quality community-based services vary considerably, particularly in staffed community houses, where some have been described as 'mini institutions' in the community. Epstein-Frisch et al (2006) suggest that a risk of cluster housing is that it will become 'the institutions of the future', because many of the features of institutional living are also risks in cluster models, including: a whole of life umbrella approach to the delivery of services; a custodial and impersonal nature of care; segregation from the community; inability to provide a home-like environment; and their difficulty meeting the physical, emotional, social and skill development needs of the groups of people living there. Emerson et al (2000) note that people living in cluster arrangements are more likely to be: living in larger settings; be supported by fewer staff (including more casual staff); be exposed to more change in living arrangements (especially when the home was also used for short term care); be exposed to more restrictive management practices (seclusion, sedation and physical restraint); lead more sedentary lives; be underweight; and participate in fewer and more restricted range of leisure and social activities.

Accessible housing

One key debate in supported living arrangements centres around building structures. The United Nations in a special report on housing in Australia commented on the lack of suitable and affordable housing for people with disability. The Report recommended that all new private and public constructions should have accessible design arrangements, which if included during the design phase, could save the costs of later modifications, and could also benefit other members of society, such as older people and young families (Kothari, 2006). O'Brien et al (2002) note the benefits of investing in adaptable housing as: reduced expenditure on adaptations to non-accessible housing; reduced accidents; delays moving to residential care; and savings in health costs. Researchers estimate that initial additional building costs are re-couped within 3-10 years.

Despite these findings about physical access, disagreements remain. Some commentators argue for less emphasis on the building structures and more emphasis on individual support so the focus is on adapting the current environment to suit the needs of clients rather than building specially designed houses (MacArthur, 2003). The Western Australia policy focus relating to accommodation support is about services first and then the built environment (DSC, 2007). FaCSIA (2007) suggest that a key facilitator to success in supported living is to establish a home-like accommodation environment, supplemented with support services. As discussed earlier, other researchers and officials argue for a separation of support planning infrastructure from service provision systems as important for providing choice and cost effectiveness, and for allowing more control and flexibility over the housing (Felce, 2000; Lord and Hutchinson, 2003).

Shared housing

One of the main barriers to goals of choice and control noted by people using services is having to share accommodation with others not necessarily by choice (either sharing at all, or sharing with particular people).

Bob seemed to have mixed feelings about living here – commenting he would like to live in a nearby suburb as his friends are there, but would prefer to live alone as he sometimes does not get on with his co-residents (Stakeholder Interviews, 2007).

Sarah [parent] says she 'shudders thinking about the future.' Zach's level of complexity means if we are forced into sharing funds with others, it wouldn't work.

Shelly lives alone, and likes it this way. She said that she is 'fearful of living with others and has been hurt in the past', saying 'you never know, they just shove.'

For people who live in shared accommodation, the ability to decide on 'macro' issues – such as the framework of support and co-residents and choices of activities and daily routines – is very important. While not everyone had these choices, it was consistently raised as desired.

Fiona lives with a co-resident, a man in his 60s, and she said that they get on well. She said that there were problems with the previous co-resident as they fought. Fiona tried living alone for several months, but it was financially difficult, and the current co-resident moved in about a year ago. Fiona said that she knew the co-resident socially beforehand, and that she had a say in who would move in (Stakeholder Interviews, 2007).

Individualised funding mechanisms and individualised service provision

A current international trend of supported living arrangements is the move away from generic models of care to more self-determined and individualised support program, including individualised funding (Lord and Hutchinson, 2003, Bostock and Gleeson, 2004). In the United Kingdom, direct payments are considered to be cost effective, with the number of people utilising them in 2001-2003 doubling, and then doubling again in the following two-year period. However, a number of concerns about this arrangement arise, a main one being how to promote direct payments while maintaining a duty of care. The operational terms and definitions also raise question, such as having vague definitions of 'capacity', 'consent' and 'risk'. This makes some providers wary of applying the direct payment program to all clients. One of the important contributors in the uptake of direct payments is the training of staff and other support workers. In the UK, successful implementation involved having a policy of mandatory duties, performance indicators and local targets. Where these are in place, the take-up of direct payments has increased (Priestly et al, 2006).

In the United States, a successful direct payment arrangement can be seen in the Illinois Home Based Support Services Program, which offers families the decision over which services to purchase, with the help of a service facilitator. Services purchased included respite, personal assistance, home modification, recreational and employment services, therapies and transportation. In an evaluation of this program, Heller and Caldwell (2005) found that families who utilised this service were found to have a lower chance of placing their family member with disability in out-of-home placement. This finding is similar to previous research that shows that consumer directed support programs tend to afford caregivers increased feelings of self-efficacy and reduced desire for out-of-home placement (Heller and Caldwell, 2005). In addition, such a program is more likely to provide the type of support desired and required by families – particularly as there are long waiting lists for community housing. Furthermore, these programs are cost efficient as families tend not to spend all of the funds made available, and are more efficient when compared to the high costs of institutionalised living (Heller and Caldwell, 2005).

An innovative payment arrangement is currently being adopted in Norway under the new housing guidelines in the Norwegian Reform Act. The guidelines outline that all people with developmental disability rent or own the house or apartment in their own names. This ensures that the people with disability paying the rent from their social security benefits or earnings, and have ownership over everything in their apartments. The person pays for food, clothing, electricity, travel, and fees associated with their recreation/ leisure activities from their own income, and in turn, the township is responsible for the assistance people needed in their homes, their places of work and in their recreation or leisure activities (Meyer, 2003).

In Australia, various Departments are experimenting with the possibility of developing individualised funding arrangements. Currently Western Australia is the only State to have successfully implemented this system, however other states (e.g. Victoria) are piloting direct payment programs. In the past, NSW has a system of individualised funding packages associated mainly with group home care (portable packages), however these were problematic, creating financial viability problems when people left the group home, and having family members being concerned about where the money was going. The NSW government moved back to a generic funding-based model with the rationale being that individual funding has challenges for programs which are based on need rather than entitlement (DADHC, 2007). NSW is currently piloting a direct funding program for attendant care (Fisher et al, 2007).

Other states in Australia are supporting the development of individualised funding arrangement. They agree that this type of arrangement, if operationalised effectively, can offer the greatest flexibility as the funding is attached to the person rather than to an accommodation type. It is also seen as a good option across the life-course (Government Interviews, 2007). The different styles of individualised funding arrangements include: direct payments, indirect payments and funding held by organisations. Services to be purchased include personal support, domestic services and social services. The implementation of such arrangements in other countries is generally through service brokers, personal agents and voucher schemes that provide assistance with budgeting, service selection, payment management and accountability. Benefits include responding to personal preferences and needs, lowering administrative costs, increased competition, and (with the opening up of some service markets to mainstream organisations) increasing employment opportunities within communities (Senate SCCA, 2007).

While individualised funding arrangements adhere to rights-based principles – and are often cited as the preferred option by people with disability and their advocates – some risks of moving to this type of arrangement arise. Critique centres around the operationalisation of such a system, including: tax implications for people and the extent of accountability by government over funds. There can also be an insufficient levels of a funding package to meet the person's needs. As the needs of a person are not static (and can change quite rapidly, particularly with episodic disability and degenerative conditions), there needs to be flexibility so that in times of high need the funding package can be supplemented. There is also an issue of no 'bricks and mortar' being attached to this type of arrangement, where securing appropriate accommodation to meet the people's needs still needs to be addressed.

One problem that is difficult for government departments to address is the economic efficiency of this type of arrangement for high needs groups (as groups setting might be more efficient, but compromise flexibility and fluidity) (Government Interviews, 2007). The recent Senate inquiry into CSTDA funding outlined the limits of individual funding as: (i) potentially being more complex for people and their families to navigate; (ii) people with disability should be able to choose the level of self-sufficiency they want and need; (iii) brokers may simply replace case managers as controlling forces over how the funds are spent; (iv) removal of direct care staff can lead people with disability to become increasingly isolated and vulnerable to exploitation by family and carers; and (v) governments might abrogate their responsibilities for individual support and service development once payments are

devolved (Senate SCCA, 2007). Despite these concerns, the Senate still recommended a review of alternative funding arrangements be undertaken through the research and development program of the next CSTDA. Such a review should specifically consider issues like the costs and benefits of individualised funding; issues encountered in the introduction of alternative funding overseas, and alternatives to allow people with disability to choose the level of self-sufficiency with which they are comfortable (Senate SCCA, 2007).

The policy direction in Australia is clear about offering supports and services based on personal requirements. There is a common call for introducing individual support packages that can be attached to the person in an accommodation setting of their choice, and there is a greater demand for in-home support rather than group arrangements. Governments would like to facilitate people exiting from groups homes, particularly for people with lower support needs, and it is commonly suggested that targeted packages need to be developed so that people can move from group homes to alternative options.

All parties recommend addressing the problems created by funding streams that segregate funds (e.g. into employment, accommodation, support), so that there is a holistic package of supported living. This would also include unbundling housing and support, which government departments are supportive of, so that a more flexible and individualised supported living arrangement can occur. Importantly, there is recognition that although ideally governments across Australia could move away from a group home (or non-individualised) arrangements; the practical implementation of this vision is slower, and for smaller services, it may not be financially sustainable. However there are some innovative approaches emerging in each State and Territory, and various departments are continuing to examine ways to develop more individualised and flexible supported living arrangements. Nationwide, the future policy emphasis focuses on matching individual needs to appropriate support preferences.

4.5 Funding and Demand

The service system does not meet demand for either affordable housing or specialist disability services. Resource facilitators and barriers include the implications of the competition for support funding; prioritising prevention or critical care; the availability of social housing and other housing stock; and costs of changing needs.

Implications for funding

In Australia, as with other countries, a recurring critical issue for people with disability is the high unmet demand for affordable and accessible housing and accommodation support (Sachs and Associates, 1991; McNamara, 2001; UK Department of Health, 2003; Foundation for People with Learning Disabilities, 2001; Bleasdale, 2006). Unmet demand is a problem that governments have had to deal with for years, especially demand for accommodation services, respite services, in-home care and supply equipment and aides (Senate SCCA, 2007). Various government departments have acknowledged the ongoing difficulty in accurately assessing the level and nature of unmet and ‘under-met’ need (Government Interviews, 2007; AIHW 2007b). The urgency to meet critical demand has had the effect of reducing the choices available to people in extreme need. The fierce rationing of accommodation support services mitigates against people being able to make lifestyle choices and

decisions, either because the hours of support they receive are insufficient or the required support is too costly (AIHWb). Most available options are locked into the current arrangements, leaving little opportunity for service providers to shift resources to maximise choice and flexibility.

