Living

not existing

Flexible support
and housing for
people with a disability

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BACKGROUND TO THE PROJECT

Disability Support and Housing Alliance (DSHA)

The Disability Support and Housing Alliance (DSHA) is comprised of people with disabilities, advocacy organisations and service providers. It was formed at the Disability Housing and Support Forum - 'Living Independently: Access to Choice' held in Melbourne in February 1999. Its aim is to develop, promote and lobby for the provision of high quality community based housing and support options for people with disabilities.

DSHA has identified housing design and availability and individualised funding as key issues which need to be addressed to enable people with disabilities to live quality lives as participating members of the community.

This project

The objectives of the project were to:

1. Survey research literature and, in conjunction with key players, identify housing and support models for people with disabilities that maximise independence and options for community living.

2. Liaise with the disability sector and key academics to develop appropriate social policy for submission to government. The social policy will address the delivery of housing and support services.

3. Lobby parliamentarians, relevant government authorities, peak bodies and key service providers for the implementation of the policy from the project.
   The proposals put forward in this report have evolved from research and discussions held over the course of the project with people with disabilities, advocacy and service provider organisations, and government personnel.

The main focus of the project was on people with physical disabilities, particularly people with high support needs. However the principles and ideas proposed have equal relevance for people with other disabilities.

SECTION 1: INTRODUCTION

Support and housing are key issues that impact on the quality of life of people with disabilities. Unless people have suitable housing in the community combined with adequate and appropriate support they are denied the opportunity to fully participate in community life.

This document proposes a flexible approach to support and housing that would enhance the capacity for people with disabilities to have control of their life and the services and resources they need to live with dignity in their community.

The document focuses on paid support and funded housing options however DSHA recognises the importance of broader community infrastructure/issues such as transport, access to both public and private buildings/space, and community attitudes. Measures to address some of these issues are discussed in Section 4: The Context for Change.

While recognising that there are restraints on public funding DSHA believes that some of these restraints are imposed by political decisions that give low priority to the needs of disadvantaged people. This document seeks to challenge those unjustly imposed limitations and proposes flexible and fair access to resources for people with disabilities.

The proposals put forward in the document are based on the following premises about the rights of people with disabilities:

Entitlement

People with disabilities are entitled to the same opportunities as others for a quality life in the community. All people in our society use a range of funded and unfunded infrastructure and direct supports. People with disabilities may require additional supports to enable them to attain a quality of life commensurate with others in the community.

If people with disabilities require support to do or be involved in ordinary activities that other people do without support then this should be available at no cost. This could include physical, cognitive and behavioural support.

In the area of housing, assistance with specialist design, access issues and modifications should be available to all who need it. Public housing should be available to people with disabilities according to the same criteria as other people, however access needs (and associated costs) should be taken into account.

Principles

Key principles for the development of housing and support options were identified at the 'Living Independently: Access to Choice' forum held in 1999. It was agreed at the forum that housing and support options for people with disabilities must:

- offer people with disabilities real choice about their housing type, where and with whom they live.
- maximise flexibility to allow for changing needs related to life cycle and disability. This applies to both short-term and longer term life-style changes.
- maximise control for the individual over the service/s they use.
- ensure that supports are adequate and appropriate to meet the needs of each individual.
- ensure dignity, security, privacy and confidentiality.
- provide access to full participation in community life.
- provide for separate administration of housing and support services in order to minimise control of service providers over people's lives and to minimise conflict of interest.

SECTION 2: EXISTING NOT LIVING

Despite the relative affluence of Australian society there are critical levels of unmet need amongst people with disabilities. This was highlighted in the review of the first Commonwealth/State Disability Agreement in1996 and again in the Crisis Account report produced by Advocacy Victoria in 1999. Many people with disabilities have inadequate levels of support and describe themselves as "existing" rather than living a quality life.

2.1 Contributing factors

There are a number of factors that contribute to this situation:

Inadequacy of the funding base

The current funding base is well below what is required to meet even basic need. This inadequacy of resources impacts not only on people with disabilities but also on their family members, friends and paid and unpaid supporters.

Workforce issues

It has become increasingly difficult to recruit and retain quality workers to provide support for people to live their daily lives. This results in gaps in care provision (unfilled shifts), workers being rostered to work without adequate training, constant demand on users to train new staff in their specific care needs. This impacts particularly severely on people who have high support and/or complex care needs. Workforce problems in part relate to the inadequate level of funding. This has contributed to the current structure of in-home and community based support work. Work is casual, isolated and low paid. Training and worker support practices vary between service providers however most workers receive very little if any support. Training is often inadequate.

Discrete, inflexible programs

Discrete programs with inflexible eligibility/priority criteria and guidelines create complexities and barriers for people with disabilities. Managing and juggling services and 'working the system' become an all-consuming struggle instead of a means to enhance quality of life.

Scarcity of accessible, affordable housing

Victoria has a legacy of inaccessible and inflexible housing stock. This results in major housing problems for people with mobility limitations. Many people are forced into the public housing system because of the difficulties faced in accessing private rental properties. These difficulties include insufficient private rental stock, the prohibitive costs of modification in the private market and the reluctance of landlords to allow modifications.

2.2 Impact on people with disabilities

These factors impact on people with disabilities in the following ways:

Quality of life

In discussions with people with disabilities through the course of this project "quality of life" was seen to relate to issues of dignity, choice, control and community inclusion. Considerable emphasis was given to recreation, which was described as "a platform for social inclusion and community participation", not an add-on extra or a luxury. This includes social contact with family and friends. Several people talked about the frustration of not being able to participate in the normal "give-and-take" of social relationships (reciprocal visits, going out to dinner with friends or family, etc).

