

Families for Change

Promoting and defending
the rights and interests
of people with
developmental disability.

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family

A D V O C A C Y

SUPPORTED LIVING for New South Wales

As we look to the future for our sons and daughters with disability, the importance of a home of their own looms large. The concept of having your own home symbolises control over the important aspects of your life; it is only in their own 'home', that our sons and daughters can decide how they live, with whom they live, and what help they get in order to live a rich and valued life.

This is in stark contrast to what is provided by the disability service system in New South Wales (NSW), where, by and large, people with disability whose families are no longer able to provide ongoing support, live in situations over which they have little control. They are forced to live with people with whom their commonality is disability, in a location that is removed from family, friends and community. Government policy stipulates that if their needs change, a person with disability will have to change services and houses!

Every week Family Advocacy takes calls from families who are damaged by this dehumanising process. A system in which moving out of home cannot be planned, and where support is only available in crisis situations, is not workable for anyone.

While Family Advocacy continues to lobby Government and take action at the systemic level, we want to encourage families to take the initiative and gain supported living for their sons and daughters, in spite of what the system offers.

Leadership by families has always been at the forefront of positive change for people with disability. In NSW, we need to do it again and we need to do it now! We need to set a vision, research the options and take steps to fashion our own version of the 'best.'

In this edition of the journal, Karen Fisher and Sarah Parker of the Social

Policy Research Centre share their most recent research on the accommodation options available in Australia and

***“The concept of
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internationally for people seen as needing 24 hour care. They found the common features that produced a good life for people with disability are:

- separation of the provision of housing and support;
- support tailored to each person with a notional budget upon which they could call;
- support provided through a mix of formal and informal support with an investment in developing informal support.

Of particular interest is the finding that when the right elements were put into place, people traditionally seen as requiring 24/7 support, no longer needed this level of intensive support.

This report provides an interesting comparison between NSW and other states. NSW for example, still utilises group homes for people leaving institutions while most other states are focusing on individualised support, increased consumer choice and participation.

Experience elsewhere shows it can be achieved. In Victoria, for example, people are moving out of group homes and into more individualised arrangements. By directing energy into building connections with people and the community, rather than trying to change large service organisations (with their unwieldy inflexible bureaucracy), families are pushing the boundaries and

helping their sons and daughters move into their own home.

In NSW, Government and services tell us that individualised supported living is not possible for people with high support needs. However, in his article, 'What choice do you have?' Ross Womersley of the Community Living Project Inc in South Australia demonstrates that families are creating the necessary framework to facilitate that very goal. He writes "...that as yet we have not been able to identify anyone – no matter what their level of disability – that can't be supported to live in a place of their own."

As regular readers of this journal will know, Family Advocacy believes that all people with disability have the right to a good life with the same options as their peers who do not have a disability. Many families dream of a 'home of their own' for their son or daughter with disability but feel that it is practically impossible. In the article 'If only our service system had these qualities....' from the Community Resource Unit in Queensland, seven strategies are listed, creating a 'checklist' of what service providers should be employing

Inside this issue:

Editorial:	1
Supported Living for New South Wales	
Policy Directions for 24 Hour Housing and Support	2
Not Waiting, Creating	4
What Choice Do You Have?	5
If Only Our Service System Had These Qualities	6

if people with disability are indeed to have an *authentic* home and not a service mediated 'home like' version of the real thing.

Family Advocacy is committed to helping families to take the next steps to secure supported living by:

- keeping in touch with families and their networks as they dream and plan;
- providing workshops and speakers that provide inspiring stories;
- providing a 'place' to thrash around ideas;
- lobbying government for :

- a funding stream to support people with disability to move into their own homes in a planned and timely fashion;
- the opportunity for families and people with disability to have control over the what, when, where and by whom of support;
- affordable, accessible community housing.

We leave you with a few 'next steps' as you read this journal.

- Reclaim your authority as a family to build a vision for your family member. Develop a circle of people

to share your vision and help to implement it.