> Brenda, a service provider, talked about competitive tendering for service provision. Her organisation did have a group home in a regional country town, but lost the contract to provide service under competitive tendering processes last year. She described the process as, '… absolutely brutal, and it's happening again with tendering out. [The Department] is rolling out money, but it pits people against one another. We work closely together [in our region], but in the end it becomes a competition.' (Stakeholder Interviews, 2007)

DSC in Western Australia, for example, received over 300 applications for accommodation support funding, from which only 80 spots were allocated (DSC, 2007). Even South Australia, which has one of the highest proportions of funding (60 per cent) in supported accommodation, still has long waiting lists (DFC, 2007).

Prevention or critical care funding

Funding of services is often reserved for people with complex, high and/or critical levels of need, which results in service gaps for people with less critical need. Due to the high levels of unmet demand, often, accommodation support becomes a crisis response, rather than preventive. In these circumstances, funding and provision of service is often not decided by personal level of need, but cost and budget (Simons, 1998; Ozanne, 2001; UK NCIL, 2006).

Some people are forced to rely on crisis funding to get enough support. In one instance where a person with disability living independently had insufficient funding to cover his required support without the addition of emergency funding. When crisis funding was unavailable (as it runs out quickly), the family were forced to move in and provide support themselves (Stakeholder Interviews, 2007). This fails to meet the goals of independent living and has a negative impact on both the family and the person.

People with disability and families not only need sufficient funds to ensure basic support, but also to facilitate supporting people 'well'. In one example, while a family were doing a great deal to include their son meaningfully in his community, supporting his accommodation arrangements, and meeting his health needs, they were continually struggling to find adequate resources to provide sufficient paid support to meet his needs (Stakeholder Interviews, 2007). Resource support is not only about financial resources as one parent explained, 'You need money, of course you do, but you also need creativity.' Sarah sees effective support as made up of creativity, fidelity to the person, funding and skill. 'Without one of these, it all falls down' (Stakeholder Interviews, 2007).

Social housing and other affordable housing stock

FaCSIA (2007) note that one of the structural barriers across Australia is the housing market, where there is limited affordable housing and high demand for social or public housing. According to AHURI (2002) analysis, the number of public housing units has decreased, which is of concern given the growth in population and number

of people requiring such housing. In addition, with increasing demand for social housing the eligibility criteria for accessing social housing has become more focused on higher need clients, which may preventing people who are in need (but not in crisis) from gaining social housing (AHURI, 2002). At the same time, the lack of affordable private rental units keeps people with disability out of the private market (NCHF, 2004), which is a an important compounding barrier for people with disability (see Bleasdale, 2006 for further discussion on the private rental market and people with disability).

The shortage of affordable housing stock is an important issue, particularly with the huge waiting lists for social housing (Government Interviews, 2007). The provision of social housing has been primarily directed to more critical cases. National community housing stock in 2002-03 was at 44,080 dwellings, with 24,176 of those funded in wholly or in part by CSHA and 14,442 funded by other sources. This was a rise of 5,461 dwellings since 2000, but is lower than the 33,325 people on community housing waiting lists. The level of demand of community housing from complex clients has also risen, with almost all of the people on waiting lists considered to be 'in greatest need' (NCHF, 2004:7).

The past two CSHA agreements attempted to address the shortage of affordable housing by requiring that the states and territory governments help people highest in need (e.g. people on social security payments), however demand still exceeds supply across all of Australia. The highest priority groups for housing under the CSHA are (i) homeless; (ii) aged; (iii) Indigenous; and (iv) complex needs. Nevertheless the waiting list continues to increase each year (FaCSIA, 2007). According to the Affordable Housing National Research Consortium, if this shortage continues the number of stressed households (households paying more than 30 per cent of their income on housing) will reach 1,000,000 by 2020 (NCHF, 2004:8).

One identified trend across Australia in funding arrangements is the move for government to take control of the funding and NGOs to manage and provide the services (Government Interviews, 2007). Although there is an increasing reliance on government funding to enable support, the funds available are insufficient to make any significant difference to unmet demand. Often private rentals are unaffordable to people on income support (see Bleasdale, 2006 for a detailed discussion on this issue). With the demand exceeding the priority, government departments have to balance urgent/crisis need with the needs of people already in the system. The demand ends up focusing policy and funding towards creating new places rather than enhancing the old or current places. Even when vacancies do occur, not all people are eligible to fill them (Government Interviews, 2007).

In addition, inappropriate housing stock that is located well away from public transport and employment opportunities is still being utilised, which also makes it more difficult to integrate services. In Queensland for example, although efforts are being made to change inappropriate housing estates, there are problems with re-selling as the old housing stock is far less valuable than the costs of new housing.

Changing demands

Some service providers are also now supporting people with very complex needs for longer periods of time, which may increase demand for services (DSQ, 2007). This may also constrain the choice of place and type of living for people with these needs.

The ageing population accentuates this problem. It is increasingly contributing to the rising levels of demand for accessible and affordable housing and services for people with disability (Government Interviews, 2007). The increasing needs of people over time due to ageing are not always taken into account in current funding arrangements. People's changing needs as they age generally mean increased funds are needed to effectively and safely support them.

Brenda, a service provider, discussed the increasing needs of their clients due to ageing. No extra funding has been made available for these people. 'That will be an ongoing issue for every service, I imagine, you know, what happens next for clients as they perhaps get dementia or have been living happily with perhaps two hours a day support and now they're needing 24/7 support. What happens? Are nursing homes going to be OK?' (Stakeholder Interviews, 2007)

Summary of funding and demand

Governments agree that the future policy emphasis must focus on developing new supported accommodation options to address the level of unmet and 'under-met' need. However, how to operationalise this within financial constraints is difficult (DFC, 2007). This is compounded by differing funding priorities for incompatible service systems (e.g. HACC versus Disability Services versus the Department of Housing) and competing pressures imposed by the Commonwealth (eg Aged Care versus Disability Services) (DSQ, 2007). Furthermore, even where good, innovative models of supported accommodation exist, lack of funding is a key barrier in being able to roll out such models on a large scale (DFC, 2007).

4.6 Staffing

The sixth barrier and facilitator is quality staffing in accommodation support, including availability, training, service approach and managerial support in the employing organisation. Staffing is well established as a key determinant to the success of service quality and outcomes for people with disability in supported living arrangements. The literature demonstrates that for people with high support needs, three key factors are important: (i) available activity for all – which involves moving from the 'hotel' model to resident participation; (ii) available personal support including well developed method for staff/resident deployment and activity planning; and (iii) effective assistance to help people who lack skills to accomplish and activity successfully (Epstein-Frisch et al, 2006).

Availability and appropriateness of staff is critical as accommodation arrangements are more than simply employment but are a lifestyle choice. Some of the key barriers to quality staffing include recruitment practices; insufficient or inadequate skill levels, especially in relation to high and complex support needs; low wages; and inadequate training (Government Interviews, 2007).

The importance of quality staffing is echoed by people with disability and their family members. It is necessary to have experienced well-trained staff who have a positive vision of what is possible for the person. Family members of people with disability in particular commented on the degree to which service quality is mediated by service staff, whereby the staff can be either be facilitators of inclusive living, or gatekeepers from inclusive living.

Community Service [the non government organisation that supports Zach] find workers who they think would be a good match for Zach (gender, personality, hours available), then the family decides if they are a good fit. If so, the worker starts on a three-month trial at the end of which time an assessment is made, looking at what the person themselves thinks (through a formal process), then they become a permanent worker. They have worked this way successfully for 16 years.

Liam said that he likes the staff at the house, saying of the staff member with him at the interview that he thinks of her more like a friend. In the past, there was one staff member who yelled at him, but that he soon left and that it is OK now. Liam's mother said that compared to his past accommodation, Liam is happy, settled and more 'mature' in the structured environment, and said that this was due to the staff's efforts and commitment.

Shelly said that 'these (staff) are great, but the next lot may be rotten.'

Brenda, a service provider, says, 'The way we provide service is very different. It's gone from that institutional model to very much creating a home for the clients that we support. And we're very big on that, we talk about that a lot, we brainstorm it a lot with staff, we try not to get stuck in that babysitting model that is easy to get stuck into working with clients with high support needs.' (Stakeholder interviews, 2007)

When people using services were asked about how they deal with a worker they are not happy with or did not like, they gave mixed responses. While they generally mentioned that there are complaint mechanisms in place which they can use, several people needed to be prompted to identify someone, and most people were not able to identify someone outside of the service who they could go to for help.

When the staff member was not present for a short period of the interview, Bob said that he likes some staff, but is not happy with others. If there is a problem, Bob said that he would ask his father for help, or a specific staff member. (Stakeholder Interviews, 2007)

Another key issue with staffing is the managerial or organisational processes of service provision. Bigby (2006) suggests that often the primary focus is on day-to-day care by staff and managers, with little weight being given to planning and vision for the quality of life of the people. Mansell (2006) argues that the culture of institutions at times persists in community group homes via the staff who have transferred from them. Training (or re-training) usually focuses on minimum service provision requirements such as health and safety issues, rather than wider issues of supporting full and equal participation. Bostock and Gleeson (2004) suggest that these issues are compounded by the lack of support for deinstitutionalisation by some labour unions, where staff are divided between multiple houses and thus less unionised. There is a fear that a lack of unionised workforce will promote the use of untrained, inexperienced and uncommitted workers.

An additional staffing issue is related to the shift towards government brokering out the majority of service support to NGOs. Sometimes contracted providers have insufficient capacity and/or funding to provide additional levels of support or skills for people higher need or more complex needs (DSQ, 2007). Young (2006) in a comparison between community living and cluster housing, found that to improve

outcomes in either arrangement, staff performance was the key indicator. Other evidence has demonstrated it is the level of staff attention to, and engagement with, the residents that produces the most positive outcomes (AIID, 2006). Overall, as government departments and service providers work towards more innovative models of supported living, it is critical that staffing, managerial and organisational practices are adapted accordingly so that the goals of the people and their advocates are aligned with the policies and services framing such goals.

Reba receives no government funding beyond the Disability Support Pension and rent and mobility assistance. Her income is not sufficient to support her, and her parents pay for additional things, such as private health insurance, using the money Reba accumulated while she was living in the family home. They expect Reba will live on an inheritance once they die.

The main problem that Shelly wanted to raise was a 'new boss', and was concerned that 'things are about to change big time.' She said, 'I think the boss is going to bully me into living with someone to suit him, not me.' She said that he said this to her on his 'first visit but has kept away since.' She thinks the reason is 'cost cutting [but] whatever, it will be under-handed. (Stakeholder Interviews, 2007)

4.7 Discrimination

Discrimination about culture, language and Indigenity are an additional barrier for some people with disability. Some accommodation support services have facilitating practices to address this risk. Socio-economic barriers and stigma about particular disability are also a barrier for access to both housing and support for independent living.