For people with very high support needs, the current maximum levels of funded support (no DHS program officially funds more than 34 hours per week) provide for "just basic survival not a life". This has been exacerbated by restrictions on the use of support hours imposed by guidelines of the various discrete funding programs. The impact of this is particularly severe on people who choose not to or cannot access some form of day program where personal care needs are met as part of that program.

Health

People with high support and/or complex care needs are experiencing physical and/or stress-related mental health problems because of:

- **Insufficient support**

This relates to the number of hours (ie. 34 hours maximum is inadequate for most people with very high and/or complex support needs) and also to the problem of shifts not being filled due to the workforce crisis in attendant care and disability services generally.

- **Type of care**

This relates to the quality of staff (level of skills and attitudes towards people with disabilities and attendant care work) and the stability of the staff team. The high turnover of staff in the attendant care industry impacts particularly severely on people with high and/or complex support needs.

- **Inadequate health practices**

Basic preventative or good health practices (e.g. exercise, nutrition and fluid intake, bowel and bladder care) are often not possible due to insufficient hours or restrictions on the use of hours.

- **Stress related to workforce crisis**

High turnover of staff and problems with recruiting staff mean that people are often having their care provided by unfamiliar attendants who have had little or no training.

- **Stress related to managing care**

Rostering, training new attendants, coping with unfilled shifts, etc. can be extremely time-consuming and exhausting.

Housing options

People with disabilities face significant disadvantage in their search for housing. A high proportion of people with disabilities exist on very low incomes (e.g. Disability Support Pension) and/or face higher than normal living expenses due to costs related to their disability. For people with mobility impairment the legacy of inaccessible housing means that suitable housing in either the public or private sphere is extremely difficult to find.

Many people whose support needs exceed the maximum limit of 34 hours per week remain in or are at risk of moving to inappropriate housing, including nursing home accommodation, acute hospitals or living with parents or other family members beyond the time when this arrangement suits either or both parties.

Real lives

The following stories illustrate the impact of these issues on the lives of people with disabilities. Identifying details, including names, have been changed to protect the confidentiality of people who told us about their lives.

Alex receives 34 hours attendant care per week and has managed well with these hours. However his disability has been compounded by age-related health issues. The community health centre has suggested regular swimming to keep him supple and to keep his body working. He cannot do this within the current guidelines and hours.

Sandra was hospitalised when ill due to lack of support hours not because her illness warranted hospitalisation. Her stay in hospital was extremely stressful as hospital staff were ill-equipped and under-resourced to meet Sandra's ordinary personal care needs. Twenty-four hour care for a day or two at home would have been more appropriate and much less stressful.

Nick lives on his own and has to spread his support hours across the day in order to have his basic needs met. To manage his evening toiletting routine within his allotted hours he gets on the toilet at the end of the early evening shift and must wait to get off the toilet until the late evening attendant arrives. Several times this attendant has not turned up and he has been on the toilet all night.

James is ineligible for public housing as his assets and income just exceed allowable limits. As he was unable to find suitable affordable housing in the city he moved to the country where he could afford to purchase housing. This has left him isolated from his existing support networks and has resulted in severe depression.

Ellen lived in a shared house with her boyfriend who assisted with some of her personal care support. She urgently required alternative housing due to domestic violence. As there was no accessible transitional housing Ellen's only option was to move into an institutional setting while she waited for long-term accessible public housing to be built and support funding to be available. Her support funding was approved after 18 months however the house was not available for another six months. Ellen was afraid she would lose her support package if she did not take it up, so she moved into the house before all the access problems had been suitably resolved.

SECTION 3: LIVING NOT EXISTING - FLEXIBLE SUPPORT AND HOUSING

The problems discussed above clearly illustrate the need for an individualised approach to support and housing that allows for flexibility in program and service guidelines and adequate levels of funding based on individuals' needs. Such an approach will significantly improve the quality of life of people with disabilities.

Housing and supports have traditionally been looked at in terms of "supported living programs". We need to move away from this program mentality and look at housing and supports as separate but related issues. This approach frees people to think more creatively about possible options.

3.1 Individualised funding for support services

The concept of individualised funding is about:

- people with disabilities getting **funding based on their individual needs**

- having **control over how this funding is used**. This means having the flexibility to meet their support needs in the way that best suits them, the choice to directly employ their own support workers or to purchase their support services through an agency of their choice.

Individualised funding is intended to encourage creative use of funds. This could be through using mainstream community services, negotiating with specialist services to tailor their services to individual needs or creating new services and supports if required.

Key principles of individualised funding

- Access to adequate funds to pay a fair price for necessary assistance.
- Flexibility to meet individual needs, culture, values and preferences.
- Power for decision making rests with people with disabilities.
- Freedom of choice and control of support providers.
- Portability, i.e. funding is retained by the individual if they move from one location to another, including interstate.
- Funding includes assistance with management of funds and supports if required.
- Responsibility by people with disabilities to be accountable, and trust by funders to allow self-determination.

Models of individualised funding

Individualised funding can be implemented in a variety of ways to suit people's needs. The administration of the funding can be with a maximum of self-management by the person or with the assistance of paid or unpaid supporters (family members, friends, advocates, guardians).

Direct payment

Direct payments are individualised funding with maximum control and maximum responsibility. Funding for assessed need is given directly to the person with a disability, who then manages the funds and purchases services, support and equipment from chosen service providers or individuals.

This system is in place in the UK, some European countries (e.g. Sweden) and some parts of Canada. Among the direct payment models there is diversity in the approaches used:

- Needs can be assessed by the individual doing self-assessment or by the funding body.

- Informal networks such as a 'circle of friends' or 'circle of support' can be set up by the person or with the help of the funder to assist in managing the funds and obtaining the services needed.

- Advice and information services about managing funds and support may be given to the person and/or their support network.

- Training in the management of funds may be provided to the individual by the funding body or some other organisation. Funding for this training may be part of an individual's package or organisations may be funded to provide this training. In some places non-profit organisations run by people with disabilities have been funded to provide peer training and support.

