family
ADVOCACY

A HOME OF MY OWN
Right, Rhetoric or Reality?

My Home

Choice

Rights

Work

Autonomy

Health

Value Respect

Relationships

Love

Meaningful Life

Friendships

A place of my own where I belong

Community Connection

My Home (Warren O'Brien)
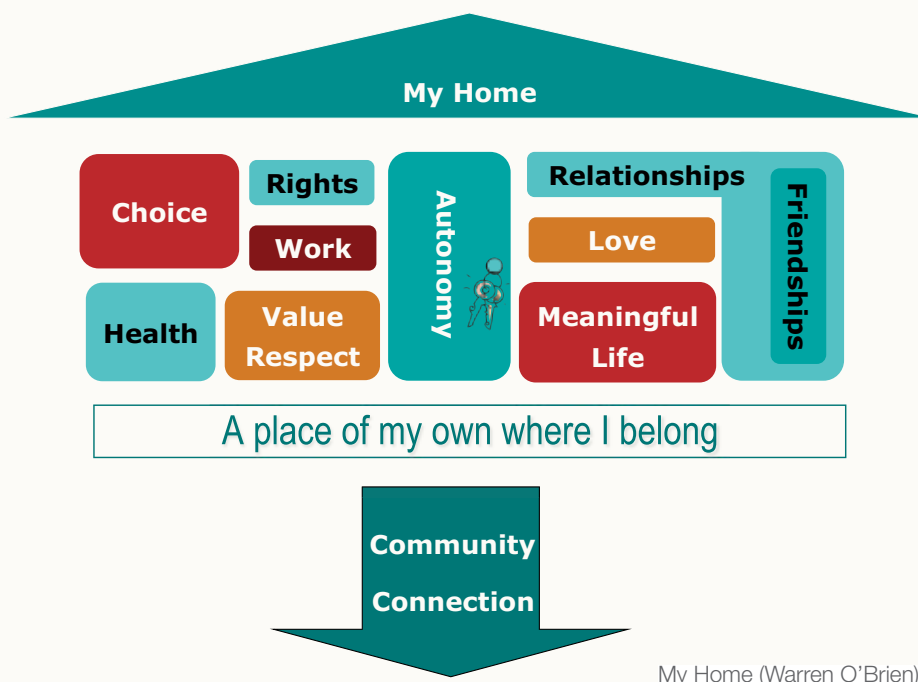
Considerations for housing and a sustainable future for people with disability in NSW

June 2010

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About Family Advocacy

Who we are

Family Advocacy is a state wide community based advocacy organisation that promotes and protects the rights, needs and interests of children and adults with developmental disability. We work in NSW with families in which there is a child or an adult with developmental disability.

Our Vision is for families to be agents of positive social change so that the inherent value of people with developmental disability is recognised within a just and inclusive society.

Our Mission is to attain positive social roles for people with developmental disability. We achieve this through strengthening the knowledge, role and influence of the family.

We work with families to encourage and support them to speak up for opportunities for people with developmental disability to enjoy the same environment, lifestyle and living conditions that are available to the majority of Australians. This means we support the philosophy and practice of inclusion.

We do our work by:

> building the leadership and advocacy skills of families including increasing families' understanding of how to bring about positive social change in the lives of children and adults with disability and by providing avenues for families to develop and enhance their advocacy skills and leadership skills

> working to change the system to remove barriers and facilitate opportunities for people with disability to lead good lives in their communities

> providing telephone advocacy information and advice

> providing a library of resources.

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What Family Advocacy believes

People with disability have the right to live in similar ways to the majority of Australians

Family Advocacy believes that people with disability have the same right as other citizens to have appropriate and relevant housing options and choices available to them. This means that the living situations of people with disability should be similar to those on offer to the general community. The difference would only emerge in the areas of home modification and in the support that may be required to live in a home of one's own.

Families have a right to expect that their adult family member who has a disability will live in similar ways to the majority of Australians with appropriate levels of support, and that this support will be tailored to their individual needs. Where people with disability require formal services, supported living arrangements will not congregate people together in houses and in neighbourhoods simply because they have a disability.

What Family Advocacy expects of governments and community

Family Advocacy believes governments have a responsibility through legislation, policy and budgetary provision to ensure that people with disability receive ongoing support which is tailored to their individual needs. If the deceptively simple idea of having an ordinary life were to be supported, then this would mean that governments and community would be ensuring that:

> affordable housing is available in a desired local area

> housing design for people with disability reflects community norms and standards, yet is able to take into account the specific needs of a person by easy modification when necessary

> the management of housing is kept separate from the provision of support

> appropriate levels of funding for housing, as well as for the provision of support, are available from State and Commonwealth Governments.

People with disability will always need strong advocacy to uphold and protect their rights and interests

Why this resource was produced

Need a voice to influence public agendas

Family Advocacy believes it is very important for people with disability and their families to have a voice about issues that affect them directly and to have an organisation that represents their concerns in order to influence change and related agendas.

Need knowledge and opportunity to make sense of the difficulties and to develop ways to work strategically to get the best outcomes

Over the years, Family Advocacy has developed policies and priorities based on our connections to, and work with, people with disability, their families and others who have an interest in their wellbeing. Through our networking we know that the majority of adults with disability remain in their parental homes and experience many problems in establishing a home of their own without the support they need to live a good life. We also know that many people with disability who live outside the family home tend to live in segregated housing arrangements with little or no opportunity to be actively part of their communities, develop relationships, enhance their life skills and pursue interests of their own.

Despite all the rhetoric about people with disability's right to a good life within the community, the reality is that achieving this is very difficult. All sorts of reasons are given and many barriers are in place. Individuals and families feel they have to find their way through a maze, often ending up with the 'least worst' option, resulting in living arrangements they are not happy with, often with someone the person with disability does not want to live with.

People with disability and their families need to have knowledge and opportunities to explore different housing options, as well as information to make sense of the difficulties involved in making this a reality. Finally, they need to develop ways to work strategically to get the best outcomes.

This resource aims to assist people with disability and their families to understand the current environment around accommodation and service provision in NSW and to help establish a framework to critique options that are currently on offer for housing and support - in order to achieve the dream of a home of one's own.

Having a home of one's own is about having options

Having a range of typical housing options with opportunity to move

Family Advocacy believes that people with disability, like other citizens, should have a range of housing options from which to choose. These options should be consistent with what is available to the rest of the community, mirroring the variety of detached and semi-detached houses, units and flats, of a variety of architectural styles, with or without gardens. This means that special or separate housing solely for people with disability should not be the key or only feature on any menu of available housing options.

Most people do not live in the same place for life. As with other community members, people with disability may want to change their home as their inclinations and needs change. A person may wish to try different places to live, to share or to live alone. Their life situation may change. They may move nearer to work or to ageing parents, or may move to be with a partner, be closer to transport, amenities or education facilities, or move for a variety of other reasons. They may wish to buy a home of their own, or to live in a place that they have inherited. These options are typical for the rest of society, so they should also be available to people with disability.

But typical housing is not always on offer because it is not suitable or affordable and/or support is not available

Yet, we know that for adults with disability the option to move into typical housing and to establish a home of one's own is often not on offer, and nor is the opportunity to change one's place of residence. This may be for a number of reasons:

> suitable or affordable housing is not available

> adequate support is not available

> people in decision making roles presume that people with disability belong away from other citizens

> housing and support are tied together in the one place.

Housing and support should be separate arrangements

Family Advocacy believes that housing and support should be totally separate arrangements. This is a major safeguard especially when a person has complex needs. Currently, housing and support go hand in hand with little or no opportunity to change one or the other if so required. If housing and support are separate, people with disability have more choice and personal freedom. It also means that if a person is refused service, they still have somewhere to live. If they are evicted, their service will support them to find another home. If they want to move, their support goes with them. This separation enables the provision of tenancy rights, ensuring that the home belongs to the person, not the service provider, nor is it the office of paid workers. Such an arrangement is crucial for services to operate in the right relationship with the individual and their family and friends.

Where people belong – the legacy of history

The importance of history

In order to understand the Australian scene now, it is important to consider what has happened over the past 50 years that has had profound influence on the lives of people with disability and the nature of housing and support.

Until the middle of the 20th Century there were only two options for people with disability: either they lived at home with their families without any other support, or they went away to be placed in some form of institutional care. Here their housing needs were met by dormitory style living arrangements with minimal care, mostly given by a small number of untrained shift workers.

People with disability used to be seen to belong together

In the 1980's a major attitudinal shift occurred in how people with disability were viewed. This had been bubbling away under the surface for many years, fuelled by the dissatisfaction of people with disability and those families and workers who believed that the way people with disability were perceived was not right. These people fought to change how people with disability were viewed and put forward that, like any other citizen, people with disability were not 'them' but in fact are 'us'.

