

Families for Change



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

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ADVOCACY

SUPPORTED LIVING FUND FOR NSW

Editorial

Welcome to this special edition of *Families for Change* that launches the concept of a Supported Living Fund for NSW.

A Supported Living Fund is a stream of government funding that would enable men and women with disability to move into a home of their own in a planned and timely way.

Built on a concept introduced in Western Australia in 2008, a Supported Living Fund would reward the initiative of families who plan and put in place informal support by providing funds for paid support. In Western Australia, this approach has led to a reduction in crisis, to the development of pathways for people to move into a home of their own and to the development of a range of innovative, person centred living arrangements in which paid support compliments informal support.

A Supported Living Fund is well grounded in evidence about the nature of accommodation that leads to best outcomes for individuals, about what a best practice contemporary disability service system would look like and about the positive impact control over one's life has on health outcomes.

The current emphasis on crisis allocated supported accommodation leaves people with disability and their families with no control over one of the most significant aspects of their lives. A strategy and funding stream that enabled parents to assist their adult children with disability to establish a home of their own, would return control to their lives and improve their health, wellbeing and longevity.

A Supported Living Fund is a big new idea for NSW and should be the centre piece of stage 2 of *Stronger Together* and a key commitment at the NSW State election in March 2011.

A Simple Idea to Enable Men and Women With Disability to Have a Home of Their Own

A Supported Living Fund is a stream of government funding that would enable men and women with disability to move into a home of their own in a planned and timely way.

The creation of a Supported Living Fund would be a proactive strategy that aims to:

- support people with disability to have their own home and life in the community;
- enable each individual with disability and their family to choose who provides the support and how it is provided;
- break the cycle of crisis by supporting and rewarding the initiative of families;
- build on the strengths and capacities of people with disability, their families/networks and local community partnerships;
- increase and evaluate the range of innovative, flexible and self directed community support options, on a statewide basis and with regard to cultural background.

Background

Every day, Family Advocacy is in contact with families across NSW who are worried about the future for their sons and daughters with disability. This includes parents in their seventies and eighties who are still the primary carers of their adult sons and daughters. They see 'homes' for people with disability described as 'beds' and allocated to people in crisis. They see people who use funded accommodation being placed in services far from their family, friends and community, minimising

Join the Family Advocacy campaign for a Supported Living Fund

Campaign details are outlined on page 6 of this Journal.

the opportunities to retain links and thwarting opportunities to shape the kind of lifestyle that they want.

The deepest fear of every family, *What will happen when I die?* makes families desperate to put plans in place. Until recently however, a significant proportion of families have been immobilised in their ability to plan and think about the future because so much of the picture seemed dependent on the whims and changing policies of government.

An increasing number of parents know that they cannot wait for government. They know they must take the lead in assisting their sons and daughters to establish homes of their own and in the process, gather support wherever they can, including government. Like every generation of parents before them, they KNOW that opportunities for people with disability most often stem from family initiative and leadership.

The first five years of *Stronger Together* saw the growth of accommodation for people in crisis, for young adults who had been in formal State funded 'care' and for people 'stuck' in the criminal justice system. This work in relieving crises was important. Crises, of course, continue and will always be a feature of a disability service system.

It is time to turn the rhetoric of prevention and early intervention into practice in the accommodation area by investing in opportunities for men and women with disability to establish homes of their own in a timely fashion while their families still have capacity to support the transition.

In this context, Family Advocacy is seeking support for a Supported Living Fund¹ for NSW as part of the initiatives to be considered in the second part of *Stronger Together*

2006-2016 and in the lead up to the 2011 NSW election.

Target group

The target group is adults with disability who meet the established criteria for specialist disability services AND are interested in having their own home in the community with the assistance of formal and informal supports. The target group will include people living in the family home and people living in circumstances that restrict their opportunities to be included in the community.

Accommodation support is crisis driven. It is allocated at the point of family breakdown and teaches families that crisis is rewarded with 'a bed'.

Why a Supported Living Fund is necessary

The NSW specialist disability service system is not effective in preventing crises and in fostering family initiative.

The disability service system has not fostered the initiative of families, encouraging dependent users of services who rely on government funding to 'fix' their situation. Whilst the menu of service types has increased, people must still choose from the limited menu and have little control over the 'what, when, where and by whom' of support. Consequently, paid support often

does not make a difference in the lives of service users because it replaces rather than compliments the informal support provided by family and friends. At the same time, fundamental needs, such as the need for relationships are not addressed.