- Take a look at the Supported Living Website, www.supportedliving.org.au. This site provides a wealth of resources to read and share with your friends.
- Take first steps to secure affordable housing. For their 18th birthday, put your family member's name on the wait list of the Department of Housing – critically, nominate that you want community housing and then visit, talk to and share your vision with your local community housing associations and the housing officer at your local council.

Policy Directions For 24-hour Housing and Support

Karen Fisher and Sarah Parker

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Sarah Parker, PhD (Sociology & Social Policy), University of Sydney, Assistant Professor, Department of Disability and Human Development, University of Illinois at Chicago.

The Social Policy Research Centre recently completed research into the effectiveness of supported living in relation to shared accommodation. The research was commissioned by the Disability Policy and Research Working Group (made up of senior Commonwealth, State and Territory Disability officials) and aimed to improve service delivery for people with disability by increasing understanding about accommodation services and housing for people with disability.

The report will be released later this year.

Karen Fisher and Sarah Parker have kindly summarised part of that research in the article below.

Government policy on housing and support for people with disability aims to fulfil a number of goals. It seeks to: uphold disability rights, improve quality of life and choices about living arrangements for people with disability, and make cost effective use of available funds. This article summarises recent directions in housing and support policy in Australia and internationally that satisfies these goals.

The trend in supported accommodation, in Australia and internationally, is the closure of large institutions (a process often referred to as deinstitutionalisation). Instead, the 24-hour staffed group home is now the most common form of residential accommodation support. The newest trends are towards semi-independent living and the development of resources to support informal care. An important

policy trend is the move towards providing individualised services and many countries are examining different methods to achieve this, including direct funding models and individualised case management.

In Australia, governments have committed to providing alternatives to institutions since institutions do not usually meet the policy goals previously mentioned. In New South Wales, most new accommodation places are in group homes, usually with three to six people with disability supported in a house in the community. In other states, policy changes are away from group homes for a number of reasons. Group homes are an expensive form of support, relatively inflexible to change and, as a model, cannot respond to the large unmet need for people who do not currently receive appropriate support.

The rest of this article discusses some of the alternatives to group homes for people who require 24 hour support in Australia and internationally.

Australian Policy Directions

The challenge for government in devising housing support policy is how to meet the needs of people who require 24 hour support. Many of the alternatives to group homes and the formal 24 hour support setting aim to enable the person with disability to actively engage with the community and foster informal support. This reduces need for formal 24 hour care, while still providing a safe environment (Table 1). Examples of how to achieve this include co-residency with people with or without disability; on-call and drop-in support in social housing; and adult foster care type arrangements.

Table 1: Disability Housing and Support Policy Shifts by Australian State

New South Wales	Closing large institutions. Clients initially moving into group homes. Now also including more flexible options for housing.
Northern Territory	Shifting to more weight on user preference. More support and funding for living at home, especially Indigenous people.
Queensland	Person centred approach. Move towards people pooling support to enable individual support needs to be met.
South Australia	Closing institutions. Increasing the supply of community housing.
Tasmania	Greater individualisation of services. More choice and more emphasis on preference of the user in deciding services.
Victoria	Strong focus on individualised support and consumer participation. People in group homes are moving to individualised support packages. Active Support framework in group homes to increase user participation. Commitment to close institutions.
Western Australia	Developmental paradigm policy for consistent care through life to prevent crisis care. Commitment to individualised service provision and funding.

Source: Interviews with government officials 2007

In relation to support services, the trend is towards individualised funding and service provision. Many innovative models, both residential and home based, provide case management and individually planned support services that provide the services necessary for the person and their changing needs. In addition, policies are supporting informal care from family and friends through home based services, such as personal care and home care, day activities and respite services.

In relation to housing settings, the Australian policy trend is towards minimising the size of the setting, both physically and in relation to the number of people accommodated in each house. This, in conjunction with the emphasis on community integration, has promoted trends towards independent community living and generic housing, either in social (public or community) housing or the private housing market.

International Approaches

In a comparative analysis of supported housing arrangements for people with an intellectual disability, Braddock et al. (2001) found Australia, the United States of America (USA), Canada and

the United Kingdom (UK) have all seen a general shift towards smaller community based settings with a similar number of people with an intellectual disability residing in group homes across each country. Germany and Italy remain focused on informal and community-based care, many times merging the two. Policy directions in the UK, other parts of Europe and USA illustrate the policy preference for consumer directed and individualised services.