While self-management of funds is viewed by many as too arduous there can be valuable spin-offs from the experience gained. In the UK some people who administer their own direct funding have been able to gain accreditation for the skills they have acquired through managing their own funds and support services and have used this accreditation in gaining open employment.

Formal support to manage funding and services

Individuals may also choose to delegate some or all of the tasks associated with managing the funding and employing support workers to another individual or organisation. (e.g. service broker, financial administrator, training and support agency, service agency).

The spectrum of services possible through other individuals or agencies include:

- financial brokerage
- partial administration of finances and/or tasks related to employment of workers
- full management of finances and tasks related to the employment of workers.

Financial broker only	Partial management	Full management
Individual/their representative is employer of workers – recruits and manages workers Financial broker/organisation processes time sheets, pays workers, pays taxes, organises Workcover, etc.	Individual/their representative is still employer of workers Assisting person/organisation manages money (payroll, Workcover, etc.) Assists with recruitment, training and management of workers May provide training and support for individual / representative in management of workers	Organisation is employer of workers but individual/ their representative is still in control of their service (tasks to be done, day-to-day management of workers, choice of workers, etc.) Organisation manages all aspects of finances and employment administration Provides training and support for individuals/their representative in day- to-day management of workers

Future possibilities

Jane lives in a small rural town half an hour's drive from the nearest regional city. She has been using attendant care for many years and has become frustrated with the limitations and restrictions associated with obtaining her attendant care service through the 'approved' service providers.

Jane would like to receive a direct payment and manage her own support system. Initially this would be with the support of an innovative local disability agency, that would provide assistance with the recruitment (placing ads, using local community networks, police checks) and the administrative aspects of employment (Workcover, payment of attendants).

Jane would interview, train and supervise her own attendants and organise all aspects of the roster.Once the system is established Jane believes she could manage all aspects herself however she may choose to leave the financial management with the agency if this arrangement is working well.

Eligibility and levels of funding

The process of establishing eligibility and individual levels of funding will always pose difficulties. Public funding will never be enough to meet all needs and decisions about overall funding are issues of social policy which transcend any individual's personal need. However it is important that people with disabilities are involved in the development of policy around eligibility criteria and the process for allocating funds.

In a presentation at the International Self Determination and Individualised Funding Conference, held in Seattle, USA in July 2000, David Young, Manager of Contract Reform for the Ministry for Children and Families in British Columbia, identified features that should be part of any public policy about fair and equitable allocation of resources. These were:

- clearly defined eligibility criteria
- outcomes based
- full disclosure of all options (services and service providers available)
- full disclosure of service quality
- full disclosure of waiting list situation
- full disclosure of decision making rationale
- open and accessible complaint procedure.

In addition the process for determining allocation of funding should not encourage a 'competitive misery' system, in which people feel they must convince funders that their situation is worse than others competing for the same funds.

Assessment, planning and co-ordination

An **assessment** system has to provide a framework for funders to provide money, however it must also allow for the complexity of people's lives. Universal assessment systems have traditionally used inflexible tools that compartmentalise people's lives. The assessment process should be a 'structure of discovery' that looks at people's aspirations, strengths and capacities as well as their needs.

In order to determine eligibility and level of funding the assessment process will require guidelines on the issues to be addressed. The process should be assisted by someone who is aware of eligibility/funding issues but independent of both funder/s and service providers.

An individual funding plan should ideally emerge from a **holistic planning** process that looks at all aspects of life. Needs should be looked at in the context of the person's aspirations and goals. Planning of resources should involve both funded and unfunded options.

The planning process should be **directed by the person** and their nominated "supporters" (if desired). If the person is not able to nominate because of cognitive impairment then their key "supporters" should be involved. "Supporters" may be family, partner, friends, advocates. This core group works out what other input is needed.

Many people will need/want assistance with co-ordination of services and resources. This may be in the initial planning, on an on-going basis or at particular stages of their lives. Some people may need assistance with organising overall services and resources. Some people may need assistance to co-ordinate discrete aspects of their services/resources.

To ensure that any professional involvement adds value and that the individual retains control of the process, planning and co-ordination assistance should be provided by someone who:

• understands and is committed to the principle of self-determination
• is a planning and co-ordination assistant rather than a case manager
• is a skilled listener to people who may use a variety of communication means
• is familiar with the range of services
• has knowledge of the challenges faced by others in similar situations
• is creative in developing service/resource solutions where none currently exist.

3.2 Accessible, affordable housing

Housing needs of people with disabilities

People with disabilities need or desire alternative housing for the same sorts of reasons as other people. These include:

- adults living with parents who want and/or need alternative accommodation
- domestic violence/abuse situations
- parents with disabilities needing family housing
- people who are homeless
- people living in shared accommodation which is not working out or who just want to change
- people wanting to move to a different location.

In addition there are people living in institutional settings (ranging from hospital/nursing home to small group homes) who want and/or need alternative accommodation.

Housing issues for people with disabilities

Development of housing options should allow for creative and innovative thinking about location, type of housing, type of tenure and funding to ensure that housing and support options can be meshed to enable a quality life in the community.

Range of housing types

People with disabilities should have access to the range of housing types available to others in the community, that is, houses, duplex, flats/units, rooming houses.

There are also particular housing arrangements that may assist with the provision of appropriate supports. These include:

Back-to-back houses to enable support staff to work with people in both houses.

- 'Granny flat' on the same property. The 'granny flat' may be either for a person with a disability to enable private living arrangements while still having support from family, friends or paid carers living in the main house, or for paid or unpaid carer/s with the person/people with disabilities living in the main house.

- Two or three flats/units in a larger complex to enable shared support arrangements. Depending on the support needs of the people concerned support may be visiting or 'live-in' with care workers located in another unit within the complex.