Accommodation support is crisis driven. It is allocated at the point of family breakdown and teaches families that crisis is rewarded with 'a bed'. A system built on such crisis intervention has many risks and unintended consequences including:

- people believing that crisis is the only way of moving from the family home;
- a reluctance to plan for or trial arrangements without having first secured funding;
- a generalised reduction in community capacity arising from too great a dependence on funded supports that push out welcoming inclusive practices and leave people with disability isolated;
- trauma and mental health problems for people with disability as well as their families;
- growth of unmet need to such levels that addressing it seems overwhelming for government policy makers and funders;
- people living in accommodation that is inappropriate to their needs;
- people being moved between vacant 'beds' in a way that is dislocating, destabilising and dehumanising.

Demographic factors make it imperative for our system to change.

In the next 20 years, the number of older people will increase markedly as will their life expectancy leading

1. The ideas in this paper draw upon Western Australian work as described in Disability Services Commission (August 2008) *Community Living Concept Plan*

to an extended period of disability. Advances in medical knowledge and practice mean that people with disability can live longer and healthier lives and more people with profound and multiple disability are living into adulthood. As a result, the demand for care and support is increasing amongst all age groups. (AIHW:2009)

Expectations of people with disability and their families are rising. People believe they have the right to more choice and control over all areas of their lives, including public services.

Too often there is little correlation between cost and effectiveness of support. More often than not, factors other than what the person actually wants or needs, determine the service response.

“When people are supported to have choice and control over the assistance they need and those choices translate into how money is spent, they deliver huge payoffs: people get personalised solutions that give them a better quality of life, allow them to participate more in society and form strong relationships at lower cost than traditional service solutions that often isolate and leave them feeling dependent.” (Leadbeater: 2008:9)

This is well understood in the UK where the government is currently involved in a process of service transformation to “replace paternalistic, reactive care of variable quality with a mainstream system focused on prevention, early intervention, enablement and high quality personally tailored services. In the future, we want people to have maximum choice, control and power over the support services they receive.” (NHS:2008:2)

If the NSW Government wants to move from crisis intervention to prevention, from having sole responsibility for long term care

and support to being a partner in care and support, it must encourage and support family initiative while families still have the capacity to partner.

If the NSW Government wants to move from crisis intervention to prevention, from having sole responsibility for long term care and support to being a partner in care and support, it must encourage and support family initiative while families still have the capacity to partner.

When adults with disability are in their 20s, their families still have capacity and energy to support them into homes of their own. Assistance at this time is part of the normal life course. As time goes on, parents feel less able to take the steps that are necessary. Their confidence in their own capacity diminishes and they are less willing to try innovative solutions.

A Supported Living Fund has the capacity to move families from a position of dependence, stress and crisis to people with capacity whose initiative is rewarded. A Supported Living Fund also has the capacity to move the NSW disability service system from crisis intervention to prevention.

Evidence base

A Supported Living Fund builds upon epidemiological research on health outcomes related to control over one’s life, on evidence of best practice in a contemporary disability service system and on evidence about the nature of accommodation that leads to best outcomes for individuals while also being cost effective for government.

The work of Professor Michael Marmot (2004), chair of the UN Commission examining the social determinants of health is relevant. Marmot is acclaimed for his seminal contribution to epidemiology that published hitherto unsuspected links between social status and differences in wellbeing and life expectancy. Marmot drew on evidence from around the world and from nearly thirty years of research to demonstrate that the extent of control a person has over their life and the opportunities they have for social participation are crucial to health, wellbeing and longevity. This has significant implications for approaches to support for people with disability and their families. The current emphasis on crisis driven funding, particularly in supported accommodation, leaves families with no control over one of the most significant aspects of their lives. A strategy and funding stream that enabled parents to assist their adult children with disability to establish a home of their own would return control to their lives and improve their health, wellbeing and longevity.

2009 research commissioned by the Victorian Department of Human Services identified best practice in a contemporary disability service system. (KPMG:2009) The Report drew on evidence from a review of international best practice in service delivery, the analysis of reform directions in Australia and an analysis of elements that enhance sustainability, innovation and

maximise opportunities for equity, access and effectiveness of service delivery to identify the key elements of the contemporary disability service system.