United Kingdom

The deinstitutionalisation of people with intellectual disabilities has been the central principle in the process of reforming disability support services in Britain. In 2004, 80 percent of people with intellectual disability in England were living in the community.

Since 1997, direct payments have been a feature of the British model of support. The British Government has a commitment to transfer social services to the private sector and since 2001, local authorities have been required to offer and encourage the take up of direct payments in lieu of services. Services are instead purchased directly by the recipient.

Sweden and Norway

In Sweden and Norway, all institutional provision of care and housing has been abolished in favour of community living, which has been enshrined as a right in law. If a person does not live in their own home or with their family, the most common support is small scale staffed residential housing such as group homes, with 0.4 per cent of the population under the age of 65 in Nordic countries (Sweden, Denmark, Finland and Norway) being supported in such settings (Hvinden, 2004).

United States of America

Most people with disability in the USA live with family and friends. A current trend in disability support is the shift towards 'consumer directed' support programs, involving individually negotiated and directly purchased personal assistance services, tailored to the needs and preferences of the person with disability. New models are aimed at increasing self determination and community living by providing sufficient levels and types of support needed in a community setting – either promoting living at home with family or other carers or in suitable community housing. The US trend is away from fixed disability support services, towards individualisation and planning tailored to the person's needs (Heller & Caldwell, 2005).

Individual Planning and Support

The most recognisable trend in the countries reviewed is that of individualised disability support. All countries in these regions have made a commitment to smaller and less institutional residential facilities and a focus on promoting the participation of people with disability through encouraging independent community-based living arrangements. It is now widely recognised that considerable problems remain with any 'one size fits all' policy founded on the provision of group homes. Developments in the UK, USA, Canada and elsewhere suggest solutions lie in a combination of increasing the individualisation of funding allocations, increasing the flexibility of potential living arrangements in ordinary housing dispersed within the community and having a more rigorous performance management of services based on the actual outcomes for people with

disability (Emerson, 2006). These directions are consistent with changes in some parts of Australia.

Direct Payments

Several European countries, such as UK, Netherlands, Italy and Austria, have identified direct payments as a central method of support provision in the future and have taken steps to encourage its growth and take-up. Direct payments to the person or their family are in lieu of services. Services can instead be purchased directly with the payments.

In Australia and the US, case managed, individualised funding is being promoted as an important method of tailoring support to the needs of the

person, especially when provided in conjunction with affordable and suitable housing.

Summary

The policy trends in disability housing support, in Australia and internationally, are towards individualised, home based support, tailored to changing needs during the person's life. Models feature independent living choices; individualised and holistic planning, funding and delivery; participation of the person with disability in decisions; and facilitating a social network of formal and informal support. They facilitate the person's choices within their family and community. They expect the person will make choices that change as their life changes, and therefore facilitate

mobility and flexibility. Importantly, they integrate informal, formal and generic support. The impact is that they can focus on client outcomes, efficient administration practices and affordable services. With this approach, Australian governments can work towards sustainable policies that meet the needs of people with disability, their families, community, providers and government.

References available on request.

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Not waiting, creating....

The experience of using disability services often makes families feel alone and powerless. People feel frustrated waiting for government to introduce the kinds of supports and funding that will give people with disability the freedom to choose how and where they live.

Many families begin to think that they can't do anything to achieve flexible, person centred supports.

But there are many families who have made their own arrangements – families who didn't wait. Most good examples of supported living in Australia have been the result of people getting started on what they want, with or without funding. What these families share is a clear, strong idea of people with disability being able to live where and how they want, with flexible, individualised support.

Supported living is already happening for many people with disability across the world. It does not matter what disability the person has or how much support they need. Supported living makes life better for people with disability.

It is for any person...and it is possible for you.