- 'Neighbourhood' arrangements – houses clustered in a locality rather than on the same site, to maximise the use of support resources. Support arrangements might include a 24 hour on-call service through the establishment of a staff flat/bed-sitter in the locality for use by on-call support staff.

- Co-operatives - participation of people with disabilities in generic co-operatives where members share resources and support. For example, in Winnipeg, Cananda, co-operative communities provide not just the housing assistance people need, but also neighbour-to-neighbour relationships to support people with disabilities and their families.

Modifications

Given the difficulties associated with finding suitable housing, people with disabilities require timely access to expert advice and funding for housing modifications. This might be required several times in a person's life. Current guidelines of the Program of Aids for

Disabled Persons (PADP) only allow for a limited allocation ($5,000) for housing modifications for any individual. This limit is clearly inadequate in the light of normal changes over a lifespan and the cost of modifications.

There is also a need for an effective register of modified public housing stock to ensure that when a modified property is vacated it is re-allocated to someone who requires such a property.

Location of housing

Location of housing should fit in with a person's aspirations, chosen lifestyle, access requirements and support needs. This may include:

• being near family/friends/social networks
• being near work
• being near support services
• being in the community/environment of their choice (regional/rural as well as metropolitan)
• accessible location (topography, proximity to accessible transport)
• safe location.

While it is recognised that there are cost issues and that many non-disabled people make compromises in relation to the location of their housing, people with disabilities should not be expected to do this more than others in the community. It is also vital that housing location enhances the capacity for people with disabilities to develop their formal and informal support networks.

Establishment/relocation costs

Current housing establishment/relocation assistance is inadequate for many people with disabilities who have limited or no informal support networks and no accumulated funds or assets. For example, someone moving from long-term institutional accommodation to community based housing will need extensive assistance with all the practical aspects of relocation (purchasing furniture and household goods, connection of gas, electricity and phone, packing and unpacking belongings). Additional support hours and funding to cover expenses are needed to enable the person to carry out all these tasks.

Choice of living companion(s)

As for others in the community people with disabilities may choose a variety of living arrangements. These include:

• living alone
• living with family (partner, spouse, parents, children)
• living with friends/housemates who may provide some support
• living with support providers (either in-house or on-site)

People's needs and preferred lifestyle change over their lifetime. Guidelines for public housing must be flexible enough to allow for such changes and for household arrangements that enable relationships and support provisions of choice.

Tenure

People with disabilities need security of tenure and control over own housing. Housing tenure and support should not be tied. Possible tenure options should include those available to other citizens, that is, rental with their name on the lease or home ownership.

(a) Rental

People with disabilities need timely access to accessible public housing rental stock or adequate levels of rental assistance that take into account the costs associated with meeting their access requirements.Tenancy management should take into account the needs of people with high support needs. This includes:

- selection of tenant/s for a property should involve looking at who will be advantaged by the particular property (location, size, layout, environment, availability of formal and informal supports) not just selecting from the top of the waiting list.
- the ratio of tenancy workers to tenants has to allow responsiveness to tenants' needs including time to liaise with support providers.

(b) Purchase

People with disabilities have traditionally faced more restrictions in this regard, due to low income and the difficulties and costs associated with finding accessible housing. In addition, support and housing for people with disabilities have usually been linked and controlled by government departments or service agencies.

Approaches to funding

We need creative ways to increase the availability of accessible, affordable housing for people with disabilities. These might include:

• *Joint purchase/lease schemes* - an example of this is a pilot project run by the Supported Housing Development Foundation (SHDF). The project focuses on people who do not have sufficient funds to purchase their own house, but are ineligible for public housing because their assets exceed the eligibility limit for Office of Housing assistance. SHDF has assisted in this situation with a joint venture, in which there is shared ownership of the property. The individual has some equity in the property but, in order to comply with Centrelink eligibility requirements, cannot have their name on the title. They therefore rent the property from SHDF and are eligible to receive rental assistance with equity up to $90,000. The aim is to keep the housing affordable, that is, the rent does not exceed 30% of a person's income.

SHDF has only been able to assist a small number of people through this scheme. However access to interest free Government funds would considerably extend their capacity to provide this assistance.

• *Housing trust funds* - dedicated sources of revenue (e.g. a proportion of real estate sales tax) or a budget allocation committed to the purpose of providing low income housing. People with disabilities (or families) can "buy into" these trusts with modest amounts of money which is then invested.

• *Housing subsidies* – financial assistance that an individual receives to help with the purchase of a home and related costs (modification costs, upgrade funds, household establishment costs). Housing subsidies create greater opportunity for people with disabilities to live in decent, typical housing that would otherwise be unaffordable.

• *Housing associations* - non-profit organisations that finance and provide assistance with housing. Housing associations use a variety of strategies to increase the availability of low and moderate income housing and create long-term stability of housing options. They may develop long term management support services to co-operatives.

• *Bank housing loans for people on disability pensions* – in Wisconson, USA significant success has been achieved in obtaining housing loans for people who receive a disability pension on the basis that their income, although low, is secure.

SECTION 4: THE CONTEXT FOR CHANGE

Increased access to accessible, affordable housing, adequate funding for needed services and resources and control over how that money is used will assist many people with disabilities to significantly improve their quality of life. However, while these are important means to achieving greater community inclusion, they cannot meet people's social and emotional needs, nor create a community that is accessible and inclusive. On-going community development is needed to bring about cultural change. A range of systemic infrastructure developments will also be needed to bring about more equitable and flexible access to housing and support.

4.1 Community development

John O'Brien, a long-time advocate for inclusion of people with disabilities, argues that the most powerful medium for changing attitudes and culture is through "personal connections". Community engagement, both through informal networks and development of services, needs to be nurtured through community development.