Government departments across Australia recognise that people from culturally and linguistically diverse backgrounds and Indigenous people with disability experience additional barriers (Government Interviews, 2007). A key issue in provision of accommodation services to diverse groups of people with disability is ensuring such services and support are culturally sensitive. This is sometimes difficult to achieve, particularly with the proximity between the housing and culturally specific community support, such as social networks and cultural facilities (FaCSIA, 2007).

Brenda (a service provider) talked about her experience in providing support to a young Aboriginal man who moved from an institution. The challenge for the service was to meet his complex needs, and to support him to re-establish relationships with his close and extended family in a culturally sensitive way. She described a big change in his character over time, which she puts down to increased opportunities to do things, move around by himself, and improved health and well being. And, to the relationship and connection with his large family (Stakeholder Interviews, 2007).

In the Northern Territory, a high percentage of Aboriginal people living in remote areas do not have access to services or supported accommodation, and are instead relocated to the urban areas – often hours away from their family and friends and in a white urban setting. The cultural mix of staff can also be problematic, with little flexibility or knowledge by service providers about cultural issues (DHCS, 2007). In a study undertaken by Carlson and Hutchinson (2001), five main factors were found to negatively affect the level of support received by people from a CALD background:

1. Isolation – unfamiliar territory can cause isolation of people and their families from the wider society. This in turn can impact on people seeking help, or only wanting minimal help.
2. Cultural beliefs and cultural differences – of how some cultures view disability, or of the support and services given to families. This also impacts on the ability of an person from a CALD background to trust a staff member from a different cultural background.
3. Language difficulties – communication can at times be difficult where there is lack of appropriate CALD staff.
4. Inter-sectoral links – limited links between ethnic community organisations and disability support services causes a lack of formal requests for support.
5. Access – A lack of availability of information in regards to services available to such people in the community and language necessary causes a lack of readiness to seek mainstream help.

Some of the strategies to overcome these barriers include: improve awareness amongst service staff of issues specific to CALD families with a disability; where possible, tailor support to the cultural norms and beliefs of the family; increase and maintain bi-lingual staff; ensure appropriate levels of liaising between various organisations, including establishing memorandums of understanding; and ensure that dissemination of all information relating to services and support is available in multiple languages and distributed through as many communities as possible. Improved data collection based on ethnic and linguistic factors can also lead to better understanding the needs of people in such communities (Carlson and Hutchinson, 2001). NSW has an Equity Unit that provides advice in relation to programs and policies for Aboriginal and Torres Strait Islanders and people with CALD backgrounds (DADHC, 2007).

It is also important to ensure that people from CALD or Indigenous backgrounds are located near to family and community where possible, which not only promotes equality and citizenship principles for the person, but can also be more cost efficient for the government over the long term. For example, in the Northern Territory there was a 22 year old Aboriginal man with an acquired brain injury who got caught up in the criminal justice system, spent time in jail, and then as part of his Supervision Order he was to live in 24-hour supported accommodation in Darwin. The cost to the Department of this was $560,000 per year. Staff then worked closely with the client, the NGO and his family (who lived in a very remote community of 30 people) to get him back to his community, as he had extensive challenging behaviours living in the house due to vast cultural differences. Over a period of six months he was back living in the community with supports in place for his family and the community – including regular respite for the family and culturally appropriate behaviour plans. The ongoing costs to the Department is now only $20,000 per year, and has been sustained now for approximately 18 months (DHCS, 2007).

In addition to cultural barriers, a number of socio-economic barriers prevent some people with disability accessing appropriate supported accommodation, such as stigma and high costs of housing. Despite the shift towards community-based housing, some communities are less welcoming and accepting of people with significant disability, which results in pressure to return to more congregated

environments (DSQ, 2007). Lack of acceptance of the potential capacities of people with an intellectual disability can also act as a barrier. For example, some formal and informal carers can disregard and dismiss requests for support with semi-autonomous activities or in enabling autonomous activities to occur (Buys & Tedman-Jones, 2004)

4.8 Flexibility and Choice

As discussed in the goals of supported living policy (Section 3), accommodation that offers flexibility and choice facilitate quality of life goals for people with disability. Unfortunately, practices, funding and approaches to service delivery are barriers experienced by many people using services and trying to access them.

Several participants in the research, both people with disability and family members, talked about the importance of services providing practical support to people to make their own choices and decisions. Flexibility of support was important to people on a range of levels: from being able to determine on which day of the week they did their shopping (when needing staff support to do so), to a family who organised hours of support to supplement the caring role they also filled during part of the week.

Sarah says that Zach makes choices and decisions about every part of his life. He has micro control, but not macro control, because he can't manage it, but Zach's life is the way it is,

> … because of the way he has been supported and respected. His life is much easier, better than for people who live a more conventional funded service life. (Stakeholder Interviews, 2007)

Although disability policy legislation principles include diversity, choice and flexibility (Section 4.1), Australian government departments find it difficult to operationalise them. As a consequence some officials and providers reflect that parts of the current system of supported living are too inflexible and lack opportunities for people to make real choices (McNamara, 2001; MacArthur, 2003).

For example, in Victoria people with lower needs who want to move into group homes must access other options due to increasing pressures on finding suitable accommodation for people with higher needs. The Department is attempting to increase the variety in accommodation support options but this goal remains aspirational. Conversely, people wanting to leave a group home have little flexibility for changes. While people with disability have the option of moving across various housing arrangements, support needs, particularly critical needs have a higher priority than personal preferences. In summary, if a person has current accommodation, even if not ideal, then they are of lower priority for both other disability and housing support options (DHS, 2007).

Similarly in Tasmania, the existing system does not readily facilitate people to move from one accommodation option to another, should a person's needs not be currently met within their existing accommodation option (DHHS, 2007). This is also true in the Northern Territory where clients have few choices about accommodation support and housing options. People can only take what is available, regardless of location or house make-up. Rarely can considerations such as placing people of similar age or

preferences within the one house be entertained (DHCS, 2007). To address inflexibility and lack of choice in NSW, DADHC keeps a 5 per cent vacancy in group homes to allow for moving around (DADHC, 2007), however this is insufficient for demand.

4.9 Informal Carers

The final facilitator and barrier is support for informal carers. Robust informal support – both practical and emotional – from both family and friends is considered to be a key facilitator of a good supported accommodation experience. This sort of support is particularly helpful in ensuring the person is viewed as more than a 'client' or 'resident'.

Sarah says more time and opportunities are needed for families to get together to plan for the future (Stakeholder Interviews, 2007).

While many adults are content to remain in the family home, often this is because of a lack of viable alternatives. EIDRN (2003) note that although family care may appear as the cheaper and more preferred option, the need to accurately estimate costs of family care remains when determining equity and measuring effectiveness and efficiency of public services. AHURI (2002) suggest that while some community care services are available to assist informal carers, often financial restraint limits access to this help, which puts long-term informal carers at risk of financial hardship.

A key barrier is the interface between formal and informal support. If a person has a well developed, effective network of support, their priority of access to more formal supports is limited, even though the level of funding or support that is required to sustain such arrangements is often relatively low (DSQ, 2007). Lack of housing options places an unacceptable demand on many families and informal carers, restricting choice and opportunity for developing an independent life for many people with disability.

In addition, some people rely heavily on informal and unpaid support, which is of concern to both them and their families as these cannot always be sustained over time. The more innovative options in which some people live are considerably lower funded than traditional group home style support. In part, this is because they are reliant on active involvement from informal and unpaid support. While these lead to a better quality of life for many people, their sustainability over a long period of time may be fragile, as the supporters age and their circumstances and capacities to provide support change. A parent stated that 'circles of support',

> … have great currency, for now, but as a hedge against the future, I don't think they will work. There is a need for adequate resources over time as well as informal supports. (Stakeholder Interviews, 2007)

With regards to quality of life for the families and carers of people with disability, the degree and type of support need is a major determinant. Where families have an abundance of social, emotional and material resources, the stress of caregiving can be minimised, however very few families have access to such levels of supports. While home-based supported living can improve quality of life for a person with a disability, it can impact negatively on the quality of life of the caregivers/family members.

Primary carers are at considerable risk of high stress, clinical depression and abnormally low subjective quality of life (Cummins, 2001). The needs of people with an intellectual disability and their informal carers can conflict, which is especially problematic for ageing carers who have care needs of their own (Ozanne, 2001). Furthermore, informal care may actually negatively impact on the independence and autonomy of people with disability, particularly people with an intellectual disability. Older parents may be overprotective of intellectually disabled children, regardless of age. Where this happens, adult children can have reduced decision making opportunities. This can be problematic when the family member can no longer care for the person with disability (Burchard et al, 1991; Buys and Tedman-Jones, 2004).

Where families have increased control over respite and personal assistance services, they experience an increase in service satisfaction and community participation, as well as a reduced staff turnover (AIID, 2006). Yet considerable uncertainty remains about the future availability of informal care, particularly as the population of both carers and people with disability is ageing (AIHW, 2003). Contemporary families are supported by a smaller number of adults leaving fewer older children to offer assistance and often in more complex social circumstances than has ever previously been the case (Cummins, 2001). The fragility of service arrangements over time is a key issue. Generally, it is the family members of a person with disability who express the most concern, with the main issues focusing on what will happen in the long term, when parents are no longer available, and also in terms of the lack of protection against change in service structures and support arrangements.

4.10 Summary of Facilitators and Barriers

The discussion about these nine facilitators and barriers to effective accommodation support (legislation and agreements, building regulations, interagency coordination, the supported living arrangements, funding and demand, staffing, discrimination, flexibility and choice and informal carers) illustrate the complexity of the policy environment. No one approach to supported living is likely to be sufficient in this context. The people and organisations involved in accommodation support have appropriately responded with multiple approaches to accommodation support as summarised earlier in Table 2.2 and Table.2.3. In order to assess the effectiveness of that range of responses, the research develops a framework in Section 5 based on the findings about facilitators and barriers to achieving supported living policy goals.

5 Framework for Effective Supported Living Services

This section defines a framework that incorporates the key components of effective accommodation support for people with disability from the findings in Section 4. The framework addresses elements of alternative models reviewed in the literature, considered core to evaluating the effectiveness of approaches to accommodation support in terms of the goals for people with disability.