The Supported Living Website gives lots of information about how to make supported living happen:

- Why supported living works for people with disability
- Key values supported living is based on
- Good ideas about how to support people - 'good practice'
- Stories of people getting support
- Links to other organisations and information
- What you can do to get supported living happening in NSW

www.supportedliving.org.au



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What Choice Do You Have?

Ross Womersley

Ross Womersley is the Executive Officer of the Community Living Project Inc in South Australia and has worked in support of people with disability, and their families, for nearly thirty years. He became involved in this area when he lived in one of the first group homes opened in South Australia. This experience helped him to understand that people with disability are not treated equally and that new ways need to be found to help people to create lifestyles that are just as typical and varied as those experienced by people without disability. He remains just as passionate about this goal today.

One of the most daunting issues for any person who has disability, and their family, is the question of “if I am not living at home with my mum or dad, then where might I be living?”

It can be a challenging subject for everyone involved, usually for a range of very good reasons. Most people who have disability require some form of support to be able to move away from the parental home. So how does someone find this support and get it in a way that suits their ambitions and their desired lifestyle?

Thirty years ago in South Australia, a group of families were concerned about the life choices available to their sons and daughters with disability, many of whom were moving into adulthood. This concern grew into alarm when a friend died, leaving her 21 year old daughter - who was well known to local community - with no-one to care for her. She didn't need new accommodation, after all she already had the family home where she had lived for years. What she really needed was the support to continue to live there.

Each of the families that observed this situation unfold, realised that their idea to develop something for the future could not wait: they had to start planning immediately.

They started to explore the options and discovered that there were no supports available to help this young woman stay where she was in the family home. At that time the only places where daily support were offered was in institutions or boarding houses. She could either languish in her own home or she would have to move.

To understand what moving might mean, the parents visited the institutions and boarding houses. They were told that these were caring places which would be good for their sons and daughters with disability - after all, the outside world didn't really suit these people and they would be happiest with their own kind. They even met some staff who seemed to care.

The parents came away shocked and devastated. None of what they saw was anything like the home they had imagined for their daughters or sons. These weren't environments of joy over which one had control and in which one's own personality, gifts and talents could be nurtured.

“...it is a joy to report that as yet we have not been able to identify anyone - no matter what their level of disability - that can't be supported to live in a place of their own.”

The parents were faced with three options.

The first option was to do nothing: to imagine that it was not possible or it was too hard to do anything different and to accept that one's son or daughter would remain living at home, and to hope you outlive them.

The second option was to concede: to give in to what the professional advice of the day recommended and to accept that institutions were really the place where everyone who had a disability belonged.

The third and by far the most challenging option was to reject what was available and demand something different; to lobby tirelessly for the development of a support service that helped people to create a home - a place that was genuinely homelike but also incorporated the support that the person needed; a place that recognised that having a disability didn't mean you weren't a citizen and community member with all the same aspirations and entitlements that everyone else without a disability has.

It was this passion that gave rise to the development of the Community Living Project Inc (CLP) and it is a joy to report that as yet we have not been able to identify anyone - no matter what

their level of disability - that can't be supported to live in a place of their own.

These days CLP supports forty people, all of whom have very different capacities and needs, to live in their local communities in southern Adelaide.

Everyone that CLP supports is encouraged to exercise as much authority over their own support arrangements as they possibly can. In some instances, CLP supports the person and their parents to employ people in their own right (sometimes referred to as self management). No matter whether the person is employing and managing their own supports or CLP is doing this on their behalf, the support everyone gets is designed specifically around the person. Everyone is expected to be involved in the selection of their own support staff and in determining the roles those people play in their life.

Nearly everyone, other than some people who live at home with their parents, lives in a home that is of their choosing in a location that fits with their own needs and interests. Where someone shares a home with someone else, this will be a person or persons of their choosing like a partner, friend, relative or boarder.

Most people rent their homes through the state housing authority, or a local housing association, while a few people rent on the private market. Several people have been supported to buy their own homes and one person (with support from family and friends) built their own home, brick by brick.

Sadly, this type of support for people to live in homes, that are really their own, is still not widespread throughout Australia. Despite all the evidence that has been gathered over the intervening years - not just evidenced by people supported by CLP but across the world - the same passion, vision and determination shown by CLP's founding mothers and fathers is still needed today, anytime anyone wants to create a real home for a person who has disability.