A strategy that supports men and women with disability to establish homes of their own in a planned and timely way would be consistent with best practice in a contemporary disability service system. It would provide a framework in which people could plan for the future and would promote their right to live independently and be included in the community (Article 19 UN CRPD). It would be person centred, support a key transition to adult life, intervene early to improve quality of life and would increase independence. Initiatives that would be funded via a Supported Living Fund would use a combination of formal and informal support, maximise social inclusion, build supports that are sustainable and responsive and build informal care networks.

Recent research into the *Effectiveness of Supported Living in Relation to Shared Accommodation* (SPRC:2007) for people requiring 24 hour care (commissioned by the National Disability Policy and Research Working Group) is of particular relevance. The research found a range of approaches that are effective in terms of quality of life of people with disability and cost. ALL had moved away from providing 24 hour care because when the right elements of formal and informal supports were put into place, 24 hour care was not needed.

Key elements of the most effective models are:

- separation 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.

A preventative strategy that will break the cycle of crisis

The Fund for Supported Living is a strategy of prevention and early intervention that will lead to the development of evidence based models of accommodation that are innovative, cost effective and that contribute to enabling people with disability to thrive. A Supported Living Fund will break the cycle of crisis by:

A strategy that supports men and women with disability to establish homes of their own in a planned and timely way would be consistent with best practice in a contemporary disability service system.

- encouraging families to plan and by rewarding their initiative;
- encouraging the development of pathways away from crisis;
- strengthening the capacity of families to continue a long term role in partnership with government;
- mobilising relationships with ordinary people in the community;
- encouraging people to use generic supports and services available to all people.

Principles that underpin the concept of a Supported Living Fund are embedded in the UN Convention on the Rights of People with Disability, the *NSW Disability*

Services Act, 1993, and *Stronger Together*. They include:

- emphasis on key elements of home, community, valued relationships, choice, contribution and security for the future;
- core values about people with disability, including that each person is valued and respected for their uniqueness and that each person has a right to make real choices and to ongoing opportunities for challenge and growth;
- a person centred approach that puts the person with disability at the centre of planning and decision making about how their life unfolds;
- information and high quality planning processes;
- active partnerships between the person with disability, family, services and government;
- systems to support each individual with disability and their family and give them the level of control they want over the resources;
- reflection and review to support an evolving lifestyle.

The concept and practice behind a Supported Living Fund builds on the experience of two similar programs in Australia.

- The **Community Living Fund in Western Australia** assists people to live in their own homes in their local communities. The support arrangements are built on community support and may be complimented by some funding (up to \$20,000 pa for community living support). This is in addition to any other funds for which the person is eligible.
- The **Older Parent Carer Program in NSW, namely My Plan, My Choice: Older Carers of People with a Disability** (a NSW packaged support program) provides older parent carers with up to \$50,000 pa to plan and prepare

for future support arrangements. The program emphasises creative and responsive solutions including informal networks, and gives the carer control over the assistance purchased including the ability to purchase supports from friends or neighbours and family members who don't live in the same residence. In addition, carers are able to choose the level of assistance they need to plan and implement supports. (DADHC: May 2009)

Key feature of the NSW context

There has been some growth in individualised support that enables people with disability and their families to have significant influence and control over the government resources targeted to their support. This can be seen through the self managed options in the Community Participation, Life Choices and Active Ageing Programs and the trial of direct payments in the Attendant Care Program.

In addition, ADHC has funded four pilot programs that enable participants to have greater control over the use of resources:

- One pilot enables 20 families of children 0-6 in metro south to use Early Start funds in a more flexible way.
- The second pilot targets families eligible for extended family support and enables flexible use of between \$20,000 and \$60,000 identified for their use.
- The third pilot targets people with unmet need for day programs offering them \$15,999 for their own individually tailored supports as an alternative to centre based day programs; and
- The fourth pilot enables 30 older parent carers in the northern region of NSW to use up to \$50,000 pa in planning for creative solutions for the future.

There is a growing interest by people with disability and families in being able to direct their own support, often expressed as a vehicle to reclaim their lives. A new generation of families see their family member with disability as having the right to a full life included in their community. An informal network of support is an important ingredient in implementing this changed vision.

A Supported Living Fund is right for NSW. It is a big idea that ought to be the centre piece of the second stage of Stronger Together. The time for action is NOW.

There are a growing number of people with disability and families in NSW who are interested in supported living. Some may require modest amounts of resources or better use of available community supports while others may require that their support funding is able to be used in more flexible and innovative ways.

Stronger Together: 2006-2016 flags a commitment to more flexible and innovative support.

People in many non metropolitan areas of NSW have access to Local Support Coordinators who provide a platform to build a more personalised local response. Their extension across NSW would strengthen the foundations for the implementation of a Supported Living Fund.