5.1 Outcomes and Goals

Living independently
(from UN Convention on Disability)

- Opportunity to choose place of residence on equal basis to others (eg. type)
- Opportunity to choose where to live on equal basis to others (eg. geographical)
- Opportunity to choose with whom to live with on an equal basis with others (eg. housemates)
- Opportunity to choose conditions of informal and informal service provision (eg. provider; times/days; length; staff)
- Opportunity to change housing and accommodation support

Quality of life
(from the University of Toronto Quality of Life Profile)

- Achieves, encourages and facilitates overall well-being
  - Physical (eg. physical health, nutrition, exercise and general physical appearance)
  - Psychological (eg. psychological health and adjustment; cognition; feelings, self-esteem, self-concept and self-control)
  - Spiritual (eg. personal values; personal standards of conduct; spiritual beliefs)
- Achieves and facilitates personal goals, hopes and aspirations
  - Practical (eg. domestic activities; paid work; education or volunteer activities; seeing to health or social needs)
  - Growth (activities that promote the maintenance or improvement of knowledge and skills; adapting to change)
  - Leisure (eg. activities that promote relaxation and stress reduction)
- Achieves and facilitates connection with one's environment
  - Social belonging (eg. intimate others; family; friends; co-workers; neighbourhood and community)
  - Community belonging (eg. adequate income; health and social services; employment; educational programs; recreational programs; community events and activities)

– Physical belonging (eg. home; workplace/school; neighbourhood; community)

Culturally appropriate

- Considers the specific needs of Culturally and Linguistically Diverse (CALD) and/or Indigenous clients
- Is a general service appropriate for CALD and/or Indigenous clients or a specialised service targeted for CALD and/or Indigenous clients
- Ensures availability of CALD and/or Indigenous staff
- Ensures cultural competence of all staff
- Involves local cultural community

5.2 Administrative Systems

Interagency regulations and coordination

- Formal Memoranda of Understanding
- Levels of coordination and referral processes

Service provider policies and practice

- Consistent with Federal, State and Territory government requirements (eg. legislation, standards, CSTDA)
- Complaint mechanisms
- Consumer participation

5.3 Service Viability

Funding for housing and support for the person needing assistance

- Availability
- Flexibility
- Mobility

Sustainability of service

- In the short term
- In the long term
- Financial assistance needed to maintain and sustain
- Extra support / staffing needed to maintain and sustain (eg. formal and informal)
- Infrastructure assistance (eg. buildings) needed to maintain and sustain

Ability to expand service

- Need or demand for expansion
- Overall scope to expand
- Staff availability to expand
- Economically efficient to expand

- Responsiveness to demand (eg. service, building, funding and changed needs)

Replicability of service

- By other organisations (eg. government, NGO or private)
- Within the State/Territory to other areas
- Across other States/Territory
- Nationally
- For people with other needs

5.4 Formal and Informal Support

Staffing – formal support

- Qualifications and experience in the field
- Staff-to-client ratio (eg. appropriateness, costs and sustainability)
- Job satisfaction
- Philosophy towards supported living
- Managerial support for innovation

Informal support

- Sustainability of informal support (eg. short-term and long-term)
- Availability of support network (eg. accessibility, consistency and level of reliance on informal support)
- Level of contribution (eg. monetary, physical and emotional support and time)
- Contribution to decision-making for family member or friend with disability

Coordination between formal and informal support

- Communication between formal and informal support
- Availability of choice between informal or formal
- Reliance on informal support for effectiveness of formal support
- Opportunities for informal to contribute to service management

5.5 Summary of Framework

The framework is designed to assess effectiveness from the perspective of people requiring the accommodation support. It is applied to the six case studies in Section 7. Section 9 discusses the implications for application to other approaches for people who require 24-hour accommodation support.

6 National Case Studies

This section describes the six case studies of alternative approaches for people requiring 24-hour accommodation support. They were chosen as representing the range of approaches for people who require 24-hour support or who would otherwise live in a 24-hour support setting, either with their family or in formal residential care. The effectiveness framework from Section 5 is applied to the case studies in Section 7.

The considerations in selecting the case studies were:

- the innovative aspect of the approach;
- variation between the case studies and the type of support needs they address;
- the approach has been established long enough for participants to have experienced costs and outcomes;
- the approach fosters a personalised path to maximise independence, choice and flexibility;
- the service receives some funding under the CSTDA; and
- availability of existing data (research or evaluation) or opportunity for face to face investigation on at least some of the case studies.

All the case studies offer 24-hour support. Usually this is in the form of a package of formal and informal support, on-call support and more support at times of greater need. A central goal of many of the case studies is to diminish the necessity for 24-hour formal support for the people using the service. The case studies also vary the level of support according to the person's changing needs.

6.1 Lower Great Southern Community Living Association, Western Australia

Overview	The person with a disability and the person providing support reside in the same rental premises and share living expenses. To assure security of tenure, the lease is held by the person with a disability. Homes are rented mostly from a non-profit housing provider. The co-resident is paid a wage including salary packaging for the care provided, usually with one day off per week plus respite available every second weekend and four weeks annual leave. The person with a disability participates in day activities (which also provides respite for the co-resident) and other community activities based on a holistic approach to the person's needs.
Innovative dimensions	Co-residency offered through Lower Great Southern Community Living Association (LGSCLA) provides an opportunity for a one-to-one personal support relationship developing over time; and for more community participation. Training for staff on non-verbal communication used by people with challenging behaviours. Employing community development worker to enhance consumer participation in the community LGSCLA supplements funds for the program through running a store.
Model of support	Co-residency is based on the person with a disability sharing premises with another person who provides needed support. The co-resident is required to provide 24-hour back-up support and mentoring if and when necessary.
Key principles	Creating the most natural context in which people can be supported in a home environment, with a strong focus on community inclusion and participation; avoiding cluster housing. Individualised approach. Partnerships with other agencies.
People supported	33 people of varying disabilities and needs ranging in age from 18 years to 67 years are currently in the accommodation program, including co-residency arrangements and other individualised options. Most have an intellectual or cognitive disability, and some have other mental illness, physical disabilities or acquired brain injury.
Benefits / challenges	Benefits: development of close personal relationship between the person with disability and co-resident; opportunity for spontaneity in lifestyle in normal home environment; community connections; individuality and ownership of household items; level of disability does not preclude people from this model of care; low turn-over of support staff; cost-efficiency. Challenges: managing host family's needs for respite and holiday periods; managing the process of transition when the existing support worker wishes to move on; responding to the level of demand – there is a waiting list for service support; local communities do not always know how to include people with disability.
Evaluation	N/A
Contact	Kathy Hough, Executive Officer, LGSCLA: lgscla@iinet.net.au

6.2 My Place, Western Australia

Overview	My Place works with people with disability and their families to find accommodation that meets the individual clients' needs. People with significant disabilities (intellectual, physical and/or sensory), are supported across the Perth metropolitan area and the South West of WA.
Innovative dimensions	Provision of flexible, individualised accommodation options including: living in the person's own or family home with support; sharing accommodation with a carer, living with a host family and support for self-management of assigned disability funding packages; management ranging from full service co-ordination and management through to self-management in accordance with the client's wishes; individualised funding arrangements with funding usually provided by government.
Model of support	Individualised options are based on personal choice. Every person supported by My Place (other than those who elect to self-manage) has a dedicated Service Co-ordinator who assists them to design the lifestyle and accommodation supports that they wish for themselves. The Service Co-ordinator then assists the person, and any involved family members, to develop informal and formal supports to help the chosen lifestyle become a reality. They work with individuals to find a house that is comfortable, well equipped, affordable, close to services and in a suburb that they prefer. 70% live in their own homes (which they may be renting or purchasing), 10% live in their family home and 20% live with a host family.
Key principles	A person-centred approach. There is personal choice and control over how and where the person lives their life.
People supported	Supports around 120 people with a range of disabilities, including intellectual disability, cerebral palsy, multiple sclerosis, autism, muscular dystrophy and spinal injury, to live as independently as possible within the community (age range 15 to 70 years).
Benefits / challenges	Benefits: Individualised approach offers flexibility and increased personal choice and consumer control. Challenges: Management and resourcing of changing needs, particularly for people with degenerative conditions.
Evaluation / research	Random client satisfaction surveys are undertaken each year. Each of the three DSC (Disability Services Commission) programs under which My Place is funded (Accommodation Support Funding, Intensive Family Support and Post School Options/Alternatives to Employment) is monitored every three years by two Independent Standards Monitors appointed by DSC.
Contact	Peter Dunn, Managing Director, My Place (WA) Pty Ltd: peter.dunn@myplace.org.au Dr Greg Lewis, Managing Director, My Place Foundation Inc: greg.lewis@myplace. Website: www.myplace.org.au

6.3 Noarlunga, South Australia (Demonstration Projects)

Overview	This program's goal is to establish and maintain successful tenancies and improve quality of life for people with a significant mental health-related disability. Partnerships are formed between key agencies to provide a range of support needs, and service provision is individualised. Any type of housing arrangement is possible. Staff assist clients to find suitable accommodation. Positive contact between client and support workers has been a significant factor in the success of the project.
Innovative dimensions	A partnership involving key agencies: Housing SA, local Mental Health Services, and NGOs contracted to provide support.
Model of support	Support services provided in coordination with the provision of housing and clinical mental health services. Provision of support services to clients is managed by a full-time coordinator. Crisis management plans for each client include 24-hour contact plans and overnight support is provided where necessary.
Key principles	Client-centred and tailored to individual needs, focusing on promoting independence and providing support across life domains. Service provision across 7 days and outside of business hours.
People supported	10 clients, each assessed as requiring between 10 and 30 hours of support per week. Client ages range from 22 to 47.
Benefits / challenges	Benefits: holistic approach (problems other than immediate mental health were identified and addressed - drug and alcohol, physical, financial, domestic violence); individualised and highly varied (wide range of providers were engaged); attending community activities; social contact with the support worker was the most significant aspect of the project; positive impact on clients' families and the service system. Challenges: Prolonged negotiations and tensions among participants about the model, target group and leadership delayed the start of the project; ongoing, if reduced, tensions between Mental Health and other agencies; providing identified support needs (actual support hours are significantly lower than allocated hours); excessive paperwork for referrals; addressing underlying causes (eg. loneliness as primary reason for alcohol abuse); generally helping clients with entrenched drug/alcohol abuse; skills and personality of the support workers need to match the client's needs; ensuring ongoing progress and goal attainment with current clients.
Evaluation / research	Evaluation report in (February 2004) by the SA Department of Human Services
Contact	