If Only Our Service System Had These Qualities:

Seven Strategies Likely To Help People With Disability To Have 'A Home'

This paper describes those service features that are considered essential if people with disability are to get real homes of their own. It is adapted from a submission to the Federal Government from a coalition of leading disability advocacy agencies across Australia.

1. Having A Positive Vision That Is Based On What 'Home' Means For Us All

Having a home is important to us all because it gives us a sense of belonging, security, identity and control. These are important yet unrecognised needs of people with disability. What people get in response to these needs is often a service-mediated version of home: home-like, but not a real home. Those who support people to have a home of their own must be highly conscious of what 'home' means in more than a physical dimension and must be skilled at supporting the fullness of having a home.

2. Recognising and According the Fundamental Rights Of People With Disability

The Australian Government was among the first of 81 countries to sign the Convention for the Rights of People with Disabilities (CRPD). Article 19, Living independently and being included in the community, is directed to the elimination of segregated, congregated and socially isolated environments in which people with disability have historically been forced or obliged to live. It requires governments to ensure that people with disability are able to live in the community with accommodation options equal to others, and that these options support their inclusion and participation in community life.

Article 19 of the CRPD also provides that people with disability must be able to choose with whom they live. In order to realise these rights, governments are obliged to ensure that people with disability have access to the support services they require in order to live

freely in the community, and avoid isolation and segregation.

3. Person Centred Ethics and Approaches

We all want to be treated as individuals. In service organisations, this is reflected in person centred approaches that are underpinned by an intentional commitment to appreciating the world through the eyes of the people who receive a service. It is also revealed in the nature of the relationship between server and served, and the capacity and willingness to share information, resources and decisions. Person centred approaches value the person's potential and authority over their own lives and create a sense of 'what could be', rather than limiting lifestyles based on what might or might not be able to be funded.

4. Appropriate Model

The support to live in a home of one's own can come from a range of sources: in a freely given capacity, from generic agencies, and from a disability support agency committed to a person centred approach and that does not also own the dwelling. Features of an appropriate housing/support model must be grounded on several understandings.

• *Effectiveness is more than economics*
An economic argument is often used to support the imposition of congregated living on people with disability. High quality outcomes for people with disability must be valued as highly as cost considerations. Research strongly indicates a consistent pattern of better outcomes and lower costs where housing is integrated into ordinary neighbourhoods rather than larger grouped facilities.

• *Many models that congregate and segregate people with disability are unsafe*

Research clearly demonstrates that models based on imposed congregation do NOT keep people safe. These models have many of the precursors to abusive social and physical environments, including mass management of those who are served, a lack of personal connection between server and served, high staff turnover, low levels of supervision of staff, and a lack of scrutiny by ordinary community members.

In addition, once group home buildings are created, there appears to be an imperative to fill them with subsequent generations of people with disability, thereby limiting the choices of those to come. And yet a group home does not solve issues of loneliness and isolation but can actually accentuate people's difficulties and sense of isolation. Vacancy management, poor matches, inadequate supports and poor need-assessment can create and exacerbate a range of emotional, communicative and behavioural difficulties.

The alternative to group homes is not necessarily living alone, or living a lonely life. Instead of investing in group homes, funds need to be invested in a range of ordinary housing options, alternative supports and the strengthening of the skills of support people.

• *Housing and support services must be separated*

Both history and legislation recognise the danger of one service having control over people's lives. There must be a separation between the supply of housing and the provision of support.

In traditional services, it is common for the support provider to be the property owner or proprietor. This creates a conflict of interest. If the person with disability challenges the service for any reason, the support they receive may be withdrawn, thereby leaving the person without housing. Similarly, if the person wishes to change their housing, they can also lose their support. People with disability often tolerate a mediocre, even negligent, service because they do not want to risk losing their home. No single service agency should have such a level of control and influence over a person's life.

• Choice must not be the only driver

Choice has generally been based on limited information and between options that research has demonstrated deliver poor outcomes for people with disability. Choice is only meaningful when it is between options shown to benefit the person with disability.