Ingredients for success

- **An identifiable strategy** that rebuts 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. The identifiable strategy may include having a Supported Living Fund as part of a broader strategy with a tool box of resources for partnerships and investments, improved practical and technical support for information, high quality planning, individual service design and the developing of ideas and responsive local level decision making.

- **Investment in vision and capacity building** across the sector, particularly with people with disability, their families and networks. This may include understanding person centred approaches and social inclusion, values based training, staff training that has a focus on deeper knowledge of people in the context of family, friends, culture and networks, and the primary importance of valued roles and relationships.
- **Strengthening family support and family leadership.** This may include practical assistance, networks and forums, access to positive examples, investment in family driven models, valuing and building on existing relationships and networks.
- **Support and encouragement to plan** including:
 - information for people with disability and their families to guide and inspire;
 - assistance with planning, facilitation and support coordination;
 - action research so that the experience of individuals is analysed, understood and shared to enhance the knowledge base of supported living.
- **Changing systems to create improved community living options.** This may include

increasing choice, removing disincentives, new approaches to funding, flexibility, trialing new ideas, improved access to equipment, assistive technology and affordable housing, increasing the focus on the development of personal relationships and networks.

- **Funding** to enable people to plan and implement future support arrangements. This funding would be provided via an individualised, self directed approach.

Benefits of a Supported Living Fund

- People will feel able to plan, leading to new pathways that build on people's strengths, relationships and resources and reduce reliance on crisis pathways.
- People will regain control of their lives with the concomitant improvement in health and wellbeing.
- Families will be supported in their efforts leading to empowerment rather than passive dependence currently fostered by the system.
- There will be a reduction in crisis as people see clear pathways that support their initiative.
- People with disability will have a life of their own in a home of their own.
- An increased range of supported living options will be generated.
- Expertise in supported living will be developed to compliment existing expertise in group living. This will inform directions on building capacity.
- Expertise will be developed in supporting families to use their own initiative, reducing reliance on the service system.
- An evidence base around individualised support and supported living will be enhanced.
- Funding will be being used in ways that facilitate and assist to build

new relationships and increase community inclusion with a shift away from the more traditional fee for service approach provided in current Business Rules.

Conclusion

The Supported Living Fund is right for NSW. It is a big idea that ought to be the centre piece of the second stage of *Stronger Together*. The time for action is NOW.

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Family Advocacy calls on the NSW State Government and all political parties to support the development of a Supported Living Fund as a centre piece of the second stage of *Stronger Together*.

Show your support for the concept by:

1. Emailing, faxing or writing to Family Advocacy. This will ensure that you are kept up to date on strategies to bring this about in NSW.

Family Advocacy
PO Box 502,
EPPING NSW 1710

Email: familyadvocacy@family-advocacy.com
Fax: (02) 9869 0722
Phone: (02) 9869 0866 or 1800 620 588

2. Raising the issue and sharing this paper with
 - ✓ people who care about people with disability
 - ✓ community and parent groups and services
 - ✓ 'people of influence' including politicians and bureaucrats

An email copy of the paper is available

Upcoming events and workshops

Supported LIVING...

what it means, what it takes



Family Advocacy invites you to participate in a telephone information session for families interested in supported living to discuss:



- What we mean when we talk about supported living
- Accommodation options currently available for people with disability
- What innovative supported living experiences people with disability are enjoying across Australia and overseas
- What we can do **NOW** to work towards a good life for people with disability in NSW

Family Advocacy is holding **INFORMATION SESSIONS** in Western NSW to meet families and workers and hear the issues facing these communities.

Broken Hill	Monday 19 April	Cobar	Wednesday 21 April
Menindee	Tuesday 20 April	Nyngan	Thursday 22 April
Ivanhoe	Tuesday 20 April	Dubbo	Friday 23 April

Moving out.... from planning to action

A workshop about how you can support your family member with developmental disability move into a home of their own with support

Yass
Tuesday 25 May

Cowra
Wednesday 26 May

Bathurst
Thursday 27 May

Katoomba
Friday 28 May

TO REGISTER YOUR INTEREST IN ANY OF THESE EVENTS

PHONE: Family Advocacy: 9869 0866 or 1800 620 588 (non metro callers)

EMAIL: workshops@family-advocacy.com

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A D V O C A C Y

If undeliverable, return to:
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familyadvocacy@family-advocacy.com

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Advocacy
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