6.4 Opening Doors Project (ODP) Riverland, South Australia (Demonstration Projects)

Overview	Supported accommodation for Aboriginal young people (15 to 25 years) whose independence is at risk due to mental illness and complex needs and who need assistance in finding and keeping accommodation. Among several demonstration projects across South Australia, this is the only one targeting Indigenous young people. It has a formal partnership between Anglican Community Care, Housing SA, Aboriginal Housing Authority, Child and Adolescent Mental Health, Riverland Regional Mental Health, and SA Department of Family and Community.
Innovative dimensions	Aboriginal sensitivity: understanding of transient life styles Inclusion of families and networks High level of presence in the community Support follows the client, rather than being tied to accommodation.
Model of support	The project supports clients to be housed and stabilised in a safe and suitable environment, whether that be at home with family and friends, or in private rental or public housing. Workers support the client wherever they live, and throughout housing transitions. Support is individualised and culturally appropriate: the program worker will develop goals and a support plan with the young person, will help establish links with their identified communities, and help them to make positive health choices and changes in their life (including developing home and self management skills, and community living skills). The program is predominantly delivered in the community, rather than being office-based. Transport assistance constitutes a significant part of service provision. A rostered staff member is available at all times by phone if the client is in crisis.
Key principles	Building capacity of the Aboriginal community; partnership among agencies; close contact with the client's community
People supported	The project currently supports 12 Aboriginal young people who have high and complex needs, including homelessness or housing instability, mental illness or risk of a mental illness, in contact with the juvenile justice system and/or child protection, and substance misuse.
Benefits / challenges	Benefits: flexibility in the extent of support provision over time and in accommodation options; holistic approach; the client's wider networks are included in the program Challenges: recruiting local Aboriginal people as support workers; managing staff workload with highly transient clients; finding agreement on eligibility criteria (severe mental health issues or early intervention for 'at risk' clients?), and accurate diagnosis; maintaining focus on both accommodation and other support needs; dealing with entrenched and chronic problems such as homelessness or substance abuse needs long-term engagement
Evaluation	Evaluation report by SA Department for Families and Communities
Contact	Anglican Community Care Riverland Project Kirsty Barnett, Manager, PO Box 1345, Berri SA 5343, (08) 8582-2344, 0417-876-289, kirsty@accberri.org.au

6.5 Tom Karpany House, South Australia

Overview	Tom Karpany House is a transitional accommodation service for Aboriginal men provided by the SA Department for Families and Communities under the Disability SA. The service assists people to improve their mental and physical health, budget planning, healthy diet (with a particular focus on diabetes management), and building self confidence, before moving into public housing with ongoing outreach support. A maximum of four clients live in the house at any one time. Tom Karpany supports Aboriginal men who have a long history of homelessness, mental illness, and/ or acquired brain injury, and/ or drug and alcohol abuse, and/ or intellectual disability. Clients have a history of slipping through service gaps, high use of services, long-term unemployment, and have been in police custody frequently.
Innovative dimensions	Tom Karpany services clients who are extremely vulnerable and have fallen between gaps in services for many years. Offers flexible, individualised 24-hour support; addresses whole of disability, not just limiting assistance to diagnostic type.
Model of support	Provides 24-hour active supported accommodation and outreach services to Aboriginal men with high and complex needs (alcohol, psychiatric, intellectual, behaviour). The goal is slow transition from homelessness to having supported accommodation, to independent housing and rehabilitation into work/education where possible. Individualised, highly flexible model of support adaptable to need. Several former residents have successfully moved into housing provided by the Aboriginal Housing Services, with ongoing support from Tom Karpany.
Key principles	Communal decision-making: Tom Karpany sets some requirements, such as a ‘dry house’, but other decisions are made jointly by the men at the service, eg. number of visitors. Patience: Service workers do not pressure clients to move out but wait until the client feels ready to live independently.
People supported	Transitional accommodation service, plus outreach service, for a total of 7 people
Benefits / challenges	Benefits: stable accommodation; Aboriginal staff help overcome cultural barriers; close collaboration with other agencies; residents decide house rules; improvements to life domains other than accommodation (eg. health, finances); participation in community activities and education Challenges: lack in police support; negative attitudes in the sector towards the program; identifying Aboriginal cultural practices
Evaluation / research	N/A
Contact	Ian Adams, Manager of Exceptional Needs Housing, DFC ian.adams@dfc.sa.gov.au, 0421-144-497

6.6 Uniting Care Wesley – South East Project, South Australia (Demonstration Projects)

Overview	One of 12 Supported Accommodation Demonstration Projects currently operating across South Australia. The target group for this project, are people with psychiatric disability who can, with support, live independently. The project aims to improve capacity and participation in activities and the community, promote personal choice, maintain housing stability and reduce acute admissions to hospital. Central to all Demonstration Projects is the concept of a partnership between government (mental health and housing services) and the contracted NGOs.
Innovative dimensions	Equitable partnership between key agencies, in this case Housing SA as the housing provider, South East Regional Community Health Service as the provider of clinical mental health services, and South East Community Living (Port Adelaide Central Mission) as a provider psychiatric disability support services. Additional partnerships, e.g. with GPs, to address service gaps.
Model of support	Clients live in housing of their choice (i.e. with family, private rental, own home) however most participants live in Housing SA housing. They receive 6-21 hours support a week from Community Support Workers in their own home and community. The program has a holistic approach and is recovery orientated. It includes a range of support such as help with household tasks, transport, attending appointments and activities, housing issues, budgeting, access to educational courses, relationship support, goal setting and self management. Support staff are available 7 days a week from 9am to 7pm and the manager is available by phone at any time. Relapse Prevention Plans are formulated with clients to help them identify early warning signs if they are becoming unwell and contact information for specialist and generic emergency services is provided.
Key principles	- Equitable partnership among key agencies. - Client choice: clients participate voluntarily and determine their own support needs. - Flexibility in level and nature of support, and over time. - Holistic - Community integration - Psychosocial rehabilitation: clients to develop independence and control over their lives through encouragement.
People supported	Eleven people are currently supported, seven of who live in Housing SA accommodation. In addition to psychiatric disability, eligible persons also have to have complex needs, be willing to receive support, and require support to live independently in the community.
Benefits / challenges	Benefits: social contact with the program workers impacts positively on many life domains; family members freed to live more independently; increased client independence reduces service needs; increased client self management; housing stability; improved health and confidence; continuity of support, case management and housing; collaboration among agencies in the sector Challenges: tensions between client/family expectations and nature and

	extent of support provided; servicing regional areas; managing staff and finances to respond to people's changing support needs;
Evaluation	Evaluation report by SA Department for Families and Communities
Contact	Uniting Care Wesley – Port Adelaide/ South East Region (SE Project), Coordinator, PO Box 3380 Mt Gambier SA 5290, (08) 8723 1125

7 Application of Framework for Effective Supported Living Services to the Case Studies

The framework to assess the effectiveness of supported living services (Section 5) is applied to the six case studies described in Section 6. The results are summarised for each case study in Table 7.1. Table 7.2 summarises the effectiveness findings in terms of implications for the development of alternative models for people who require 24-hour support.

Table 7.1: Effectiveness of the Case Studies in Relation to the Framework Criteria

Dimensions	Criteria	Model 1 LGSCLA	Model 2 My Place	Model 3 Noarlunga	Model 4 Riverland	Model 5 Tom Karpany	Model 6 SE Project
Outcomes and goals	Independent living	Co-residency (mostly rental from NGO), plus other options; day activities and flexible services	My Place helps clients find suitable accommodation of their choice; help with organising other support needs	Staff help clients find or maintain suitable accommodation of their choice; other support services wide-ranging and individualised	Staff support clients to establish stable and safe accommodation of their choice; flexible in types and extent of support over time	Transitional group home plus outreach; flexible and wide-ranging service provision, towards independent living	Independent living with support, mostly in social housing; flexible in types and extent of support over time; client determines support needs
	Quality of life	Close relationship with co-resident; extensive community connections through co-resident; ownership of household items; help with managing disability funding	Close relationships where clients live with family or a co-resident; help with service access and developing informal support	Good relationships with support workers; holistic approach (incl. drug and other problems); community activities; increased independence	Involves client's families and networks, where possible; holistic approach (incl. health and home management)	Holistic approach (incl. health, budget planning, self-esteem); communal control over house rules; community activities, education; increased independence	Good relationships with support workers; holistic services (incl. housework, budgeting and transport); increased housing stability; community integration; increased independence
	Culturally appropriate	Can be provided in culturally sensitive manner if required, eg. client and co-residents can be from the same group	Not mentioned, but accommodation option can theoretically be culturally appropriate, if required	Not mentioned, but can theoretically be provided in culturally sensitive manner, if required	Targeted at Aboriginal young people; sensitive to cultural needs; involves the community; but: difficult to recruit local Aboriginal people as support workers	For Aboriginal men; Aboriginal staff; sensitive to cultural needs within reason	Not mentioned, but support can theoretically be provided in culturally sensitive manner, if required
Adminis-trative systems	Inter-agency regulation and coordination	Participation in service provider networks; partnerships with government local area coordinators	For-profit business, but 87% of all funding received is annexed for direct client support and transferred to a separate non-profit NGO. All direct staff are employed by and supervised through the NGO.	Formal partnership among key agencies; integrated services; initial tensions among partners about the model, target group and leadership	Formal partnership among key agencies; successful, long-standing collaboration; effective collaboration with other agencies	Government-funded service; formal inter-agency links with other service providers and police	Formal partnership among key agencies; additional partnerships to address service gaps; project has increased collaboration in the sector

Dimensions	Criteria	Model 1 LGSCLA	Model 2 My Place	Model 3 Noarlunga	Model 4 Riverland	Model 5 Tom Karpany	Model 6 SE Project
	Service provider policies and practice	Encourages clients to make choices; develops individual support plan with them; regular client satisfaction surveys – client feedback mostly positive; policies (eg. about complaints) were revised in response to client feedback	Develops individual support plan with client; helps client adjust the plan as circumstances change; helps with plan implementation; regular client satisfaction surveys – client feedback mostly positive	Clients participate in the development of their individual support plans.; The evaluation shows clients are satisfied with their input into decision-making; written policies on complaints, appeals, program exit etc.)	Service provision is individually tailored. Support is responsive to client needs; comprehensive policy and procedure manual (for referrals, appeals, grievances, risk management)	'Dry-house' policy set by the provider, residents decide other house rules collectively; individual plans are developed with the clients	Developing individual goal and support plans was difficult – needed to establish trust first; flexibility in support over time; clients satisfied with support, and feel they can raise any problems with the support worker
Service viability	Funding for user	Client is individually funded by the government; funds are portable, and client has control over them; LGS charges 15 per cent for staff and administration; lease for the residence is held by the person with a disability; co-resident is paid a wage	Client is individually funded by the government; funds are portable, and client has control over them; My Place charges 13% of total funding for service management and co-ordination.	Clients pay 25 per cent rent from their pensions; most have their funds managed by the Public Trustee	Clients pay 25 per cent rent. Program has access to brokerage funds which may support them with loans (for buying furniture etc.)	Residents pay 55 per cent of their pensions for board and lodging; they have control over the rest	Clients pay 25 per cent rent.
	Sustaina-bility of service	Depends on government funding to clients; LGS has grown year by year, but government funding not sufficient to always provide high quality care; two people sharing reduces costs	Depends on attractiveness of the service to potential clients: they freely choose to engage My Place to manage their funds	Depends on ongoing direct funding from government; service provider is optimistic because outcomes are positive	Depends entirely on ongoing direct funding from government; needs suitable staff to establish the service within the Aboriginal community	Depends on ongoing direct funding from government; optimistic because program is included in department's strategic plan and it services politically sensitive clients	Depends entirely on ongoing direct funding from government; government seeking further efficiencies to ensure maximum value for money.
	Ability to Expand Service	Demand exists, but LGS is hesitant to expand further. Expansion, however, is occurring, with a focus on maintaining the best interest of existing clients	Capacity reached in full service co-ordination, some growth capacity in self-managed options	Capacity reached, but overall demand exceeds available places for eligible participants	Depends on government funding and availability of suitable staff;	Depends on government funding; demand exists; would need a second or larger house; outreach services have already expanded	Waiting list; servicing more people with current funds would compromise quality of support and viability of the service

