

family

A D V O C A C Y

Institute for Family Advocacy & Leadership Development Assoc. Inc.

*A New South Wales association concerned with the rights and
interests of people who have developmental disability*

Friday, 26 February 2016

Dr Padmini Saxena
Director
Housing, Market and Providers Division
National Disability Insurance Agency

Dear Minni,

Thank you for hosting the consultation on the NDIA's specialist disability accommodation pricing and payments framework (henceforth, the Framework) in Sydney.

After attending the consultation and reading the Framework with interest, Family Advocacy provides the comments and recommendations below.

Sincerely,

Meg Clement-Couzner



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About Family Advocacy

Family Advocacy is a state and federally funded disability advocacy organisation in New South Wales (NSW), founded by families of people with disability. Our goal is to advance and protect the rights of people with developmental disability to achieve meaningful lives and enjoy the same opportunities and living conditions as the majority of Australians. The organisation has a high presence and profile across the State:

- building the capacity of families to undertake an advocacy role and providing advocacy related information, support and advice;
- running a successful ongoing capacity building project for families of people with disability, called Resourcing Families;
- developing leadership skills in families;
- and making representations to Government regarding legislation, policy, funding, monitoring and practice and the extent to which they reflect the needs of people with developmental disability.

Family Advocacy performs a combination of family and systemic advocacy in NSW. “Family advocacy is an independent, community-based model that usually involves family members acting on behalf of a son or daughter or sibling” (Weafer, 2003, p.39), and “systems advocacy lobbies for reform and change of social systems and structures that discriminate against, abuse and neglect people with disabilities” (Seymour and Peter, 2004, p.12).

Family Advocacy helps families to advocate on behalf of their family member with disability for a good life with the things most of us would expect in Australia: a place to call home, roles in the community amongst friends and family, and the supports, informal and paid, necessary to make that happen.

Comments on the Framework

Introduction

Family Advocacy has a position statement on housing as a general guide for policy makers. This is attached as an appendix. However, in summary Family Advocacy has a vision of an inclusive society, and that means inclusive housing, too. An inclusive housing system is one that caters to the needs of all people, including people with disability, and provides for and encourages social mix. Diverse communities are good for everybody.

A housing system that is inclusive of people with disability has four features:

- Separation of support and housing
- Deinstitutionalisation, including devolution of group homes

- Adequate affordable housing
- Accessible housing

This is a view that many people around the world share. The United Nations Convention on the Rights of People with Disability supports “the equal right of all persons with disabilities to live in the community, with choices equal to others.”

Family Advocacy is also part of the Disability Network Forum (DNF) in NSW and was recently involved in developing a forum called “Beyond accommodation: Housing that works for people with disability”. We support the DNF response on the pricing framework, which was based on this event, and will draw on it here.

Family Advocacy is cognisant of the high expense of housing in Australia. We are based in Sydney, one of the most expensive cities in the world, and we know that most people do not have unlimited choice in this area of their lives. However, what we seek to ensure is that people’s disability does not disadvantage them in this area, either due to capacity based limitations of their disability or the costs associated with overcoming the same.

We are an organization made up of the families of people with high level support needs, most often intellectual or very complex physical needs. What we have found is that with the right supports, even people with such serious and complex needs can live in the community, in housing that is not clustered, not congregate, where they can be part of a neighbourhood that provides possibilities for more connections and a good, regular life.

Effectiveness of supported living

Family Advocacy was deeply involved in the development and implementation of the Supported Living Fund (SLF) in NSW. This fund was set up with the idea that everyone deserves their own home. Parents wanted to support their adult child to move out of home, with appropriate funding and support, while they (the parents) were still active and capable of supporting a transition. As ADHC states:

The Supported Living Fund (SLF) is a form of individualised accommodation support funding for adults with disability aged 18 to 64 years. The funding is portable, remains with the individual and is administered by a service provider of the person’s choice.