5. Investment In Small Community-Based, Person Centred, Service Providers

Community based organisations have demonstrated innovative ways to meet the needs of people with disability. These organisations share common characteristics that make them more responsive to people. These characteristics include: positive beliefs about the value of people with disability and family members, positive beliefs about the potential in people's lives, an idealised sense of 'home', few layers in the bureaucracy or where people with disability have authority over their own support arrangements, and a consciousness about the vulnerabilities of the people who are served and the primary purpose of the service. Good stewardship of funds is also critical.

6. Individualised Funding

For the person with disability, individualised funding assists people to change services or move geographically. It also supports choice and flexibility; when the resources 'belong' to individuals, their bargaining position in negotiating their support is enhanced.

In order to support individualised funding, community services also need appropriate funding of their infrastructure. This has been little recognised. Funds are required not only

to coordinate support arrangements, but also to meet the accountability requirements of government and the wider community.

7. Quality Assurance (QA) That Focuses On Outcomes Rather Than Systems

The key to active involvement of people with disability and family members in any QA system begins with a strong belief that involvement is important and valuable.

“...funds need to be invested in a range of ordinary housing options, alternative supports and the strengthening of the skills of support people.”

Key indicators of a quality housing/support model should include: how the person came to live in their home, their degree of involvement in decision making, how compatible the person is with others sharing the home, how support workers are recruited, inducted, supervised and trained, and the degree of involvement by the person being supported. The potency, usefulness, flexibility and the degree of individualisation of the support should also be considered.

A home of one's own and full membership in the life in the local community are not yet realistic expectations for most people with disability. Yet, despite many constraints, an increasing number of people are supported to achieve these valued goals. We know from the many positive examples that have been created and sustained since the mid 1980's, that people with disability can be supported to live in their own homes and achieve authentic and meaningful home lifestyles, live with housemates without disability, develop freely given relationships, and become respected members of their neighbourhoods.

The features identified in this article are critical to building a service system that supports these goals in ways that are sustainable for the person, their family, the service system and government.

References available on request.

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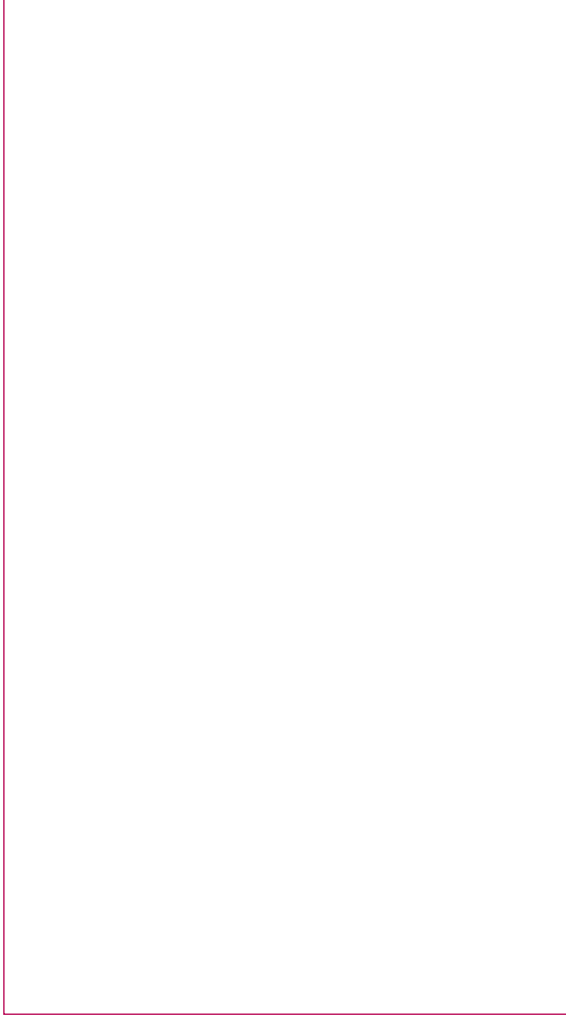
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