Community development aimed at inclusion of people with disabilities involves "systematic effort to:

- increase the number of community members who are directly engaged in good relationships with people with disabilities in such roles as classmates, neighbours, co-workers, association members and friends
- assist people to organise and maintain support circles, family groups, assistance cooperatives, and other associations aimed at offering personal support and helping people effectively manage their personal assistance systems." (O'Brien, 1999)

DSHA supports the strategy of funding community development workers to work with local communities to:

- develop local responses to housing and support needs
- act as community facilitators to support participation of people with disabilities.

It is exciting to see this sort of community building approach taking place in Victoria through the Bracks Labor Government's RuralAccess Initiative. RuralAccess workers are to be based in key community organisations and Local Government Authorities. The Initiative aims to:

- *mobilise and provide support for people with disabilities to enable participation and integration in the life of their local community.*
- *build and strengthen the community's capacity to provide support to people with disabilities and their families through a range of strategies, including networking, community education, and development of policies, partnerships and specific projects.*
- *develop a framework for integrated local community planning and coordination that engages and involves people with disabilities and their families, disability service providers and community organisations.*
- *work with existing networks of disability service providers to enhance their capacity to provide relevant and appropriate supports in the community.*
- *improve access to information about relevant services and community activities available to people with disabilities in their communities.*

(DisAbility Services Division, Department of Human Services, April 2001)

DSHA believes this community building approach is required in both rural and metropolitan Victoria and looks forward to seeing its extension into metropolitan regions in the near future.

DSHA also notes that the recently released report of the Social Housing Innovations Project (Bisset 2001) proposes a number of community based approaches for the implementation of the Social Housing Initiative. These include housing associations (not-for-profit community organisations with the capacity to develop, own and manage social housing) and social housing partnerships between small community organisations and either a housing association or the Office of Housing. It is important that these initiatives include access by people with disabilities. Community development workers could play a vital role in ensuring participation of people with disabilities in any new housing development initiatives.

Future possibilities

John is a disability-focused community development worker based in the metropolitan municipality of Southbury. John is approached by a self help group (people with a degenerative neurological condition) seeking assistance with housing and support needs. One member of the group, Ken, owns a house in Southbury, and now shares the house with another group member, Jan. Jan and Ken pool their funded support hours so they can employ a live-in carer, whose 'pay' also includes free accommodation. Several of the group members have been unable to remain in their homes due to the breakdown of voluntary support arrangements and are living in highly unsatisfactory situations, including aged care nursing homes. They are keen to live in Southbury so that group members can pool resources and more easily provide each other with social support. John puts them in touch with a number of other people with disabilities who live in the local area and are looking for ways to 'stretch'/make best use of their support resources and a more broadly based housing and support co-operative is formed.

John assists the co-op to bring together relevant local resource people to work on finding a solution. They meet with representatives from an attendant care provider that works in the region, the specialist housing officer from the regional Office of Housing, a worker from the regional housing association and a representative from a disability housing resource organisation. This forms the core of an on-going working group that assists with obtaining funding for the purchase of several houses in a small geographical area.

An advocate from the regional advocacy group assists the people who are living in nursing homes to obtain support funding. Individuals in the co-op maintain the majority of their support hours individually, however they decide to pool some of their support funding to contribute to the provision of an out-of-hours service. The attendant care agency is able to combine the pooled individual funding with some additional resources to provide a locally based mobile night-time attendant care service that makes rostered visits and is also be able to respond to unexpected needs that arise.

4.2 Funding issues

Funding base

DSHA believes it is essential that there is acknowledgment of the real costs of ensuring basic rights and full participation of people with disabilities in the life of the community. While it is recognised that governments have finite resources it is unacceptable that many people with disabilities are still without even the most basic support services.

There is an urgent need for joint Commonwealth and State Government action to extend the funding base for disability services. For example, some form of disability insurance, funded through a mechanism similar to the Transport Accident Commission (TAC) or Medicare levy, is one possible model for expanding the funding base.

In the housing area consideration could be given to dedicated sources of revenue (e.g. a proportion of real estate sales tax) committed to the purpose of providing accessible, affordable housing.

Flexibility in program and funding guidelines

Flexibility in program and funding guidelines is needed to enable a 'whole of life' approach. Discrete programs, with their own strict eligibility/priority criteria and guidelines, create complexities and barriers for people with disabilities with consequent adverse effects on their quality of life. An individualised approach, that allows for flexibility in program and funding guidelines so that individuals' needs can be met in the least disruptive way, will significantly improve the quality of life of people with disabilities.

DSHA considers that the proposals for the revised HomeFirst support program, to come into effect in July 2001, represent a very positive move towards a more responsive system for people with disabilities.

Urgent action is also required to address the situation of the significant number of people who are receiving insufficient support as their needs exceed the 34 hour per week maximum available through existing programs. The effects of this include health problems sometimes resulting in hospitalisation, stress on the individual and their voluntary and paid carers, and inappropriate residential placement in institutional settings, including nursing homes and acute hospitals.

4.3 Workforce issues

As previously noted there is a critical problem in recruiting and retaining good quality staff to work with people with disabilities in a range of settings. The impact of this is particularly serious in the provision of personal care services where staff shortages and inadequacies create severe problems for people in very basic areas of their lives.

There is an urgent need for examination of and improvements to work structures for people working in direct care services for people with disabilities. Action should include:

- an extensive examination of workforce issues, including casualisation, pay levels, staff support, training and career opportunities.

- development of work structures that enhance the capacity for service providers to recruit and retain high quality staff.

These issues need to be addressed to enable the flexible support model to work.