This simple but profound change meant a whole new way of thinking about and viewing people with disability. This new rights based view stated that people with disability, just like other citizens, should have the right to:

> choose the type of housing appropriate to their needs

> live in a home of their own with the people they choose to live with

> live in their community of choice

> have access to adequate support.

Parallel to these ideological changes were some practical changes to living arrangements, started by some families who questioned institutional living and who began to independently establish smaller group housing options with live in or shift based supports. This movement encouraged government to think about the group home model as a better alternative to institutions and by the 1980's, supported by reports of abuse in large institutions, the dominant housing model was smaller living arrangements for people with disability.

Now people with disability are seen to belong together in ordinary homes in local neighbourhoods where they participate and contribute to community life

However, the reality for the vast majority of people with disability remained the same. They still stayed at home or went away to congregated living arrangements where staff catered for their collective needs. Although small community based housing was often better than the large institutions, they still operated in similar ways by putting people together and stereotyping their needs. This practice still supported the premise that people with disability belonged together 'with their own kind' and not with the wider community.

Why typical housing and real life may not be on offer

People can 'talk the talk' but may not deliver in practice

Since the 1980's, theoretical perceptions of people with disability have changed. Today, most people would say they agree with the ideals of citizenship, rights and ordinary lives for people with disability and tend to talk and write as though these things automatically happen in practice. Most people who work in housing provision and disability support services, as well as government, now write about and talk about ideas of inclusion and community participation.

However, the reality remains that the ordinary options and choices available to other citizens, such as having typical housing and support to lead a real and meaningful life, are often not available in practice. This is especially so when people have high or complex support needs.

What is often the harsh reality?

Consider these facts:

> The great majority of adults with disability are still expected to live with their parents or family members, often with little or no support, and without the opportunity to move out to live in a home of their own.

> Congregation of people in housing on the basis of their disability is still the dominant housing solution in NSW, especially for people with high or complex support needs.

> Placement of people in a vacant bed, where they usually do not know other residents and where they do not choose to live, is promoted in policies such as vacancy management.

> Housing and support are still largely entangled, with many landlords controlling all aspects of a person's life, leaving them highly vulnerable.

> New segregated housing options, considered innovative in spite of their inappropriateness, are promoted as 'new ways forward' (for example the redevelopment of Large Residential Centres).

> People with disability remain without control over setting the expectations and influencing the decisions affecting their lives because the right relationships are not in place with them or their families and friends.

This means that in spite of all the great many human rights advances made in Australia, and in spite of legislation supporting the rights of people with disability, few real choices are actually available. Many ingrained beliefs about people with disability survive, along with outmoded forms of housing and support. Some people still believe deep down that people with disability do not belong in the community and do not deserve to have typical housing or a decent life. Such prejudice still influences economic and political priorities and available options.

And so the struggle continues….

The past still influences the future

About good housing design

Good design benefits everyone

One of the ways in which real choices around housing can exist for people with disability is through the promotion and practice of inclusive housing design, supported and funded by government and local councils. Good housing design benefits everyone and can be used by all people to the greatest extent possible, without the need for further adaptation or specialised design. Good housing design avoids building barriers that exclude, isolate and discriminate against people living in, working in, or visiting a home.

About universal housing design

The term that is often used to indicate this inclusive design and construction is Universal Housing, which has the following expectations:

> to meet the housing needs of people of all ages and abilities, enabling their residence and participation in their community throughout their lifetime

> to accommodate a wide range of individual preferences and abilities

> to provide appropriate size and space for approach, reach, and use regardless of body size, posture, or mobility

> to minimise hazards and adverse consequences of accidental or unintended actions

> to communicate necessary information effectively to the user by being easy to understand, regardless of the person's experience, knowledge, language, cognitive ability or concentration level

> to be easily and economically adapted when a person has more complex needs

> to allow for a diverse range of householders to occupy a place of residence cost effectively and equitably over time

> to provide for people to visit and stay for an extended period

> to provide a place in which it is safe to live in, work and visit

> to ensure useability and attractiveness are mutually compatible

> to achieve broad market appeal.

Safe and equitable access for everyone

Therefore, accessible housing is not just about having ramps and grab rails, but rather is about safe and equitable access to everyday home environments for everybody.

About good design and modification

Some elements of good design that benefit people with disability

Good housing design should incorporate the following:

> having an accessible path of travel from the front boundary, garage or car park and throughout the entry level of the dwelling

> having entry on the main level with living area, food preparation, accessible shower, hand basin, toilet and bedroom also on this same level

> having living areas and bedrooms which, when furnished, allowing for adequate circulation space for a person using a wheelchair

> having door handles, switches, controls and outlets within reach and able to be used by all

> having potential for vertical access by a person in a wheelchair in future adaptation to any dwelling with two or more levels

> having reinforced walls in toilets and bathrooms to enable future fixing of grab rails.

Modifications may be necessary to meet a person's specific housing needs. Any modification, however, is much easier and much more affordable when universal housing principles have been used in the design and build in the first place.

About modifying housing

In NSW, home modification and maintenance for people with disability is provided through the *Home and Community Care (HACC) program*, which is jointly funded by Commonwealth and State Governments. The program is administered by the NSW Government agency of Ageing, Disability and Home Care (ADHC), who oversee the provision of work by the *Home Modification and Maintenance Services (HMMS).*

There are currently 106 HMMS across NSW. Eligibility for home modifications can be assessed by an Occupational Therapist who will suggest what is needed. You can contact your local HMMS to see what can be provided, how much this will cost including possible subsidy. Contact NSW HMMS Council at www.nswhmms.org or call (02) 6622-8386 to locate your local service outlet.

Home modifications can be minor such as supplying and installing grab rails, hand held showers or modifying the home by placing ramps, step wedges, easy steps or path, or can be major for example changing bathrooms, changing kitchens or re-assessing the safety of the dwelling. HMMS can also provide home maintenance support relating specifically to safety and access, for example repairing stairs, adjusting hot water systems or adjusting the height of tables and chairs.

About expectations for typical housing

Typical housing is what other citizens also experience

The expectations of many people with disability and their families are that they would have similar options in housing to what is available to other members of the community. This means that there would be no grouping of people with disability unnaturally into particular locations. It also means that people would not be expected to move into inappropriate housing because it is available or because there is a vacant bed.

They would have choice about many of the following criteria:

> the community where they wish to live – rural, town, suburbs, city

> the location where they wish to live – availability of transport, amenities, shops, services

> maintenance of significant networks – proximity to family, friends, significant others

> maintenance of lifestyle – work, education, recreation, spirituality

> who else lives with them – alone, family members, friends, partners

> suitability for the lifestyle of people living together – single, family, children, house sharers

> the type of housing – detached or semi detached, flats, units, houses

> architectural style - preferences

> affordability of housing

> age of housing – maintenance

> size of surroundings – garden, court yard, no yard

> size and space of dwelling – based on who lives there and their need

> well designed housing for specific need – low set, wider doorways, larger toilet and bathroom areas, easily modified, own bathroom, larger bedrooms, fully accessible

> a choice of tenancy options – public housing, private rental, community housing, ownership

> consideration of privacy, relationships and intimacy

> safety and security – of person, tenancy, possessions, etc.

Considerations: Where? With whom? Size? Space? Lifestyle? Tenancy? Affordability? Specific needs? Design? Privacy? Safety and security?

What makes a good home?

A home is much more than having possession of a vacant bed in someone else's place

People will often talk about housing or accommodation for people with disability, but do not always consider what makes a good home and what constitutes a good home life. A home is much more than having possession of a vacant bed in a facility, or even in someone else's house in a suburban street. A home is about the nature of what goes on in the private realm of life where one lives.

A good home is dependent on many of the following:

> feeling comfortable, belonging and a sense of ownership over the whole place, regardless of whether it is rented or owned

> having a relaxed atmosphere and a feeling of intimacy and safety with people who choose to live together

> having privacy of person, possessions and information

> experiencing freedom to be yourself, and knowing that you are not on show or judged by the outside world

> having control or influence over the activity and routine of daily life

> putting in place personal touches that reflect the essence of a person, their possessions, their interests and their preferences

> feeling pride in where you live and how your life is lived at home

> having shared space and private space

> sharing hospitality with others only by invitation

> being safe from intruders or outside interference, and from those you choose not to be with

> having security of tenure with a sense of permanence to home life until you choose to move

> not being vulnerable and open to the whims of others

> having others who visit one's home in paid service roles appreciate and respect:

– the person

– their dignity

– their identity

– their privacy

– their feelings

– their relationships

– their lifestyle

– their home and possessions

– their customs and culture of daily life.

What are some typical housing options?

Social Housing

Social housing is government funded housing that provides appropriate and affordable housing to people who cannot afford, access or sustain housing in the mainstream housing sector. Social housing is made up of rental accommodation owned and managed by the NSW Government (Housing NSW) and housing owned and managed by non government community housing associations (Community Housing).