Dimensions	Criteria	Model 1 LGSCLA	Model 2 My Place	Model 3 Noarlunga	Model 4 Riverland	Model 5 Tom Karpany	Model 6 SE Project
	Replicability of service	yes	Yes	yes	yes	yes	yes
Formal and informal support	Formal support	Co-resident: lower turnover than regular support staff; individual coordinator for each client; staff use a flexible rather than clinical or structured approach	Service coordinator manages client's support funds	Recruits staff who are skilled in empowerment and rehabilitation; client's needs should be matched with staff's strengths	Needs local Aboriginal staff as support workers; uses local Aboriginal elder to increase service's credibility	Half of staff are Aboriginal as a policy; staff provide emotional support to the clients and engage in community activities together with them	Project staff provide day-to-day support; psychosocial rehabilitation approach: doing things *with* the clients, not *for* them; social contact between client and staff very important to program's success; other formal support from Mental Health
	Informal support	Community-based model of care helps to maintain the client's existing network	Client usually lives in the community, retains informal support	Families are involved with client's consent	Most clients live with family; understanding of mental illness and acceptance of the program are limited	Clients were homeless before – usually bad relationships with family	No reliance on families for support; clients can build their own networks through attending community facilities; family members can live more independently
	Coordination between formal and informal support	Client gets involved in the co-resident's networks; contacts with other clients through LGS activities	Client alone, and/or with their family, decides how much formal support they wish to buy	Noarlunga support workers help clients to form new relationships or re-connect with family	Staff work closely with families and networks if client consents; sometimes they mediate between client and family (eg. around contributing to the household); staff work hard to gain acceptance for the service within families and the community; goal of community capacity building	Families are involved if client consents	Family involvement in the program is encouraged if client consents

Table 7.2: Summary of the Effectiveness of the Case Studies in Relation to the Framework Criteria

Dimensions	Criteria	Summary
Outcomes and goals	Independent living	In all models, clients are encouraged to choose where, how and with whom they live, and to live as independently as possible. The range of options depends on the client's capacity to choose and live independently. Some models support clients with high accommodation needs (especially Tom Karpany and Riverland) and try to increase their independence and ability to choose accommodation, while continuing to support them along the way.
	Quality of life	All models have a person-centred, holistic view of the client and address a range of support needs in addition to accommodation. Service workers or paid co-residents are highly engaged in practical and psychological support of their clients. The private service, My Place, is more restricted in this regard, but clients are aware of this and engage My Place by choice.
	Culturally appropriate	Riverland and Tom Karpany are specifically targeted at Aboriginal clients and try to be sensitive to cultural needs, e.g. by engaging Aboriginal staff. The other models have not mentioned any cultural issues, but their client-centred approach makes it likely that services could and would be tailored to different cultures.
Adminis-trative systems	Inter-agency regulation and co-ordination	There is a wide spectrum among the models: My Place is a stand-alone business, LGS participates in provider networks, and the other four models work in formal partnership with other agencies. It is not obvious that any particular level of coordination increases effectiveness of support for the client. Even among the formal partnerships one works very well and another has ongoing internal tensions.
	Service provider policies and practice	All providers develop individual support plans with the client. They keep plans flexible and adjust them according to the client's changing needs. All models seek client feedback, and policies and procedures are adjusted in response. Riverland even shifted the main focus of its support.
Service viability	Funding for user	All clients have full control over their government support funds, unless funds are managed by the Public Trustee. Two of the models are fully government-funded, while the other four charge clients a relatively modest percentage of their disability support. Of these, Noarlunga and Tom Karpany charge the most, but that amount covers rent and, at Tom Karpany House, food.

Dimensions	Criteria	Summary
	Sustaina-bility of service	Four of the models rely on direct government funding. Among these, the SE Project is under pressure from government to stretch the money across more clients, and Riverland needs suitable Aboriginal staff to keep the service viable. My Place receives 90% of its funding directly from government and the other 10% from compensation pay-outs. LGS is funded through client contributions, and has managed to expand its client base. LGS finds, however, that government support to clients is not always sufficient to provide quality care.
	Ability to Expand Service	Unfilled demand exists for three of the models, and additional government funding would enable expansions. Among the others has reached its capacity, with the exception of clients who wish to self-manage and only use My Place's funding administration services; Noarlunga has reached capacity, but services a very specific and therefore small potential client pool, so that expansion would be gradual and modest; and Riverland is still establishing credibility within the Aboriginal client community. As credibility grows, demand will presumably grow, along with a need for increased government funding.
	Replica-bility of service	All models are replicable, as long as funding and well-trained, suitable staff are available. None of the models require large capital outlays or any other material resources that would restrict replication in other towns, areas or states, or by other organisations.
Formal and informal support	Formal support	All models assign individual client support workers or other ongoing contact people (including co-residents) to each client. Personal relationships form and contribute significantly to the models' effectiveness. Support is always flexible and client-centred.
	Informal support	As part of their holistic approach, all models help clients to enhance their own support networks in the community. The client retains control, and their families are involved only if the client consents.
	Coordina-tion between formal and informal support	If the client consents, staff may work with their families to determine support needs, finetune ongoing support, or build and improve relationships. The SE Project frees families to live more independently by taking over some of their support work.

8 Cost Effectiveness Analysis

8.1 Introduction

The following analysis compares the six case studies described in Sections 6 and 7 with the Stancliffe and Keane (2000) analysis of outcomes and costs for people living in group homes and semi-independent living, NSW. Where the data are available, it includes costs to all stakeholders, including government, clients, service providers and informal carers. Other costs are not included in the analysis, such as costs to other government departments, increased use of generic community services (e.g. emergency and health services), unintended consequences or possible future costs associated with providing unsuitable or incomplete services. These are noted in the analysis where relevant. Comments on cost impact of rural and regional differences are included in the discussion where the data are available.

The benefits include client outcomes found to be significant between the two models in Stancliffe and Keane: social networks eg. friends and quality family contact; empowerment to make choices and decisions; use of community services eg. parks, clubs, shops; and participate in domestic tasks.

Data sources were a cost survey to the six case study providers, interviews with the managers and clients, financial records where available and comparison to the Stancliffe and Keane analysis.

Average number of all clients

All data in the analysis are about the group of clients supported in the same accommodation support service, unless otherwise stated (Table 8.1), for example, all clients in the same house or all clients supported by the case managers or family.

Table 8.1: Number of Clients and Model Identification

	Case study models						Comparison models*	
	LGSCLA	My Place	Noarlunga	Riverland	Tom Karpany	SE Project	Semi-independent	Group home
Model	1	2	3	4	5	6	7	8
Average number of clients in this accommodation support service	33	90	17	15	6	11	27	27
Average number of all clients using services from this organisation	51	90	17	15	7	11	-	-

Notes: * Stancliffe and Keane (2000). Clients were from a number of services, some living with other clients

8.2 Costs and Funding

Housing costs

None of the service providers own properties. Although the Stancliffe and Keane analysis did not include housing costs, this is likely to be the biggest cost difference between these models and group homes. The case study models assist clients to make housing arrangements in a range of housing options. Some service providers did not

supply housing costs for the analysis because housing costs are commonly fully met by the client (Table 8.2). Costs to government, such as social housing, are not quantified here. Government costs in these options are the same as costs for other members of the public.

Table 8.2: Housing Costs per Client, Annual ($)

Model	1	2	3	4	5	6	7*	8*
Rent	25% income - social housing	Social housing or client cost	3,370	client cost	3,484-12,000	3,292	-	-
Other expenses eg utilities, maintenance	client cost	client cost	2,000	client cost	36,120	client cost	-	-

Notes: Does not include cost to government of providing social housing
* housing costs were not included in the Stancliffe and Keane analysis.

Most other housing costs are also paid for directly by the client, such as electricity and gas, water, telephone, cleaning and gardening. The managers did not have figures for depreciation of furnishing, fixtures and equipment. Housing costs, including rent, are low compared to market rates because most people in these models live in social housing, shared housing or with informal carers. Some models have direct links to social housing providers (eg. LGSLA and Tom Karpany). In others, housing with informal carers and co-residents is part of the model design, which has the effect of reducing housing costs.

Accommodation support hours and cost

All models only provided accommodation support rather than providing owned housing. The support hours are to assist the client to live in their current housing eg. support to shop, cook, personal care and case management (Table 8.3).

Table 8.3: Accommodation Support Hours per Client

Model	1	2	3	4	5	6	7	8
Average hours p.w.	41	78	10	46	38	39	10	42
Range hours p.w.	-	7-168	5-30	-	-		2-30	20-71
Average cost p.a	40,587	62,201	15,875	90,530	50,553	38,532	13,434	41,173
Range cost p.a.	17,000-105,000	8,666-112,835	7,800-46,800	-	-	-	2,426-36,972	17,032-137,083

Notes: p.a.= per year; p.w.= per week
Stancliffe and Keane costs are Consumer Price Index (CPI) adjusted from December 1997 to 2006 (155.0 to 120.0, price increase of 29.6 per cent www.rba.gov.au).

The number of support hours available to clients depended on their needs and varied considerably (average 42 hours per week per client; range 5-46). Average accommodation support hours (42 hours) were the same as group home support hours in the Stancliffe and Keane (2000) research. Most models include low hours options, similar to the Stancliffe and Keane semi-independent living models (only average hours (46) were available for the young Indigenous program (4) Riverland). Most

approaches also include options for a high number of support hours depending on client needs (except (3) Noarlunga, which provides 5-30 hours per week). The average hours and cost disguise the range of support hours within each of the models. Most models reported only qualified staff hours (except two). All models also rely on informal care hours, except Tom Karpany. Some models also incurred other direct accommodation support costs, which the managers included in this category, such as travel and activities.