4.4 Co-ordination and collaboration

Co-ordination and collaboration within and between relevant departments and levels of government and between government and the community sector is critical if people with disabilities are to be enabled to live in the community. Examples of co-ordination and collaboration that would make a difference to the lives of people with disabilities include:

Within DHS

- Co-ordination between housing and support services – DSHA members are aware of many instances when people have been unable to take up housing when it became available because support services/funding were not available, or conversely could not take up community based support options because accessible housing was unavailable. Co-ordination between the Office of Housing and DisAbility Services is essential to enable people to take up community based living options. Measures to ensure intra- and inter-Departmental coordination could include the establishment of joint working groups, liaison meetings or designated liaison positions.

- Funding for complex care needs with health component – as discussed above people with very high support and/or complex care needs are often unable to manage their care needs within the available support levels and are therefore at risk of inappropriate placement into a health facility, e.g. nursing home, acute hospital. Collaboration between DisAbility Services and Health to develop a joint approach to funding a high level support package would significantly alleviate this problem.

Interdepartmental

- Development of policy and regulations to ensure that the majority of new housing is designed and built so that people with a mobility impairment are readily able to visit (no step or provision of a ramp, reasonably wide doors, and an accessible toilet on the main level). This would require co-ordination and collaborative work by the Departments of Infrastructure and Human Services.

Between levels of government

- Expansion of the funding base for disability services (discussed above) will require collaboration between and commitment from State and Commonwealth Governments.

- There are currently over 4000 younger people with disabilities living in nursing homes around Australia. Over 1000 of these people are in Victoria. There is urgent need for a joint approach between State and Commonwealth Governments to ensure more appropriate housing and support options for people with high support needs.

Between government and community

- In order to develop flexible housing and support options that contribute to a quality life for people with disabilities we need a collaborative approach, with all stakeholders working together in a climate of mutual trust and respect. We need an environment that allows for innovation and creativity, a willingness to try things and to talk about them whether the outcomes are good, bad or equivocal. An on-going working party comprising people with disabilities, representation from generic and disability service providers, advocacy organisations and DHS could progress developments towards more flexible, individualised funding and services. Such a group could oversee funding of innovative local approaches to supporting people with disabilities in their community.

4.5 Training and advice

Resources will be required to enable appropriate training and advice for various stakeholders. This includes:

- Advice and information services to assist people with a disability and/or their support network to manage funds and support services, e.g. non-profit organisations run by people with disabilities to provide peer training and support.

- Training in disability issues for regional housing officers (DHS) and community based housing workers to ensure the needs of people with disabilities are appropriately addressed.

- Designated specialist disability housing officers (that could be found from existing staff) to aid the development of appropriate expertise within regional offices of the Office of Housing.

- Resource workers (locally or regionally based) and resource organisations to assist with the development of local housing and/or support options, e.g. Housing Options, a national independent advisory service in the UK which aims to open up a wider range of housing and support options, through the provision of independent advice and information. The service responds to individual queries, and also carries out 'capacity building' training and consultancy activities with a range of organisations.

4.6 Accessibility of housing

If people with disabilities are to fully participate in community life then they must not only live in a house that meets their access needs but they must also be able to visit family, friends and neighbours. This requires that we develop policy around universal housing design for both public and future private housing.

The Queensland Department of Housing (June 2000) has produced a paper on universal housing design which defines universal housing design as follows:

> *Universal design translates as sensible design, which is useful and marketable to people with diverse abilities, and hence, aims to meet everyone's needs and avoids discrimination against any users. Universal design makes as little as possible exceptional and as much as possible <u>standard</u>.*

> *<u>Universal design</u> aims for minimal adaptation over time to meet changing need whereas <u>adaptable design</u> acknowledges the need for significant adaptations over time to meet changing need and aims to make those adaptations as simple as possible.*

England, Wales and Scotland now require new housing to be designed and built so that people with a mobility impairment are readily able to visit (an accessible entrance to the dwelling, access 'within' the main level including access to a toilet).

The initial implementation of universal housing design involves additional construction costs. Suppliers are not 'tooled up' to provide the required products and the design and building practice takes time to change. However over time the skills and materials needed to provide visitability (as is required in the UK) and accessibility would increase greatly across the building industry and additional cost would become minimal.

DSHA is pleased to note that the Office of Housing has taken positive steps to ensure that most future public housing stock will be "visitable". The Construction Standards (Version

1.0), which were issued by the Office of Housing in January 2001, contain a number of measures that require that:

> *"potentially accessible" new housing will be "visitable" by people who use a wheelchair as they will be able to enter the dwelling and access the living areas and toilet and, if required in the future, will be suitable to be modified to accommodate a resident in a wheelchair.*

In addition, the report of the Social Housing Initiatives Project (Bisset 2001) recommends that "Social Housing Initiative funded projects be required to design developments in accordance with the Adaptable Housing Code".

The implementation of these policies/recommendations, particularly if future planning and building codes also require this for new private dwellings, will eventually lessen the need for costly modifications. However there will continue to be a need for the provision of expert modification advice and assistance because of the legacy of inaccessible housing. In addition different individuals require specific modifications to suit their particular needs.

SECTION 5:
CONCLUSION AND RECOMMENDATIONS

The past 18 months has seen significant positive liaison and dialogue between government and the community based disability sector through a range of formal and informal processes. DSHA has been pleased to participate in these processes through the course of this project and looks forward to continuing dialogue to further the development and improvement of support and housing options for people with disabilities.

The project has highlighted a number of key issues related to support and housing that affect the quality of life of people with disabilities and the capacity of communities to fully include them. These are:

- adequate, flexible support funding based on individual needs
- accessible, affordable housing
- systematic community development
- an adequate funding base for disability services
- flexibility in program and funding guidelines
- improvements to work structures for people working in direct care services for people with disabilities
- co-ordination and collaboration within and between relevant departments and levels of government and between government and the community sector
- appropriate training and advice for stakeholders.