A number of people with disability in NSW live in social housing. The eligible person becomes a tenant of Housing NSW or of the Community Housing Association. Tenants pay 25% of their taxable income as rent. They are offered a 2, 5 or 10 year fixed term lease based on their current household circumstances with the length of tenancy matched to need. Since disability does not tend to change over time, people with disability are considered to be an ongoing priority for public housing and tenure will likely remain after the lease period. This is assessed on a case by case basis.

Housing NSW or the community housing association maintains the dwelling and will modify an existing dwelling to suit the needs of the tenants. The person with disability fills out an application stating their needs and is put on a waiting list. Eligible clients who apply for public housing and who have not demonstrated an urgent need for housing are placed on the Housing Register in order of application date. People assessed as having priority need for housing are offered property as it becomes available.

Special Assistance Priority Housing

People with disability who have special circumstances or an urgent housing need may be eligible for priority housing assistance. In NSW this program is called Special Assistance Subsidy – Disability (SAS-D) and is managed through Housing NSW. A subsidy is paid to a person with disability approved for priority housing who has reached their turn on the public housing waiting list, but for whom a dwelling suitable for their needs is not available. The SAS-D makes up the difference between the rent the client pays for a private rental property compared with a Housing NSW property. This subsidy aims to alleviate the disadvantage people with disability face due to the lengthier period of time it may take for suitable dwellings to become available. When an appropriate Housing NSW property subsequently becomes available, the individual moves out of the private rental market.

Private Rental

Private rental is usually established via a signed lease with a real estate agency or a private owner. This form of rental can be more expensive than public housing, with payment of a bond expected before moving in. There are some private rental assistance options available to people with disability. The Commonwealth Government runs the Government Rent Assistance Program, which is available to people on the Disability Support Pension in private rental. Enquiries for this program can be made through Centrelink.

Housing NSW also provides Rentstart to people who have found a private rental property and who need help with bond, and in some cases, advance rent. Rentstart provides payment of up to 75% of a required bond and also provides additional assistance for people facing severe financial barriers to private rental, severe housing stress, or homelessness. Rentstart can provide payment for temporary accommodation, assistance for people facing eviction or assistance for people leaving public housing and moving into private rental.

What are some typical housing options?

Community Housing

Community Housing is owned and managed by community associations that rent housing to people on low income. Housing Associations manage their own properties which tend to be scattered throughout the community. Community Housing operates in a similar way to public housing and applications are made through the public housing process. When applying for public housing, the applicant is given the option to express interest in being housed by a Community Housing provider. Community housing is generally considered to be good quality, secure and affordable housing and can be a very good option for a person with disability. The waiting time varies between Community Housing Associations. In the majority of cases, to be eligible for community housing you must be eligible for public housing, but a small number of local councils manage properties and may have a special focus on particular groups within their local area.

Non Profit Housing Companies

This is a small sector in the housing market. Non profit housing companies establish a self-sustaining property portfolio based on initial government grants. Housing stock is rented as subsidised housing to low income earners at 75% of the reasonable market rent. Non profit housing companies are a new and innovative idea as funding levels for public housing are declining and an increasing number of low to moderate income households find the private rental market very difficult to afford. In NSW, City West Housing is an example of a non profit housing company providing affordable housing to people living and working in the Ultimo/Pyrmont or Green Square area of Sydney. Housing NSW provided the initial grants to purchase the properties and the City West Housing group then manage the portfolio of housing stock.

Housing Cooperatives

Housing Co-ops work on the six international principles of cooperation with all housing managed by the tenants, who form themselves into a community organisation. This enables the people who live in the dwellings to be in direct control of the housing, in effect becoming the landlord and the tenant. In NSW Co-op housing is subsidised by government, making it affordable. There are a number of housing co-ops in NSW and information regarding them can be accessed through the Housing Cooperatives Association of NSW that has a focus on making their housing stock more accessible to people with disability.

Home Ownership

Many people with disability hold the aspiration to achieve the great Australian dream of owning their own home, giving increased control and security over life choices. Buying and maintaining a residence on limited income, however, can be unachievable. Apart from the initial deposit, additional outlays include legal fees, conveyancing and stamp duty. The Federal Government's First Home Owner's Grant has been available to every Australian irrespective of income. Some people have utilised the grant to place a deposit on housing properties. Also, some major banks, including National Australia Bank and ANZ, in partnership with some charities, offer small loans to people who don't own a house and whose income is solely from government benefits. These loans are competitive with reasonable interest rates and could provide opportunity for people with disability to find a deposit to purchase a property.

About accommodation with support

The tied package

In NSW the majority of supported accommodation services provide accommodation and support tied together as a package, with the landlord and support agency as the same entity. These packages are provided by government disability services, non government agencies and the private for profit sector. In the main, the government funds the community sector organisations providing the packages.

Having accommodation and support bundled together can seem an attractive option as a complete package can seem simple to manage. However, personal choice can be restricted to limited, inflexible service options as these packages offer 'all or nothing' deals. If an individual is not happy in their home environment but is happy with their support services, moving will result in loss of service. Similarly, if a person is happy in their home but not with their support service, they cannot receive new service without moving, as the accommodation and support are bundled together.

These forms of supported accommodation rarely reflect everyday living in the community. Most people prefer to have real choices about where, how, and with whom they live, how they spend their time and with whom they have close relationships.

Group Homes

The most common form of supported accommodation in NSW is the group home. These combined housing and disability services are managed by non government service providers as well as government. The size of group homes can vary with as many as 10 people living together in one home. Their establishment was dominant in the 1980's after the Richmond Report recommended people with disability move out of institutions into the community with support.

There is no denying that, at the time, group homes were a better model of support for people with disability than large institutions, and that some people are happy in the group home in which they live. Intrinsic to the group home model, however, is the notion that people with disability must live together, leaving little opportunity for individual lifestyle decisions.

 Places in group homes are allocated through a vacancy management system; in other words, if a bed becomes available in a group home, an individual on the waiting list will be placed in that vacancy with existing clients, structures and practices. The individual will then need to adapt to the home they have been placed in, making personalised support and community connections and relationships difficult to achieve. Due to long waiting lists, individuals find it difficult to reject a vacancy in a group home and this often results in residents being located away from their families and communities, thereby often losing ties with loved ones and the people who know them best.

In addition, residents in group homes are licensees only, and do not have the protection of a tenancy. This leaves them vulnerable to eviction and fee increases without notice.

About other forms of supported accommodation

Licensed Boarding Houses (Private Hostels)

Due to the severe shortage of government funded supported accommodation options in NSW, a number of private for profit agencies offer packaged housing and support to people with disability. Some of these private hostels operate like group homes, catering for a small number of residents. Others are much larger, re-establishing large size institutional care arrangements. Residents must pay for their accommodation and services out of their own pockets.

Services provided by private hostels sit outside the *NSW Disability Services Act 1993* (DSA) and therefore do not have to meet the same quality standards as funded disability services. Private hostels are licensed under the *NSW Youth and Community Services Act, 1973.* ADHC is responsible for issuing licenses but is only responsible for ensuring that the physical and structural requirements of the hostel are complying with the needs of the residents. Local governments are responsible for the fire safety and health standards of the premises.

There are no bodies responsible for the service provision given to residents, as a government department does not fund the service. Service standards can therefore be poor, with low numbers of adequately skilled staff and few, if any, meaningful activities for residents. Other concerns about these facilities include lack of privacy, security and safety, eviction at short notice, financial exploitation and poor quality of food, leaving individuals highly vulnerable.

Unlicensed Boarding Houses

Unlicensed boarding houses are one of the largest growing areas of accommodation for people with disability. They are privately run and target single people who are homeless or at risk of becoming homeless. They fall outside the DSA and any regulatory authority, providing communal living and food, with no services for people with disability. Due to the severe shortage of accommodation options for people with disability, there are large numbers of individuals living in boarding houses, leaving them highly vulnerable with no supports.

Emergency accommodation

The Homeless Persons Information Centre assists people to find temporary accommodation (1800 2234 566). In NSW emergency accommodation is generally provided in shelters for people who are homeless, women and children at risk of domestic violence or people in drug and alcohol rehabilitation. For people experiencing domestic violence, the 24 hour help line operates across the State giving advice, information and referrals for refuge shelters. Centre based respite care may also be available to people with disability and their families in an emergency situation.

Other

Due to the significant shortage of housing, some people with disability are permanently living in unsuitable accommodation such as nursing homes and respite facilities.

Whose home is this?

The expectation of moving into a home of one's own is typical

The expectation of moving into a home of one's own is typical. At some point in most young adult's lives, people begin to think about moving away from parents and establishing a home of their own. This move is formative in establishing an identity as an adult with new and different responsibilities, separate from our parents. Yet for many people with disability, this every day expectation is not considered at all because the required support is simply not available.