> I live in a Housing SA house. I have support workers who come and help me to go shopping and get out of the house. My brother and my mum spend some time with me every now and then. (6)

The managers reported flexibility in the accommodation support in relation to when it is provided (7 days per week); which agencies or partnerships provided it; the amount of support (eg. increase or decrease as clients' needs and preferences change and at short notice should a crisis occur); and in which housing. The Riverland manager described how the support workers for a client remain stable, even when the clients change where they live.

Management and overhead costs

In addition, accommodation support incurs overheads through the organisation that employs the support staff or administers the funding (Table 8.4). In some cases this relates to direct service provision, such as travel. In other cases, the overheads are not directly attributable to any specific service but can be allocated over all the services. The Western Australian models are funded for 15 per cent administrative costs.

Table 8.4: Management and Overhead Costs per Client ($)

Model	1	2	3	4	5	6	7	8
Total cost p.a.	513,408	839,711	148,465	71,610	130,000	98,127	-	-
Cost per client p.a.	10,067	9330	8733	4774	18,571	8921	5490	13,980

Note: Stancliffe and Keane clients were in a number of services
Stancliffe and Keane costs are Consumer Price Index (CPI) adjusted from December 1997 to 2006 (155.0 to 120.0, price increase of 29.6 per cent www.rba.gov.au).

Administrative costs were similar for all models, at about $10,000 per annum per client. Exceptions were (5) Tom Karpany, which has higher costs from vehicles, managers and other costs associated with the complex multiple needs of this client group; and (4) Riverland, which also provides less formal care than the other models because of travel and different preferences of young people. The reason for pairing of the highest average support cost with the lowest management cost in (4) is unexplained. The management costs for the case studies are higher than the comparison semi-independent study but lower than the group home administrative costs. The data might not be comparable however, because the Stancliffe and Keane published discussion of the research does not include details about what is included in these costs.

In summary, average cost per client per year was between $24,611 for the model with lowest hours of support to $95,308 for the model with high levels of support for all people using the service (Table 8.5).

Table 8.5: Summary of Average Accommodation Support and Management Cost per Client per Year ($)

Model	1	2	3	4	5	6	7	8
Accommodation support	40,587	62,201	15,875	90,530	50,553	38,532	13,434	41,173
Management and overheads	10,067	9330	8733	4774	18,571	8921	5490	13,980
Total	50,655	71,533	24,611	95,308	69,129	47,459	18,931	55,161

Note: Range varies greatly in all models
Stancliffe and Keane costs are Consumer Price Index (CPI) adjusted from December 1997 to 2006 (155.0 to 120.0, price increase of 29.6 per cent www.rba.gov.au).

In comparison, cost data from the Productivity Commission (2007) shows the cost to Australian governments of accommodation support varies between settings and between providers. Government expenditure on NGO provided accommodation support services in group homes was $82,203. Expenditure on similar government provided services was $98,629 per user. Unlike the analysis in this report, these averages do not distinguish between different support needs and staff hours.

Funding

The case studies are consistent in the sources of funding or income including fees, government contracts and client expenses (Table 8.6). All accommodation support and management costs are state-funded. Housing costs are generally borne by the client, although if the clients access social housing, state government agencies responsible for housing share the cost. In these cases, clients pay a proportion of their social security payment, usually 25 per cent. These data also do not include the economic cost to informal carers for housing and accommodation support.

Table 8.6: Funding Sources for Housing, Accommodation Support and Management

Model Cost	1	2	3	4	5	6	7*	8*
Housing	Client	Client	Client	Client 95% State 5%	Client 25% State 75%	Client	-	-
Accommodation support	State	State	State	State	State	State	State	State
Management and overheads	State	State	State	State	State	State	State	State

Notes: Does not include cost to government of providing social housing
* Stancliffe and Keane did not include housing costs
In cases of individualised funding, 'State' means allocation of individualised funding for these costs

Some service providers reported funding for management was sufficient to also cover development funding such as community development, staff development and contributions to changing the broader service systems to be more inclusive of their client group.

8.3 Client Benefits

The analysis includes the client benefits that Stancliffe and Keane found to be significantly different between people in semi-independent living and group homes (Table 8.7). The service providers were asked to estimate and explain the average impact on wellbeing for clients in the service compared to clients in other accommodation support services. Clients were also asked about the same measures of change in quality of their lives. The manager data could include upward bias, which was addressed by asking the managers to explain the answers with examples and triangulating with the client data.

Table 8.7: Client Benefits

Model / Benefit	1	2	3	4	5	6	7	8
Social networks eg. friends, quality family contact	Above average	Excellent	Above average	Above average	Below average	Above average	Significant difference[1]	
Empowered to make choices and decisions	Above average	Excellent	Excellent	Above average	Average	Excellent	Significant difference[2]	
Use community services eg. parks, clubs, shops	Above average	Above average	Above average	Above average	Average	Excellent	Significant difference[3]	
Participate in domestic tasks	Above average	Above average	Above average	Above average	Above average	Above average	Significant difference[4]	

Note: Stancliffe and Keane 2000: 296, Table 5

1. Social dissatisfaction – semi-independent less dissatisfied 0.97-2.03
2. QOL-Q empowerment – semi-independent more empowered 24.11-22.02
3. Frequency of community use and number of community places used without social support – semi-independent used more 159.78-128.85; 9.22-6.22
4. Domestic participation – semi-independent participated more 19.37-16.96

Social networks

The reasons given for why social networks were above average included that many people in these models had previously lived with their families until the need for supported accommodation arose. The models of support adopted enable the person to remain connected with friends and family and supports are built around these, rather than replacing them. It is easier to maintain friendships and relationships than develop new ones, especially for people who have been socially isolated.

A couple of the clients mentioned that their previous housing had not been close to their family, isolating them and also meaning that they were unable to receive the support that they might have received from family:

> I didn't like living in [city]. It was too busy and I was isolated away from my family. I like where I live now as it's closer to family and closer to shops (4)

In addition, clients are supported to discover local options for meeting people and developing friendships. Support workers encourage people to reflect on their

interpersonal skills with family members and friends. The workers, family members and friends can assist clients to bridge communication gaps and encourage healthy relationships.

> I like to spend time with my friend … who comes out on day leave. My brother … and my mum also come around. I like spending time with my neighbour who visits me regularly and also my support workers. (6)

One client talked about her support workers believing in her and encouraging her to get her children back:

> My support workers helped me believe that I could get my kids back. My psychiatrist, mental health worker and support workers helped me to believe that I could have a normal life (4)

In contrast, the poorer rating in the Indigenous service is explained because families have often ditstanced themselves from the clients and many friends had drug and alcohol problems. The support service aims to gradually rebuild more constructive relationships. One of the clients said that he would like to live with his family but that this was not an option for him, 'I'd rather live with family but that's no good for me or my sister.' (1)

Empowered to make choices and decisions

Each of the models starts from a client-centred approach in service planning, design and provision. In many of the models, the clients live alone or are the leaseholder for their housing, empowering them to control their housing environment. Their ability to make choices is enhanced with information, skills training and control over their funding. Several programs provide skill development for self management (SE Project) and assertive communication (LGSLA). Workers support clients to face challenges that increase their abilities and skills. Some decisions are restricted for legal reasons, such as guardianship, parole and bonds in Tom Karpany.

Several of the clients mentioned that they like where they currently live because they have the choice to do what they want to do when they would like, 'What I like about where I live is that I can do what I want.' (3)

> I lived at my mum's place before I moved here. It is better here because I have my own space and my own bedroom area. I can also smoke inside the house sometimes. It is worse here because I have to do all the cooking myself and I don't get to have mum's cooking. (6)

Use community services

Use of community services is generally through formal and informal support to access mainstream services. The managers emphasise engagement in activities that are meaningful to the client. LGSCLA also invests in community development to assist mainstream services to become accessible for everyone in the community. The Noarlunga manager described the purpose of using community services as follows,

> Clients are encouraged to participate in community services as much as possible, in order to reduce isolation and increase their abilities to get out of the house, and feel comfortable doing so.

Other managers reported improved access to health services and professionals, which has had the effect of reducing hospital admissions (eg. SE Project).

Participate in domestic tasks

All clients reported participating in domestic tasks. The level of independence depends on their skill level and support needs of the clients. Service providers described assisting people to develop their skills to create independence. It is also dependent on clients' choices as to the focus of their support hours. Skill development ranges from classes to individual prompting. Many clients had never had a home of their own to look after so the timeframe for skill development is long term.

One of the domestic tasks that the clients talked quite a lot about was food preparation. Food preparation varied from client to client. Some clients prepared their own meals and liked that they were able to choose their own meals and others had their meals preapred for them.

> I choose what I buy at the shops, what I cook and what I eat for dinner. I do most of it by myself. My brother helps me sometimes when he is here. I eat by myself, and sometimes with my mum, brother or my neighbour. (6)

Other benefits

A small number of clients were asked about aspects of their personal wellbeing. The number of respondents is too small for quantitative analysis. It is still possible to make some comparisons. The scores show clients receiving these models of accommodation support have a high level of personal wellbeing across most domains (Table 8.8).

Table 8.8: Personal Wellbeing of Clients in Case Studies (range)

Model	1	2	3	4	5	6
How happy do you feel about:						
Your life as a whole	5-9*	9-10	-	-	6-9	2
Things you have	7-10*	9-10	-	-	5-7	10
How healthy you are	5-10	8-10	-	-	7.5-8	4
Things you make or things you learn	9-10	9-10	-	-	5	9
Getting on with the people you know	7-10	9-10	-	-	8.5-9.5	10
How safe you feel	9-10	9-10	-	-	3	5
Doing things outside your home	8-10	9-10	-	-	8.5	9.5
How things will be later on in your life	5-9	9-10	-	-	4-9.5	5
Number of respondents	4 (*5)	4	-	-	2	1

Note: Personal Wellbeing Index (PWI). Scale 0-10 where 0=completely unhappy, 10=completely happy (IWG, 2005; Cummins & Lau, 2005)

This is consistent with the Stancliffe and Keane (2000: 296) analysis, where all clients had positive scores for measures of personal wellbeing and people in semi-independent living had higher scores than people living in group homes on the measures discussed above. Given complexity of support needs, the Tom Karpany manager noted that progress can be slow but that the clients have experienced good progress in some life domains. This variation is also evident in the Tom Karpany clients' self assessment of wellbeing.