DSHA believes that action on these issues is vital and therefore recommends that:

Community development

1. The Department of Human Services provides funding for community development workers in both rural and metropolitan regions to work with local communities to: - develop local responses to housing and support needs - act as community facilitators to support participation of people with disabilities.

Funding and support

2. The Commonwealth and State Governments take immediate action to extend the funding base for disability services.

3. The Department of Human Services

   (a) develops an individualised funding system with funding levels adequate to meet needs. Such a system would include a range of services to assist people with a disability and/or their support network to manage funds and support workers.

   (b) establishes an on-going working party comprising people with disabilities, representation from generic and disability service providers, advocacy organisations to progress developments towards the individualised funding system.

4. The Department of Human Services takes urgent action to address the situation of people who are receiving insufficient support as their needs exceed the 34 hour per week maximum. Such action should include collaboration between DisAbility Services and Health to develop a joint approach to funding a high level support package.

Workforce issues

5. The Department of Human Services, in collaboration with people with disabilities and the service sector, undertakes an extensive review of workforce issues, including casualisation, pay levels, staff support, training and career opportunities with a view to development of work structures that enhance the capacity for service providers to recruit and retain high quality staff.

Co-ordination and collaboration

6. The Department of Human Services revises internal communication and responsibility mechanisms to ensure better co-ordination and collaboration between housing and support services. Possible measures could include the establishment of joint working groups, liaison meetings or designated liaison positions at both head office and regional level.

7. The State and Commonwealth Governments take action to ensure more appropriate housing and support options for younger people with high support needs living in nursing homes.

Training

8. The Department of Human Services, in consultation with relevant agencies, initiates a training program in disability issues for Departmental housing officers and community based housing workers to ensure the needs of people with disabilities are appropriately addressed.

Housing

9. The Department of Human Services provides additional resources to enable people with limited support systems and financial assets to establish themselves in community based housing.

10. The Department of Human Services designates specialist disability housing officers to aid the development of appropriate expertise within regional and area offices of the Office of Housing.

11. The Department of Human Services, the Department of Infrastructure and other relevant agencies take measures to ensure adequate availability of appropriately designed or modified housing and related services. These include:

• Development of policy and regulations to ensure that the majority of new housing (both public and private) is designed and built so that people with a mobility impairment are readily able to visit (no step or provision of a ramp, reasonably wide doors, and an accessible toilet on the main level).

• On-going monitoring of compliance with regulations relating to accessibility/adaptability.

• Provision of expert advice about and assistance with housing modifications.

• Establishment of a comprehensive register of modified housing stock.

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BIBLIOGRAPHY

Asher, C.C., Asher, M.A., Hobbs, W.E. and Kelley, J.M. (1991) "On Consumer Self-Direction of Attendant Care Services: An Empirical Analysis of Survey Responses" in *Evaluation and Program Planning,* Vol.14, pp. 131-139.

Attendant Care Coalition (July 1999) *Living Well: Community Living Solutions for Victorians with a Disability who have Significant Health Needs,* Melbourne.

Australian Housing and Urban Research Institute (January 2001) *Deinstitutionalisation and Housing Futures: Work in Progress Report*, Sydney.

Bartnik, E. (2000) *Making Disability Services and Supports More Personal, Local and Accountable: Local Area Co-ordination and Direct Consumer Funding in Western Australia,* presented at the First International Conference on Self-Determination and Individualised Funding, 29-31 July 2000, Seattle.

Bisset, H. (November 2000) *Social Housing: Building a New Foundation* (Social Housing Innovations Project, Consultant's Report to the Office of Housing), Department of Human Services, Victoria.

Commonwealth Department of Health, Housing and Community Services (1991) *National Report on Consultations on New Policy Initiatives in Disability Programs: Consumer Focused Funding Approach (CFFA) and Individual Needs Analysis (INA),* Canberra.

Community Education and Public Awareness Campaign (CEPAC) (1999) *Crisis Account,* Advocacy Victoria Inc., Melbourne.

Department of Health (March 2000) *An Easy Guide to Direct Payments,* Central Office of Information, UK.

DisAbility Services Division (September 2000a) *State DisAbility Services Plan: Overview and Context – Consultation Paper 1,* Department of Human Services, Victoria.

DisAbility Services Division (September 2000b) *State DisAbility Services Plan: Inclusion and Participation – Consultation Paper 2,* Department of Human Services, Victoria.

DisAbility Services Division (September 2000c) *State DisAbility Services Plan: Support for Individuals, Families and Informal Networks – Consultation Paper 3,* Department of Human Services, Victoria.

DisAbility Services Division (September 2000d) *State DisAbility Services Plan: Accessible and Responsive Services – Consultation Paper 4,* Department of Human Services, Victoria.

DisAbility Services Division (September 2000e) *State DisAbility Services Plan: Improving Outcomes – Consultation Paper 5,* Department of Human Services, Victoria.

DisAbility Services Division (September 2000f) *State DisAbility Services Plan: Developing the System – Consultation Paper 6,* Department of Human Services, Victoria.

DisAbility Services Division (October 2000) *The Aspirations of People with a Disability within an Inclusive Victorian Community,* Department of Human Services, Victoria.

DisAbility Services Division (December 2000) *State DisAbility Services Plan: Consultation Report,* Department of Human Services, Victoria.

DisAbility Services Division (April 2001) *Rural Access Initiative,* Department of Human Services, Victoria.

Disability Support and Housing Alliance (1999) *Living Independently: Access to Choice,* Report of the First National Forum of the Disability Support and Housing Alliance, 23 February 1999, Melbourne.

Dowson, S. and Salisbury, B. (2001) *Foundations for Freedom: International Perspectives on Self-Determination and Individualised Funding* (Based on the First International Conference on Self-Determination and Individualised Funding, Seattle, 29-31 July 2000), TASH, Baltimore.