Even when possibilities are on offer, a person with disability may have very limited options from which to choose when compared to his/her contemporaries. When disability services are involved as the landlord, concepts such as personal possession, rights and tenure can become quite clouded.

For a person with disability to have a real home of their own, certain safeguards need to be put in place to ensure that the home is really theirs. A person's private home should not operate like a facility, nor should it have as its focus the requirements of paid staff where routines, rules and regulations primarily benefit the staff and take over the needs and interests of the person who lives in the home.

The focus of home should not be about routines, rules and regulations for ease of landlords or paid workers

To safeguard the person's possessions, rights and tenure of their home:

> there should be separate responsibilities for housing and support – the person's landlord should not be the same service as the one that provides the support to the person

> there should be a typical housing agreement in place, which sets out tenure and the rights and responsibilities of both landlord and tenant

> unless in a family relationship, separate agreements should be made with each person living in the home

> staff should not have an office in a person's home. Staff should come and go to support the individual and their lifestyle, not take over part of their home

> whilst worker safety is critical, all lengths should be taken to avoid Occupational Health and Safety requirements taking precedence over lifestyle

> all lengths should be taken to maintain the spirit of 'this is a person's home' and acknowledge that people who do not live here are visitors who are expected to show the usual courtesies afforded to anyone who has their own home.

Who else lives here?

Placement can still happen without choice on the basis of the person's disability

Although much of what is being discussed is around people with disability having their own homes and living ordinary lives, the practice of placement is still alive and well in the disability sector. The NSW disability service system primarily runs on a 'vacancy management' system whereby a vacant bed becomes available in a facility that needs to remain financially viable. This can mean that some people with disability end up living with people they have never met, do not like, have never chosen to live with and with whom they may have very little in common, except the label of disability.

The vacancy management system serves the interests of government and service providers at the cost of individual needs and lifestyles. It supports the view that people with disability belong together.

What we know about the life experiences of people who do not choose to live together

It cannot be underestimated how important it is to have choice around the people with whom we live. Consider what research has shown when the need for placement overrides individual personal needs:

> One's personal identity is reduced to impairment with people not seen as individuals.

> Needs are stereotyped and dealt with collectively.

> The ability to be included is greatly reduced, people's differences stand out further in neighbourhoods and wider community engagement becomes limited.

> People have less capacity to get support from one another and often have support that reflects economy of scale – a person who cannot speak is put with others who cannot speak, or a person who cannot move about easily is put with others who cannot move about easily. This means a worker becomes the focus for all assistance and relationships.

> Natural relationships and informal networks are not given the opportunity to grow and develop.

> The risk of abuse and neglect is disproportionately higher – this being especially so when people who are 'challenging' are placed together, or when co-tenants compete for attention and assistance from workers, or they do not get along with one another.

> People are very unhappy and dislike where they live, but have no option to move out and live elsewhere.

How services can support people to have a good life

The quality of service provision in NSW varies widely - there are some excellent services with good core values, however there are many that do not demonstrate good service provision. It is therefore important to check out the values and beliefs upon which a service is based. Staff from a good service will demonstrate their belief that people with disability can be supported to live a valued life by ensuring their conduct, as well as their support of the individual and their roles and routines, mirror what is expected and valued by others in the community.

Supporting roles and routines that mirror those that are valued by others

Depending on the needs of the person and the nature of the support, a good service will demonstrate that:

> each person is treated well, with dignity and respect, shown in every day interactions, feelings and language

> individual vulnerabilities are safeguarded

> a person's home is much more than a bed in a house in a street: it is a private place where life is played out in a unique and personalised way

> typical roles and routines are supported, with paid workers facilitating natural relationships with others

> each person is supported to be included in the fabric of their neighbourhood and local community, and given opportunities to have real connections and relationships, as well as opportunities to participate and contribute to everyday life

> activities and relationships are not prescribed or unnaturally restricted to congregate settings with other people who have disabilities

> the local community is richer because of people's participation and contribution

> life is played out in ways that take up the moving feast of opportunities, experiences, relationships, decision making, challenges and change

> the service puts structures in place to ensure minimal hierarchy, and that service staff who make decisions that impact on the person, actually know the person

> the service recognises there is more to life than the service and paid people

> the service supports continuous improvement and is prepared to reflect on how their staff goes about their work.

Having a range of lifestyle activities and relationships that are not prescribed or unnaturally restricted to segregated settings

What is personalised support?

More than just any individual service

Personalised support should not be confused with some traditional ways of providing support to people with disability. Personalised support operates within an ethical framework with guiding values and principles that determine how life and relationships are played out. There is no one model of service within the personalised support approach, but as many different models as there are people who are supported.

Principles that guide action

> People with disability belong in community life and are entitled to live a valued lifestyle based on the same rights, relationships, expectations and opportunities as other citizens.

  This means an acknowledgement that the person has a unique life and should receive personalised support that is dignified, respectful, responsive, flexible and creative. The support should be highly relevant to and facilitate relationships of ordinary life.

> People with disability have a natural authority to influence the direction of their own life. This influence is extended to family members and significant others when they have remained faithful and committed to the person's well being.

  This means the person is well known and listened to, and the service does all it can to support the person's vision of life. The formal service system is acknowledged as only part of the solution with family, friends and significant others playing a legitimate and valued role. Decisions are kept close to the people involved.

> Collective oversight of the governance of the service is vested in the people who use the service and/or family and significant others who are closest to them.

  This means that the people who use the service share a vision of what it takes to be a good service and are involved in decision making about major directions and policies of the organisation.

> All people involved acknowledge that formal services can lose their way and increase the vulnerability of the person with disability.

  This means that safeguards must be put in place that protect the person in daily life and feedback from people with disability and families must be valued in the operation of the service.

About personal authority and its use with services

People have a natural authority to influence their own lives

All people have a natural authority to influence the direction of their own lives. This fundamental fact is often misunderstood in the context of people with disability, most especially and often by paid workers who come and go on a regular basis. They may easily dismiss the importance of the individual's wants, needs and aspirations or the family's knowledge and understanding, often replacing this with what is easiest for them. It is essential that paid workers understand their role as supporting the person, not taking over their life.

Workers in government and in services can often wrongly use their positions and power to make decisions about which they have very little background knowledge and understanding, and over which they have very little mandate. Sometimes these decisions can be life defining for the person as well as for their family, with sometimes devastating consequences.

When the person has limited decision making capacity, family members and significant others can have both natural and legal authority, as long as they have remained faithful and committed to the person and their wellbeing. This is particularly important in relation to people's vulnerabilities and is recognised in law through such bodies as the NSW Guardianship Tribunal.

The natural authority of families

Research shows that the greatest safeguard for any person comes from committed family or significant others in their life. This is because family members or those who love the individual:

> know the person most for the longest period of time

> typically care about the person

> hold their history and culture

> are usually recognised as having responsibility for the wellbeing of their family members and are expected to care for them

> have a stake in the outcomes for family members and have to live with consequences of their decisions and actions

> are expected to stand up for or advocate for family members

> bring a wide range of talents and experiences

> know how things add up in the person's life

> can imagine better and pursue the person's own lifestyle and future

> are witnesses to the performance of professionals

> are free from the vested interests of the system.

About having right relationships with services

The concept of 'right relationships' builds on the notion that the formal service system is only one part of the support solution for any individual and that it is important for the person with disability and/or their family and the service to work together.

Having an understanding of what is personal/family business and what is service business

This concept is different from the idea of partnership, as it puts forward that there are certain aspects that remain the business of the person or their family, and certain aspects that remain the business of the service. Having an understanding of what is personal/family business and what is service business is the key to developing right relationships with services.

For example, it is the responsibility of the individual with disability and their family to develop and hold a positive vision and plan for the future, to uphold their values, customs and story and to defend their privacy, health and well being. It is the responsibility of the service to keep the support needs of the individuals central to all activity, ensure support staff have the safety and welfare of the individual as their sole priority and work respectfully with informal supports that are naturally there.

What does it take to create a sense of working WITH

Working in right relationships with one another involves:

> having mutual respect, openness, honesty, trust and a real sense of 'being in this together'

> supporting and encouraging significant people to be in the individual's life, to help them and the service imagine and create better options with the person, especially when they have significant support needs

> having the person and those closest to them contribute their abilities, gifts and talents and exercise control over their future

> having processes that are people friendly, without having daily life consumed by bureaucracy. The service acts as the buffer against such requirements

> doing planning around a personal vision for life, not around what a service can offer, in the spirit of 'this is a person's life, not our life'

> having the ability for people to have expectations, refuse options and negotiate on matters of concern, including the hiring and dismissal of staff

> having shared values, vision and understanding of what it takes to provide a personalised service

> having control of the majority of directions and policy decisions

> having mechanisms that feed in information from the people who are being supported by the service.