Several of the clients mentioned that they liked having their 'own place' because it gave them their own space and they did not have to share with other people. It gave them something that was 'their own':

> Yes. I lived in a group home with a lot of other people. What is better about where I live now is that there are less people. Where I live now is 'my house'. (3)

Being able to have their own place rather than living in a group home also meant that some of the clients could now have their children live with them.

8.4 Summary of the Cost Effectiveness Analysis

Direct housing costs to the disability government agencies, service provider and person with disability in the case studies seem to be less than some group home models. This is probably because of the range of places that people live and the source of contributions to the housing costs. These included clients contributions, co-resident contributions, subsidised rent through social housing and economic costs to family members through informal care arrangements. The implication is that the other economic housing costs associated with these approaches are incurred by other parts of government (eg. social housing) or families. The analysis does not capture information about other parts of government or families incurring the economic, if not financial, cost. None of the service providers own the housing in the case studies.

Accommodation support and management costs for these case studies appeared to be lower than or similar to group home costs. The range includes lower costs where people's support needs change following stabilisation of suitable accommodation support and housing.

The effectiveness results are also consistent with the Stancliffe and Keane (2000) analysis, which found that the benefits are likely to be higher for clients in these alternative models of accommodation support than for matched people living in a group home. Clients and managers reported high levels of benefits in the fields found to be different between people supported in group homes and semi-independent living in the 2000 analysis.

9 Conclusion

Trends in Australian accommodation support policy for people with disability are consistent with international policy changes. Governments are considering innovative methods of providing sufficient levels and types of support for the needs of people with disability in a cost effective manner. This report presented findings about factors most likely to be associated with cost effective approaches to accommodation support. These include a focus on client outcomes, administration practices, affordability of services (for client, provider and government) and sustainability.

Examples of innovative models from Australia and internationally were outlined in order to exemplify current theoretical and policy trends. Six Australian innovative case studies were analysed in detail in regards to the above factors in order to determine cost effectiveness. The case studies have independent living as a central feature, either as their accommodation setting or as a goal for attainment following a transitional program. They all also provide individualised services and support planning and encourage the participation of the client in the decision-making process where possible. An important issue for many of the programs was cooperation between accommodation support providers, housing providers and funding bodies (both government and private). Cost effectiveness of accommodation support in the alternative models analysed was shown to be greater than in traditional group homes. Outcomes for clients were shown to be better while costs were generally similar, and in most cases, lower.

It is evident, then, that future models of support and accommodation provision for people with disability traditionally needing 24-hour support should, irrespective of the accommodation setting or level of support needed, be focused on an individual approach to accommodation support. This can facilitate mobility, flexibility as needs change and options for integrating informal, formal and generic support. The research shows this approach is also most likely to meet the goals of supported living policy in terms of human rights, quality of life, independent living and cost effectiveness.

Appendix Selected Relevant Evidence-based Research

Australian

Author/s: Bigby (2006)

Method: A qualitative study with 58 Australian people being transferred from large institutions to small group homes about their current living arrangements.

Overview: The study reviews the issue of relocation of people with intellectual disability from institutions to community living, and the contributing factors to success of such living arrangements.

Key Finding: The study found that issues of information sharing and coordination (or lack thereof) as well as staffing levels and training affected the flexibility of environment and satisfaction of client. In addition, accessibility and suitability of homes affect staff service effectiveness and user satisfaction.

Author/s: Buys and Tedman-Jones (2004)

Method: A focus group was held with six participants including service users, informal carers and service providers.

Overview: The study examined barriers to successful transition to autonomy for older adults with an intellectual disability.

Key Finding: The study found that options available to older adults with an intellectual disability are inflexible and do not foster autonomy. In addition to this, the study found that older informal carers (mostly parents) can present a barrier to autonomy and choice by being over-protective and not promoting autonomous action.

Author/s: Carlson and Kooten (2001)

Method: Group interviews with 18 disability support and ethnic community workers were held as well as two individual interviews with family carers of CALD backgrounds.

Overview: The study examines services provided to people with intellectual disability of culturally and linguistically diverse backgrounds and the barriers to good support services

Key Finding: The study found that five main factors negatively affected effective service provision and utilisation: i) isolation from wider society; ii) cultural beliefs and differences, especially regarding intellectual disability; iii) language difficulties; iv) limited inter-sectoral links (e.g. between CALD community organisations and disability support services); and v) lack of access to information regarding help available.

Author/s: Stancliffe and Keane (2000)

Method: Interviews and questionnaires with 31 group home residents, 56 semi-independent residents and 35 support service staff.

Overview: The study examined the difference between semi-independent community living and group homes in relation to outcomes and costs for people with an intellectual disability.

Key Finding: The study found semi-independent community living arrangements to be more beneficial to people with intellectual disability than group

homes, especially on issues of community participation, empowerment and domestic capabilities.

Author/s: Young et al (1998)

Method: Reviewed 13 Australian studies regarding deinstitutionalisation of people with intellectual disability published in peer-reviewed journals.

Overview: The study quantifies and reviews Australian studies relating to the effects of deinstitutionalisation on people with intellectual disability.

Key Finding: The study found generally positive outcomes obtained from deinstitutionalisation, mainly with issues of adaptive behaviour and community participation.

Author/s: Stancliffe (1997)

Method: Qualitative research with 65 people living in households with five or less occupants.

Overview: This study examines the effects of the size of the living unit, and the level of support staff presence, on the levels of choice making of people with an intellectual disability.

Key Finding: The study found that lower levels of staffing and smaller living units foster more capability for choice and autonomous action even when other factors, such as levels of intellectual disability are taken into consideration.

United States of America

Author/s: Heller and Caldwell (2005)

Method: Longitudinal qualitative and quantitative evaluation of 301 families using the program and 835 families on the waiting list.

Overview: The study evaluated the Illinois based Support Services Program, which offers families of people with intellectual disability individually tailored support services.

Key Finding: The study found lower levels of necessity for out-of- home placement of the member with an intellectual disability in families using the program as well as higher levels of satisfaction

Author/s: Kim, Larson and Lakin (2001)

Method: A quantification and review of 33 American studies (all longitudinal or contrast group studies) regarding deinstitutionalisation was conducted.

Overview: The study followed on a previous review of studies of deinstitutionalisation of people released between 1976 and 1988. This study was to ascertain whether relatively recent research supports the earlier findings that positive behavioural outcomes were closely associated with deinstitutionalisation of people with intellectual disability.

Key Finding: As with the previous study, almost all of the studies showed statistically significant increases in overall adaptive behaviour, although there was less agreement regarding levels of challenging behaviour.

Author/s: Howe, Horner and Newton (1998)

Method: Qualitative and quantitative evaluation of the lives of 20 matched couples of participants in Oregon, half receiving traditional

residential services and half receiving supported living services. Service costs for each participant were also studied

Overview: The study compared supported living with traditional residential services.

Key Finding: The study found that participants receiving supported living services experienced significantly better integration into the community. Costs were calculated to be similar for both types of support.

Author/s: Burchard et al (1991)

Method: 133 adults with mild or moderate levels of intellectual disability living in either small group homes, supervised apartments or with their natural family participated in the study. They were examined on issues of adaptive behaviour, lifestyle normalisation, problem behaviour, satisfaction and personal well-being. Care providers were also interviewed.

Overview: Examined aspects of success of different living arrangements of adults with intellectual disability.

Key Finding: The study found that although social integration, that is participation in activities with peers without a disability, was very limited for all participants, people living in supervised apartments had the most normative lifestyle and choice-making capacity. Levels of well-being and satisfaction were similar for participants in all three groups.

United Kingdom

Author/s: Priestly et al (2006)

Method: Interviews with 102 lead officers in randomly selected disability service purchasing authorities throughout the UK.

Overview: The study examines the availability, take-up and differences of direct payments and direct government service provision.

Key Finding: The study found that direct payment programs were popular with service users and had growing level of take-up by recipients of support services. The study found lack of understanding and apprehension among authorities to be main reasons for low levels of take-up in some areas.

Author/s: Emerson et al (2004)

Method: Process and outcome variables were collected on 169 adults with intellectual disability living in cluster housing and 741 living in dispersed housing.

Overview: The study compared the outcomes of two different types of living arrangements (cluster housing and dispersed community housing) for adults with intellectual disability.

Key Finding: The study found that there were many more benefits to dispersed community living arrangements than to cluster housing, especially on issues such as restrictiveness of atmosphere, level of active lifestyle and staff interaction.

Author/s: McConkey et al (2004)

Method: 20 focus groups were held with 180 adults with varying degrees of intellectual disability. Views regarding living arrangements in general

were studied as well as preferences regarding unfamiliar kinds of living arrangements.

Overview: The study examines living arrangement preferences of adults with an intellectual disability in the context of existing arrangements policy changes.

Key Finding: Themes identified as commonly important to most participants included social interaction (especially with family members), participation in household activities and having ones own room. Most participants preferred their current living arrangements to others proposed.

Author/s: Fakhoury et al (2002)

Method: Existent literature regarding supported housing for people with mental health issues was quantified and reviewed.

Overview: The study examines research methods and models of housing and support services for people with a mental illness.

Key Finding: The study found that new supported living arrangements tended to 'cream-off' the less disabled and less antisocial in favour of people who were difficult to leave unsupervised, meaning the most disabled were many times lumped together and supported in the worst conditions.

Author/s: Robertson et al (2001)

Method: Examined the size and make-up and contributing factors to social networks of 500 people with intellectual disability receiving different types of residential support.

Overview: The study examines social networks of people with an intellectual disability in a residential setting.

Key Finding: The study found that personal characteristics of the participants affected the size of their social network, with participants who were younger, with lower levels of intellectual disability and less challenging behaviour having the largest social networks. The study also found that living arrangements also affected size and make-up of social networks, with participants living in supported community living and family homes had the largest and most diverse social networks.

Author/s: Mansell, McGill and Emerson (2001)

Method: Longitudinal observations of staff and clients as well as evaluation of user skills and adaptive behaviour.

Overview: The study examines quality of life of people with severe or profound intellectual disability and challenging behaviour who have been moved from institutional care. The study also outlines and evaluates the work of the Special Development Team in the UK set up to help local authorities take care of such people.

Key Finding: The study found that clients generally showed significant increases in participation in meaningful activities after removal from institutions, without a rise in challenging behaviour exhibited. Staff interaction with clients increased and became of a more personal nature.

Comparative Research

Author/s: Lord and Hutchinson (1998)

Method: Examining existing evaluations of each program according to an equating study template.

Overview: The study examined 10 programs from Australia, the United States and Canada that aimed to supply individualised funding for people with disability with which they can purchase support services.

Key Finding: The study found that issues important to the success of such programs included: a holistic and coherent policy framework, facilitators/brokers instead of case managers and equity and accountability of funding to the user and the funding body.

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