Flanagan, S.A. (2000) *Using Intermediary Service Organisations (ISOs) to Facilitate Individuals' Use of Participant-Driven Support Service Programs: An Overview,* presented at the First International Conference on Self-Determination and Individualised Funding, 29-31 July 2000, Seattle.

Holland, P. *Balancing Personal Freedom Against Public Accountability*, presented at the First International Conference on Self-Determination and Individualised Funding, 29-31 July 2000, Seattle.

Hornsby Challenge (1999) *Annual Report July 1998 to June 1999,* Hornsby Challenge Foundation Limited, Eastwood, NSW.

Housing Queensland (December 1997) *A House To Come Home To: Housing Strategy for People with a Disability 1997-2000,* Queensland Department of Public Works and Housing, Brisbane.

Housing Queensland, Housing Policy and Research (July 1999) *Housing and Support for People with a Disability,* Occasional Paper No. 001, Queensland Department of Housing, Brisbane.

Housing Queensland, Housing Policy and Research (December 1999) *Meeting the Challenge - A Progress Report on A House To Come Home To: Housing Strategy for People with a Disability 1997-2000,* Queensland Department of Housing, Brisbane.

Housing Queensland, Housing Policy and Research (June 2000) *Universal Housing Design,* Occasional Paper 5, Queensland Department of Housing, Brisbane.

Hulgin, K., Walker, P., Fisher, E., Handley, M. and Shoultz, B. (July 1995) *Housing for People with Severe Disabilities: A Collection of Resource Materials,* Centre on Human Policy, Syracuse University, Syracuse.

Jenkinson, S. and McNamara, C. (2001) *Individualised Funding,* presentation at Individualised Funding Forum, 24 January 2001, Melbourne.

Joseph Rowntree Foundation (November 1999) *Housing and support for people with learning difficulties: a local authority development programme,* http://www.jrf.org.uk

Joseph Rowntree Foundation (June 2000) *The impact of independent advice and information about housing and support options for people with learning difficulties,* http://www.jrf.org.uk

Joseph Rowntree Foundation (September 2000) *Developing new lifestyles with disabled people,* http://www.jrf.org.uk

Joseph Rowntree Foundation (January 2001a) *Crossing the housing and care divide,* http://www.jrf.org.uk

Joseph Rowntree Foundation (January 2001b) *Recruiting and retaining employees in low-paid labour markets,* http://www.jrf.org.uk

Laragy, C. (2000) *Individualised Funding: England, Scotland and USA,* presentation at Individualised Funding Forum, 20 November 2000, Melbourne.

Marrone, J. (2000) *Highlights of Balancing Personal Freedom and Public Accountability Discussion,* notes from the First International Conference on Self-Determination and Individualised Funding, 29-31 July 2000, Seattle.

Martin, D. (2000) *Balancing Personal Freedom Against Public Accountability*, presented at the First International Conference on Self-Determination and Individualised Funding, 29-31 July 2000, Seattle.

McInerney, J. (1999) "High Support Needs and Successful Tenancies: Supported Housing Development Foundation, Kew (Vic) in *Building a better system Manual,* based on "building a better system: a national expo of best practice in community housing", April 1999, Adelaide.

Melbourne Citymission (1999) *Study into the Accommodation Needs for Young People Requiring Nursing Home Level Care: Summary of Findings*, Melbourne.

Mobile Attendant Care Service Inc. (undated) *MACS Service User's Handbook,* Brisbane.

O'Brien, J. (1999) *Community Engagement: A Necessary Condition for Self-Determination and Individual Funding,* Responsive Systems Associates, Inc., Lithonia, Georgia, USA.

O'Brien, J. and O'Brien, C.L. with Brost, M. (August 1999) *Guiding People Home: The Role of Wisconsin's Supported Housing Specialist,* Wisconsin Council on Developmental Disabilities, Madison, USA.

Office of Housing (July 2000) *Victorian Homelessness Strategy: Consultation Paper*, Department of Human Services, Victoria.

Office of Housing (November 2000) *Segmented Waiting List Review: Consultation Paper,* Department of Human Services, Victoria.

Office of Housing (January 2001) *Housing Standards Policy Manual: Construction Standards* (Version 1.0) Department of Human Services, Victoria.

Shaddock, A. (2000) *Person-Directed Planning: Where Is It Going and Is It a Good Place to Go?* Presented at the 8th National Joint Conference of the National Council on Intellectual Disability and the Australian Society for the Study of Intellectual Disability, 22-25 October 2000, Fremantle.

Shoultz, B. (1998) *A Home of One's Own,* Centre on Human Policy, Syracuse University, Syracuse.

Taylor, C. (2000) *What Does It Take to Individualise Block Funded Grants,* presented at the First International Conference on Self-Determination and Individualised Funding, Seattle, 29-31 July 2000.

Walker, P. and O'Connor, S. (1999) *Not Just a Place to Live: Building Community in Toronto,* Centre on Human Policy, Syracuse University, Syracuse.

WESTRAID Incorporated (undated) *"Living by Your W.I.T.S.S.": Western Individual Tenant Support Service Manual,* Newport, Victoria.

Yeatman, A. (July 1996) *Getting Real: The Final Report of the Review of the Commonwealth/State Disability Agreement*, AGPS, Canberra.

Young, D.W. (2000) *Deciding Who Gets What: The Interplay of Personal Planning, Public Policy and Professional Expertise,* presented at the First International Conference on Self-Determination and Individualised Funding, 29-31 July 2000, Seattle.

Some useful websites

Joseph Rowntree Foundation: **http://www.jrf.org.uk**

Paradigm, UK: **http://www.paradigm-uk.demon.co.uk**

Seattle 2000 Conference: **http://members.home.net/directfunding**

The Centre on Human Policy: **http://soeweb.syr.edu/thechp**

Notes