The importance of holding a vision for life

The vision of an ordinary life is often knocked out of you or lost

Many people with disability find that throughout life's journey, many doors to ordinary life opportunities, experiences and relationships remain firmly closed to them. Over time they, and their families, can lose any vision about ordinary life or have it knocked out of them by constant conflict with the service system. The vision of being a valued member of their community can seem too unattainable, especially when they have had to fight for any support or funding. This does not allow the option to take the 'ordinary road' through life.

Even when support or funding has been made available, it is quite likely that it has been offered through a more segregated track rather then an inclusive one, especially when the person has high support needs. Often the individual and their families end up taking any offer as the battle to achieve support has often been so fraught and difficult there is fear of losing it all together.

In thinking about a vision for life it is often easier to clarify what you don't want, which can then help in identifying what you do want. For example:

What I don't want	What I do want
Grouped living where my home is nothing more then a bed in a house or an institutional setting.	A real home of my own, chosen by me, where I have choice over who I live with. Flexible supports are separate from my housing.
Going from my home life where I was cared for and loved, to be looked after by a paid person who must attend the needs of a whole group.	A personalised service that focuses on supporting my life by learning to understand me, my situation and my vision and plans for my life.
A service that only focuses on the basic necessities through care and control.	A service that assists me to have an ordinary life and lifestyle, with all the ups and downs that an ordinary life entails.
A rigid, unchanging service.	A service that will change with my needs and aspirations over time.
A service that replaces or diminishes my natural connections.	A service that welcomes and supports my natural connections with my family, neighbourhood and community.
A service that tries to fix me or to mould me to their routine way of life.	A service to acknowledge me for who I am and to support me through natural opportunities for change and growth.

Planning for the future

The best way to predict a future is to create it

The harsh reality for many people with disability and their families is that living in a home of one's own with appropriate support does not eventuate by either waiting for it or by allowing others to do it for you. As the best way to predict a future is to create it, the following thinking and action may be helpful in creating your desirable future:

> dreaming about what is possible

> getting others around you to share your hopes and fears

> developing clarity of vision about what makes a good life

> recognising the barriers that stand between what you want and what is on offer and planning good strategies that move your agendas forward

> taking positive action and developing ways to sustain your vision over time.

Get others involved in life

The strategy of getting others involved is really important, as it can be even harder and more isolating to attempt to achieve this on your own. The benefits of developing a personal network around your son or daughter can include:

> sharing knowledge about what it takes to develop a good life that can start to work now and into the future

> helping to establish what needs to happen to secure a future

> enabling wider commitment to flourish

> preparing for future challenges

> seeing a better future beginning to unfold in action now

> feeling greater security and peace of mind about the direction life is taking.

Some strategies for families

Other elements in planning for the future that families may need to consider, especially when a person has high or complex needs, can include:

> ensuring long term housing tenure and security in a home of their own

> considering financial security – how wills and estates might set up ways that will enable the person to continue to have a good life when parents are less able or have died

> considering ways you might be able to contribute financially

> considering safeguards and ways to monitor quality of life.

Housing Legislation

The National Affordable Housing Agreement

In 2009 the *National Affordable Housing Agreement* was developed, aspiring for all Australians to have access to affordable, safe and sustainable housing in order to contribute to social and economic participation.

NSW is party to this agreement and has committed itself to working with the Federal Government and local governments to provide direction for a range of measures to increase social housing, assistance to people in the private rental market, support and accommodation for people who are homeless or at risk of homelessness and home purchase assistance.

NSW Housing Act 2001

Housing NSW operates under the *Housing Act 2001* to manage the NSW Government's housing portfolio and develop housing strategies. The aims of the Act are to maximise the opportunities for all people in NSW to have access to secure, appropriate and affordable housing and to ensure public housing is available to those most in need. The Act sets the framework for people who live in public housing and their rights as tenants.

Residential Tenancies Act 1987 and *Residential Tenancies Regulation 2006*

Most residential tenancies in NSW are covered by the *Residential Tenancies Act 1987*, which, together with the regulations, sets out a standard residential tenancy agreement giving clear rights and obligations to landlords and tenants. The Act gives the Consumer, Trader and Tenancy Tribunal (CTTT) power to hear and settle disputes about residential tenancies, including bond disputes. The Act sets out your rights and obligations as a tenant.

The Act covers private tenants who have a written or oral residential tenancy agreement and also covers public and social housing tenants, including tenants of Housing NSW, Community Housing and the Aboriginal Housing Office. This Act does not cover motels, hospitals, nursing homes and hostels.

NSW Disability Services Act 1993

The majority of NSW Government agencies, including Housing NSW, have a legislative responsibility under the *NSW Disability Services Act 1993* (DSA) to develop a Disability Action Plan. The DSA supports the equal rights of people with disability and sets out a series of principles and applications of principles for the provision of services for people with disability in NSW. Compliance with the DSA and a Disability Action Plan is very important, given that people with disability make up about 1 in 3 of current public housing tenants and about 1 in 5 of tenants in community housing.

Disability Discrimination Act (DDA) 1992

The *Disability Discrimination Act (DDA) 1992* prohibits discrimination on the basis of disability. The Act aims to ensure that people with disability have the right to equal treatment before the law and aims to promote community understanding that people with disability have the same rights as other citizens.

NSW Housing Policy

Vision of Housing NSW

Housing NSW is the primary housing management agency in NSW. It works with other Government departments and organisations to address homelessness in NSW, manage the public housing portfolio, fund and regulate the provision of community housing and crisis accommodation and manage Aboriginal public housing.

Housing NSW is committed to:

> making a sustainable difference to social outcomes

> helping people in need

> treating everyone with respect

> serving and strengthening the community

> working with their partners.

Disability policy

In May 2009 Housing NSW released its Draft Disability Action Plan (The Plan) committing to provide affordable and accessible housing assistance to people with disability. 'The Plan' is an acknowledgement by Housing NSW that it has obligations under the DSA and that their policies should be consistent with the *Guidelines for disability actions planning by NSW Government Agencies.*

The Plan has seven priority areas which focus upon ensuring that people with disability are able to access housing services and products; providing information in a range of accessible formats; improving physical accessibility of Housing NSW dwellings; assisting the participation of people with disability in consultations with Housing NSW; influencing other agencies to improve the quality of life for people with disability; and providing quality specialist and adapted services to meet the needs of people with disability.

The Plan is a response to the increase in demand for public housing by people who also require additional supports from the disability system. The Plan reports that the number of people with disability coming into social housing has been increasing by an average of 1% per year since 2001, resulting in approximately 5,200 additional tenants with disability in public housing by the end of 2013.

The Plan acknowledges that greater collaboration between Housing NSW and ADHC is essential to make it easier for people to get all of the services they need.

Disability Legislation

The United Nations Convention on the Rights of People with Disability (UNCRPD)

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) came into force on 3rd May 2008. Australia is a signatory to this Convention and is therefore responsible for carrying out the intentions of the Convention. The UNCRPD aims to ensure that people with disability enjoy human rights, freedoms and respect like other people. It holds all States who have signed the Convention responsible for taking effective and appropriate measures to ensure the full inclusion and participation of people with disability in the community.

Article 19 of the Convention outlines the right of people with disability to live independently and be included in the community. It requires countries such as Australia to take appropriate steps to help people with disability enjoy this right by making sure they have:

> the opportunity to choose where they live and who they live with, just like other people

> access to in home, residential and other community support services to help increase community inclusion and to reduce isolation

> equal access to community services and facilities that are available for the public, which should take into account the needs of people with disability.

NSW Disability Services Act (DSA) 1993 and the Disability Service Standards

The NSW Disability Services Act (DSA), introduced in 1993, establishes the framework for the provision of services for people with disability in NSW. The DSA requires services to 'enable people with disability to achieve their maximum potential as members of the community', 'further integration', 'achieve positive outcomes' and 'promote a positive image' of people with disability.

The rights of people with disability and the requirements of services are further elaborated upon through a set of Principles and Applications of Principles that are part of the DSA. Principles particularly pertinent to the right to supported living include rights to live in and be part of the community, realize individual capacities, choose one's own lifestyle, have access to information and participate in decisions that affect one's life.

The NSW Government developed the *Disability Service Standards* as a working document to support the implementation of the DSA. Unfortunately, Disability Service Standards have reduced the richness one looks for in life to a set of signposts that do not reflect the intent of the aims of the DSA: the aims of integration, positive outcomes and positive image.

NSW disability policy

Strategic directions for people with disability and services in NSW

Current NSW disability policy is focused on *Stronger Together: a new direction for disability services 2006-2016*. *Stronger Together* is not a coherent set of disability policies; rather it is a 10 year plan setting out the strategic priorities and directions for services provided and funded by Ageing Disability and Home Care (ADHC).

The first five years of Stronger Together focused upon:

> strengthening families

> promoting community inclusion

> improving the system's capacity and accountability.

Stronger Together provided significant growth in supported accommodation but the vast majority of places were allocated to people who had been in the care of the Minister, people with disability in the criminal justice system and people in crisis.

The second five years of the plan will commence in 2011/12, and it is anticipated that the government will invest an additional $2 billion in disability services.

Who is eligible for supported accommodation in NSW?

Currently, individuals over the age of 18 who have intellectual disability with moderate to high support needs are eligible for supported accommodation. An independent assessment determines an individual's level of support needs. Priority of access is given to:

> people with complex multiple needs

> people with assessed complex challenging behaviour

> people with forensic issues

> people who are at risk of entering more restrictive options

> people whose carer is likely to be at risk unless entry into a service is facilitated

> people who are homeless or who are at risk of becoming homeless.

Individuals considered most in need are eligible to be placed on a waiting list in this crisis driven system where those most in crisis are served first. Those with supports at home are less likely to be eligible for supported accommodation in the near future.

Supported accommodation provided by government and non government providers is managed as one system through a vacancy management process. Vacancies in existing houses and services are offered to the person in most critical need that matches the vacancy. There is seldom opportunity to choose where the person lives, who the person lives with or who supports them and how. People are often housed far away from their family or community.

Broader policies for supported accommodation

In 2006 ADHC recognised that the system needed to be more flexible and provide a wider range of accommodation options. The Innovative Accommodation Framework was developed, outlining ADHC's plan for different accommodation models. Many of the models require people with disability to live together with other people with disability (often in large numbers, for example, Large Residential Centres, clusters, villas and co-located models). More individualised options are also outlined, including flexible packages, alternate family placement, drop in support and in home/attendant care support.

Unmet Need – Trends effecting housing

There are many people who need affordable housing in NSW

Over many years, successive State and Commonwealth Governments have not invested in social housing. In addition, rental properties are less affordable than ever and vacancy rates are low. The lack of affordable housing is often referred to as housing stress with an increasing number of low and middle income families and singles spending over 30% of their income on mortgage repayments or rent.

The lack of affordable housing is a national issue. The high levels of unmet need are evidenced by:

> long waiting lists for public and community housing

> people waiting a long time before being allocated housing

> long term placements in inappropriate environments

> an increasing number of young people with disability trapped in aged care facilities

> an increasing number of people with disability who are homeless or in crisis accommodation

> a high numbers of people with disability living with their families well into adult life.

New initiatives in public housing

The Commonwealth Government has acknowledged that social housing stock needs to increase substantially on a national level, and has developed a range of programs that aim to address this need, including targeted assistance to First Home buyers and a National Rental Affordability Scheme.

In addition, the Commonwealth Government has agreed to fund the development of thousands of new social housing dwellings nationally, and the States and Territories have agreed to better manage their housing stock and better integrate vital services for people living in their dwellings. Through a national agreement, all governments have agreed to develop social housing that is affordable, safe and sustainable.

Developments in community housing

Community housing is the most suitable form of social housing for people with disability because it is well integrated into local communities. (Public housing estates tend to congregate large number of people in difficulty. In some circumstances, this may lead to difficulties for some people with disability.) In addition, Community Housing Associations, as smaller, non government organizations, may be in a better position to work closely with local communities. They may be better placed to respond more quickly to tenants' needs and be more flexible about how they manage their stock and resources.

The NSW Government is in the process of transferring thousands of properties from management under Housing NSW to management under Community Housing Associations. This is a positive step by Housing NSW towards trying to address the needs of tenants within their own communities. All housing stock, however, will be managed through a vacancy management system.

Unmet Need – Trends effecting support

NSW has a poor record in relation to its support for people with disability. Despite a large investment of funds through *Stronger Together,* the vast majority of people with disability do not receive the support they need to move into a home of their own. Those who do receive accommodation support do not have their needs met in ways that allow them to have a decent life, let alone a good life connected to family and community.

Few real attempts have been made to gain an accurate understanding of the longer term personal, social and economic costs and consequences of forcing people with disability to remain in the family home well into adulthood. In addition, there is little research into what future housing and support is required and where this is likely to be located in order to maximise opportunities for community connections and continued supports to enable a real home. Resources continue to be directed to outmoded forms of accommodation that lead to poor outcomes for people with disability while innovative ideas have been largely resisted.

Other factors contributing to unmet need are population growth; increasing numbers of people with disability who are living longer; increasing pressure on individuals and families; concerns about adequate long term planning and the spiraling costs of support.

Unmet need is also exacerbated by lack of effective planning as a result of lack of relevant information; different ideologies and vocabularies; policy fragmentation; divided responsibilities and poor coordination between and within State and Commonwealth programs. Consequently, infrastructure development is haphazard and the capacity to assess the usefulness of current arrangements or identify changing needs is restricted, with grave implications for policy and program development.

The capacity of the disability sector needs to be developed through investment in innovation

The priority for NSW needs to be in developing options that use paid support to compliment the informal support provided by family and friends. An identifiable strategy is required to rebut the notion that the only way for people with disability to move out of the family home is for them to move into a government allocated place.

Government must allocate resources to assist families to understand the options, to build a vision and to plan so that their son or daughter can have a home of their own. This includes providing families with the tools, support and knowledge to plan for their loved one's future.

 Simultaneously, ADHC needs to work with agencies such as Housing NSW, advocacy organisations and small community organisations doing innovative work to provide the infrastructure to support men and women with disability to have a home of their own.

About deinstitutionalisation

Until the mid 20th Century, families of children with disability had only two options – to place their child in an institution or provide care themselves at home with no supports or services. As a result, a significant proportion of people with disability lived in large institutional facilities where they were largely 'invisible'.

There were two main reasons why governments moved away from providing institutional care towards the end of the last century:

1. Moral obligation

Community pressure forced government action for reform. This was influenced by:

> obvious violations of human rights and negative publicity about living conditions in institutions

> changes in the beliefs about people with disability and the nature of human service delivery

> legal requirements for a decent life and not just custodial care

> strong criticism of the value of segregated and congregated care based on solid research, especially around the abusive culture of such places

> proof of better lives for people with disability following relocation into community options.

2. Saving money

The high cost of institutional care for all people, regardless of their support needs, motivated the exploration of less costly alternatives.

The shift to community care came about in the 1970's and 1980's when the ideas of 'normalisation' and 'Social Role Valorisation' became popular. All around the Western world, the rights of people with disability were slowly acknowledged including the right to a 'normal' life as part of the community. These ideas were embraced by the governments of the time and provided the underpinning for the Commonwealth *Disability Services Act 1986* which focused on community integration.

At the time it was believed that that the group home model was the best form of care for people with disability. The institutions themselves would be shut down through an official policy called 'devolution'.

However, group homes still operate along institutional lines

The NSW government moved very slowly in closing institutions until in 1998 evidence of significant abuse as well as community pressure led the Minister to commit to close all institutions by 2010. Eleven centres have been closed since 2000, but as of July 2008, 1729 people with disability still lived in 32 institutions (now called Large Residential Centres (LRCs)) in NSW.

In 2006, the NSW Government revised its policy of closing institutions to a policy of redevelopment. Whilst the term 'institution' is no longer utilised by government, the modern day LRC is very much an institution, housing large numbers of people with disability in one facility. LRCs can vary in size and can house up to 480 people. Stockton, Peat Island, Grosvenor and Lachlan are all institutions that have been redeveloped rather than closed.

What makes people vulnerable?

People with disability, particularly those with significant support needs, are at risk of becoming increasingly vulnerable when the opportunities for an ordinary life are not realised. Some housing and support options, by their very nature, can increase people's vulnerabilities more than others.

Some options increase people's vulnerability more than others

Some factors, which are known to increase vulnerability, are:

> when people are congregated together in large and small institutional settings

> when housing and support are operated by the same service

> when all of life is controlled by the decisions of a paid service

> when care or subsistence is provided by a service as a lifestyle

> when people are housed with people they do not like

> when people whose behaviours are challenging are housed together

> when life is the same organised routine for all

> when life is played out behind closed doors

> when paid support arrangements take over the personal and family business of the person

> when family, friends and committed others are not valued or welcomed in the person's life

> when professionals think they know the most about a person and their life

> when the welfare of paid workers overrides the welfare of the person

> when safeguards such as privacy and complaints are used against the person

> when no one knows the person well and there is no one as an anchorperson in their life, maintaining a long term commitment to them

> when no one will speak up for the person when it is difficult for him or her to do so

> when no valued roles are expected and the person has no support to participate and contribute to every day life

> when community membership and citizenship are denied by segregation

> when human rights are denied in abusing or neglectful environments

> when the person is not respected.

About abuse in residential settings

It should be no surprise that poor conditions of residential life will generate stress and conflict and stimulate a range of negative reactions that can attract abuse and neglect. Congregated living can be dominated by competing and unmet needs. Low staff to resident ratios inhibit the capacity to respond to each individual in ways that offer genuine opportunity for personal choice and independent action.

Abuse and neglect are more likely in congregated settings

Stress reactions such as frustration, anger, anxiety, boredom and depression result from low staff ratios and can generate conflict and destructive responses into which residents, as well as workers, are drawn. Residents become labelled as 'difficult' and abuse and neglect become more likely.

Abusive and neglectful settings can be characterised by:

> ignoring universal need for positive human interaction

> reducing individual needs and aspirations to one common denominator

> limiting personal choices and regulating behaviour through punitive treatment

> enforcing incompatible groupings

> establishing inflexible regimes, standardised services and routine activities

> focusing on physical needs and limitations and overlooking quality of life

> having inequitable sharing of resources.

Statistics on abuse are of great concern

Statistics on abuse in care are of great concern. The reality is that physical, sexual and emotional abuse and neglect are common in congregate settings, and its occurrence is significantly higher than in the general population. This is because separating individuals from the wider community makes them more vulnerable. Being part of the community is an essential safeguard against abuse.

Although child abuse has received considerable attention, abuse of adults with disability has received relatively little attention. Available information suggests a serious problem. Australian studies have found adults with disability were 2.9 times more likely to experience physical assault and women with disability were 12.7 times more likely to be sexually assaulted. The majority of these cases involved staff or co-residents of group homes and other residential settings. Canadian statistics confirm that this is a common experience for people with disability in congregate care all over the world.

Neglect is a different form of abuse as it is an action of omission. It is one of the most common and devastating harms done to people in residential facilities and happens most frequently to people with intellectual disability and those who require personal care. Neglect can involve failure to provide medical care, failure to protect against abuse, or even the failure to provide the very basic necessities of life such as food and water.

Creating safeguards

Having a home of one's own and good support makes people safer

Whilst not every congregate setting is abusive, the evidence is overwhelming that abuse in care is more likely. Many good intentions can be sidetracked by the needs of services and systems, so it is important to ensure that the well being, safety and security of the individual is maintained over time and at the centre of planning and service provision. This is especially important for people with intellectual disability, high support needs and personal care needs as these people are particularly vulnerable.

What we do know from research and case studies is that when people live in a home of their own their quality of life and standard of living improves. There is also evidence that a home of one's own results in an increased amount and quality of contact with family, friends and workers. In fact, having people who love and care about the person in unpaid roles is one of the greatest known safeguards for a person with disability. Having good paid support, which is personalised and operates from a values base consistent with personal and family expectations can also provide a safeguard.

Sometimes people think that a having a home of one's own is not possible for people who have high or complex needs. Yet, we already have some wonderful examples of people with very high needs and challenging behaviour living in their own home. Of particular interest is the fact that that many people who had previously been considered to need 24/7 paid support actually require less support and experience low levels of behaviour problems when supported in their own homes by people who know them well.

What keeps people safe?

> Having housing separate from support.

> Having security of tenure of housing and security of funding for support.

> Having unpaid people in one's life who love and care for the person.

> Having a vision of what makes a good life and not compromising on this vision.

> Keeping decisions close to the person involved.

> Having clarity about what is the business of the person and their family and what is the business of the service.

> Being open to involvement and monitoring by the person, family and friends.

> Having safeguards in place that minimise the vulnerability of the person, such as friends regularly dropping by during service hours.

> Having personal selection processes for paid support staff that involve the person and their family and friends.

> Choosing staff with the right values base to provide paid support.

> Having supports that operate in ethical and principled ways.

> Maintaining the person and their life as the focus over policies, procedures, regulations, financing and technology.

About rights and complaints

Making a complaint does not always mean that human rights are achieved

According to the Universal Declaration of Human Rights, everyone has the right to a decent standard of living with access to food, clothing, medical care and necessary social services. This right has been further enshrined for people with disability in the UN Convention on the Rights of People with Disability. However, the reality is that this fundamental human right is often not achieved for the most vulnerable in society.

As users of services, people have the right to raise issues and have them dealt with appropriately. Everyday issues are usually sorted out at the point of concern. How and where a formal complaint is handled will affect how well it is sorted out. If it is taken seriously and agreeable action follows, a good solution can occur even in difficult circumstances. This is even more likely to happen when complaints are dealt with independently as this avoids conflicts of interest. Unfortunately, sometimes there is an unexpected cost. Raising issues or making a formal complaint can do the opposite – it can make a person more vulnerable or label them as a trouble maker.

Complaints about services

Both Housing NSW and ADHC have internal complaints mechanisms, and individual services are also required to have a complaints procedure. Complaints should be made through these channels. If you are not happy with the internal complaints channels and wish to have the issue reviewed at another level you can lodge a complaint with the **NSW Ombudsman.** The Ombudsman can investigate complaints made against the NSW Government and against funded services and will try to work with you and the service to resolve your issue. You can find out more about the NSW Ombudsman at www.ombo.nsw.gov.au

Complaints as a tenant

Tenants NSW is an independent service set up to deal with complaints about rental housing. It is the gateway organisation for both the Tenants Union and the Network of Tenants Advice and Advocacy Services. Tenants NSW has a website informing you about your rights and responsibilities as a tenant, where to get tenancy advice, the Tenant's Union policy and legal work and the latest news about rental housing. Their website is www.tenants.org.au.

Discrimination on the basis of disability

> Discrimination against someone on the grounds of his or her disability is illegal. If refusal to gain housing appears to be on the basis of disability, a grievance can be lodged at the **NSW Anti-Discrimination Board** who can then investigate the complaint and help you find a way of solving your problem. Contact the board at www.lawlink.nsw.gov.au/ADB

> If the Board is not able to solve the problem for you, you can take your complaint to the **Equal Opportunity Division of the Administrative Decisions Tribunal,** which can make a decision like a court. Their website is www.lawlink.nsw.gov.au/adt

> **The Australian Human Rights Commission (HREOC)** can investigate complaints of discrimination, harassment and bullying based on disability. Complaints to the Commission are resolved through a process known as conciliation. Complaint outcomes can include an apology, reinstatement to a job, compensation for lost wages, changes to a policy or developing and promoting anti-discrimination policies. For more information: www.hreoc.gov.au/complaints

> **The NSW Disability Discrimination Legal Centre (DDLC)** promotes and protects the human and legal rights of people with disability and their supporters through legal advocacy. They do this by providing free legal advice and representing people with disability in discrimination cases. For more information: www.ddlcnsw.org.au

> If you require a legal advice, there are a number of legal rights services such as the Intellectual **Disability Rights Service** www.idrs.org.au or **Legal Aid NSW** www.legalaid.nsw.gov.au

> If you wish to seek advice on a systemic legal issue and bring it to the public eye, you can contact the **Public Interest Advocacy Centre** www.piac.asn.au

About advocacy

Promoting, protecting and defending

People with disability are highly vulnerable and can be more susceptible to harmful things occurring in their lives. This can be caused by the impact of their disability, social situation, human services or general discrimination. Their human rights can be ignored and their ability to enforce these rights can be easily restricted or denied. When there is a constant struggle for justice and for having a decent life, additional support is needed.

Advocacy can play a very important role in ensuring the needs and interests of people with disability are respected and protected. By standing by, for and with a vulnerable person, good outcomes can occur. However, as advocacy is often in opposition to the dominant system and practices, these outcomes can be difficult to achieve and it can take some time to attain the desired positive outcomes.

Families are usually the main people who speak up for their family member with disability. In addition, there is a limited number of paid advocacy services and since funding for advocacy is poor, it may take time to find a suitable advocate who is able to assist.

The principles and elements of advocacy

As advocacy can be used to achieve good or do harm, principles govern its use with people with disability. These are:

> to protect fundamental human rights

> to ensure social justice

> to promote inclusive living.

Advocacy practices involve:

> taking positive, ethical action on behalf of a person with disability (or group)

> being clearly on the side of the person with disability and doing no further harm

> understanding the person with disability's position and their real and potential vulnerabilities

> striving to be autonomous and independent of other systems that can cause conflicts of interest

> focusing on the fundamental needs, welfare and best interests of the person with disability

> working vigorously and with a sense of urgency

> remaining loyal and accountable to the person over time.

There are two main kinds of advocacy:

> **Informal advocacy** happens as the result of the commitment of people to one another. It is done in an unpaid capacity, usually by parents, partners, brothers, sisters, other family members or a close friend.

> **Formal Advocacy** is an organised paid response of individuals or a collective advocacy effort. The typical forms of advocacy are:

　– individual advocacy – an individual is matched to an advocate

　– citizen advocacy - an individual is matched to an unpaid advocate

　– systemic advocacy – focused on trying to make large scale policy and system changes.

Why people with disability may need advocacy

The impact of impairment

People with disability, especially those with complex needs, often find that the limitation of their functional abilities can shape or even define their lives. An inability to communicate their needs, a difficulty in expressing choice, limited awareness of danger and reliance on others to meet their needs can often place people with disability in extremely vulnerable positions.

Many people in our society perceive people who are considered to be 'different' negatively. Individuals can become marginalised and powerless to address their own situation. Many people with disability experience negative attitudes and stereotyping, stigmas and labels, lack of opportunity, exclusion, segregation, abuse, neglect and no recourse to justice. Without appropriate and independent support these problems may never be addressed.

Effects of human services

Many people with disability rely heavily upon human services to meet many of their basic needs. Most of these services, however, are imperfect and cannot meet all human needs. The services can often lose their way and serve their own interests rather than the interests of people with disability. At times services can actually reinforce negative stereotypes and myths, can medicalise life, can have incompetent workers and can be life defining and life wasting.

How can advocacy assist?

When people take on advocacy roles they are often working against the dominant beliefs and ways of operation in our society. Advocates believe people with disability:

> are as valuable as any other person, regardless of what they can or can't do

> need to live well and have the same things in life as other people, such as their own home, being known, having relationships and having a sense of belonging, love, affection and safety

> are part of the connections of ordinary life and are to be included in the rich fabric of our communities and not to be segregated, congregated or isolated on the basis of their disability

> will make mistakes, have courage, be fearful and will be as likeable or as unpleasant as any other human being.

Some useful advocacy strategies

When taking on the role of an advocate or looking for an appropriate advocate, the following strategies may be helpful:

> clarify your values about life with the person and hold a clear vision for their life

> clarify the information you need

> take strategic action on the person's behalf by thinking through the action and the moral dilemmas involved

> don't do important things alone – always take someone with you, even if they only sit there and take notes

> identify things that can happen now and goals that lead towards the vision for a good life for the person

> be able to explain to others about the vision you hold and have ideas about what it would take to achieve that vision

> identify the key people you need to influence

> plan and be strategic in how you go about doing things

> have specific expectations and questions relating to what needs to happen

> be clear about the bottom line you will accept and could live with, and the difference between compromise and a sell out

> anticipate their answers and develop counter arguments to their excuses

> instead of having to justify your position, ask them to justify theirs – ask why can't certain things happen?

> don't get caught up in the agendas of government or services by trying to solve things for them

> challenge the legitimacy of decisions that are unfair or unjust, or have harmful consequences or take the person out of ordinary life

> don't attack people personally or be rude – take issue with what is happening to the person you are advocating for and be polite but firm

> don't be confrontational

> keep records of phone calls, meetings and other significant events

> ask for certain things to be followed up

> thank people who do the right thing

> believe in the justness of what should happen for the person so that they have a good life, free from harm

> believe in yourself and your common sense

> pick your battles; know when to step forward and when to step back

> take care of yourself

> become involved with others in the advocacy movement.

Personal and income support in NSW

Personal support

Home and Community Care Program (HACC)

The HACC program is a joint Australian, State and Territory Government initiative. In NSW, ADHC is responsible for the administration of the program, which provides a range of basic maintenance and support services for frail older people, people with disability and their carers. HACC services can provide for a range of services including social supports, domestic assistance and personal care, respite care and allied health care.

HACC High Need Pool (HNP)

The HACC High Need Pool (HNP) was established to provide clients who require 15 hours or more service per week but also have a capacity to manage with a maximum of 35 hours of service per week. The aim of the HNP is to assist clients to live independently at home and in the community, thereby preventing premature or inappropriate admission to long term residential care. Young people with disability and their carers who require high support levels are eligible for the HNP.

To see if your family qualifies for HACC funded services you will need to contact the HACC program.
Web: www.dadhc.nsw.gov.au
Call: 02 8270 2000

Attendant Care

The Attendant Care Program provides packages of portable, flexible and individualised support for people with a physical disability who need personal help to complete activities of daily living. People who are aged 16-65, who live in their own home or with family, who require more than 15 hours of personal assistance per week and are also not suitable for other ADHC funded accommodation services in the short to medium term, are eligible to apply for Attendant Care.

Applicants need to apply for the program through ADHC's Attendant Care and Physical Disability Unit.
Email: acphnp@dadhc.nsw.gov.au
Call: 02 8270 2000

Income support

Disability and Carer payment rates

For information on the Disability Support Pension, Carer Allowance, Carer Supplement and Mobility Allowance.
Web: http://www.centrelink.gov.au/internet/internet.nsf/publications/co031.htm
Call: 13 27 17

Special Disability Trust

The Australian Government has introduced this trust to assist immediate family members of people with severe disability to make private financial provision for the future care and accommodation support for that person with a severe disability. To find out if you can set up a Special Disability Trust, contact Centrelink's Special Disability Trust Team. The Assessment Officer can provide more information.
Email: cao.west.w@centrelink.gov.au
Call: 1800 734 750

Useful housing contacts

Housing NSW

You can contact Housing NSW if you are looking for information on public housing:
General Inquiries:
Head Office: 02 8753-8280
www.housing.nsw.gov.au

Community Housing

To find out about how to get on the waitlist for community housing run by community groups:
1800 330 940
www.rch.nsw.gov.au

Homeless Persons Information Centre

1800 234 566
7 days per week 9am-10pm (closed 1-2)

Home Modification and Maintenance Services (HMMS)

(02) 6622 8386
www.nswhmms.org.au

Commonwealth Government Rent Assistance

http://www.centrelink.gov.au/internet/internet.nsf/payments/rent_assistance.htm

Housing Cooperatives Association of NSW

If you want to know more about Housing Cooperatives and if there are any near your home:
(02) 9361 6834
www.arch.asn.au/coop.htm

Emergency Shelters

For information on homeless shelters and who you can contact go to this website:
http://www.youth.nsw.gov.au/youth_links/links/leaving_home/emergency_accommodation

24-Hour Domestic Violence Help Line

1800 656 463

Tenants Advice and information on Tenants Union

1800 251 101
www.tenants.org.au

Consumer Trader and Tenancy Tribunal

1800 135 399
www.cttt.nsw.gov.au

Useful disability and other contacts

Ageing, Disability and Home Care (ADHC)
Head Office: 02 8270 2000
www.adhc.nsw.gov.au

ADHC Regional Offices
Metro South: 02 9334 3700
Metro North: 02 9841 9350
Hunter: 02 4978 6222
              1300 205 268
Northern: 02 6621 1400
              1300 364 563
Southern: 02 6128 9200
              1300 841 566
Western: 02 6841 1594
              1300 134 450

Disability Council of NSW
02 9211 2866
1800 044 848
www.disabilitycouncil.nsw.gov.au

NSW Ombudsman
02 9286 1000
1800 451 524
www.ombo.nsw.gov.au

NSW Guardianship Tribunal
02 9556 7600
1800 463 928
www.gt.nsw.gov.au

NSW Trustee and Guardian
02 9252 0523
www.tag.nsw.gov.au

Human Rights Commission
1300 656 419
www.hreoc.gov.au

National Disability Service (NDS)
NSW 02 9256 3111
www.nds.org.au

NSW Anti Discrimination Board
www.lawlink.nsw.gov.au/ADB

Administrative Decisions Tribunal
www.lawlink.nsw.gov.au/adt

Family Advocacy
02 9869 0866
www.family-advocacy.com

People with Disability
02 9370 3100
www.pwd.org.au

NSW Council for Intellectual Disability
02 9211 1611
www.nswcid.org.au

Multicultural Disability Advocacy Association
02 9891 6400
www.mdaa.org.au

Legal Advocacy
Intellectual Disability Rights Service
02 9318 014
www.idrs.org.au

Legal Aid NSW
1300 888 529
www.legalaid.nsw.gov.au

Public Interest Advocacy Centre
www.piac.asn.au

Disability Discrimination Legal Centre
(02) 9310 7722
www.ddlcnsw.org.au

Other Useful Information

Supported Living
www.supportedliving.org.au

In Control Australia
www.incontrol.com.au

Homes West
www.homeswest.org.au

My Place (WA)
www.myplace.org.au

Inclusion Press
www.inclusion.com

Disability Lifestyles Website
www.disabilitylifestyles.org.au

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Community Resource Unit	2005	*On Being the Change We Want To See: A Collection of Writings from Crucial Times,* Vol 3 CRU: Brisbane
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Department of Human Services - Housing NSW	2009	*Housing NSW Disability Action Plan 2009-2013*, Draft May 2009: Sydney
Queensland Government	2000	*Strategic Framework for Disability 2000-2005* Queensland Government
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family ADVOCACY