A member of Family Advocacy and her daughter, Sarah¹, were successful in applying for SLF and the following case study is about their positive experience:

¹ Not her real name.

Case Study: Sarah can be 'her own boss'

This case study is a direct quote from the Disability Network Forum's response to the Framework.

"Sarah" is a 24 year old woman with a significant intellectual disability from Southern NSW. Three years ago, Sarah's younger sister was planning to move to Wollongong for university, her older brother had already left home. Sarah decided "the youngest shouldn't move out before me".

Initially, Sarah rented a four bedroom house with the idea of sharing. SLF funding allowed for a rental subsidy for house sharers who provided in-kind support. Her first housemate was a young woman her own age. Although her housemate received orientation, the relationship didn't work out. An ex-support worker, studying nursing asked to move in; an arrangement which worked well for 6 months until she left to work in Sydney. After the experience of sharing and gaining confidence in her own place Sarah decided she would prefer to live alone and moved into a two bedroom unit. She lives with a support worker who is paid an 'availability allowance' to assist Sarah in emergencies.

Since moving out of home, her capacity has increased tremendously. Sarah can now do her own washing, grocery shopping and get to places she needs to go on time. She rides her bike to and from work at a bakery, the shops and her voluntary position in a creche. Eight hours drop-in support is provided by a local woman Sarah found via Gumtree. In addition to formal support, Sarah has an informal network of family, friends and community members who help her out when she needs it. These networks also provide informal safeguards which have activated when Sarah has experienced random events such as an accident riding her bike. Sarah loves her life, and her own home is a big part of that. She loves being 'the boss' of her own things and has no intention of moving back in with her parents!

Sarah's story shows that like everyone, people with disability need to be able to change their circumstance as it suits them. People in Sarah's life having high expectations of her has allowed her to thrive, and being embedded in the community has strengthened her informal support networks. Without flexible funding provided by the SLF, Sarah would need far more paid support (at greater cost).

As the Disability Network Forum (DNF) states:

The final SLF packages were allocated in 2012. People with packages continue to be supported, but it is unclear whether flexible uses of the funding (such of provision of a rent subsidy for a home sharer) will be viewed by the NDIA as a 'reasonable and necessary' component of their NDIS package (2016, p.2).

We wish to make particular note of the research into the *Effectiveness of Supported Living in Relation to Shared Accommodation*. This report is available online and is

linked to in Selected References at the end of this document. As the DNF response to the Framework notes: “[o]ver time, all approaches 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. An important element of success explored in this research was support being provided through a mix of formal and informal mechanisms, with an investment in developing informal support” (p.4).

We also wish to point out the more general benefits to living in the community in a manner that is socially and culturally valued (i.e. renting or in a home of one’s own). These include general increase in adaptive behaviours (Kim et. al. 2001), increase in sense of well-being, decision making, connectedness, self-care and domestic skills (Stancliffe and Keane 2000).

For whom in what circumstances: choice and control in housing?

Family Advocacy is concerned about the direction of the Framework with regard to choice and control for people with high support needs. We consider that some of the statements in the Framework are based on negative assumptions about the capacities and potential of people with complex needs.

The Framework states at [73]:

Participants with high levels of complex or specialised needs can find it difficult to source the support that they need (particularly for example some rural and remote regions). Setting up and maintaining very high intensity support programs for participants requiring 1:1 or more support for long periods (for example 24 hour care) are particularly difficult to reliably source and staff, even in some metropolitan areas. Providing support for participants in a shared living arrangement, where staff and other resources can support more than one participant is often an effective strategy in these situations.

Family Advocacy is concerned that this statement indicates that the NDIA will not provide housing support for people with requiring one on one or 24 hour support who do not wish to live in congregate care.

Additionally, the Framework states at [78]:

Cost effectiveness of maintaining the participant in the community

Participants requiring very high levels of support, especially 1:1 support, are very expensive to maintain individually in the community. This is particularly so for participants who require 24 hours care per day or who require more than one carer to be in attendance at any one time. Supporting all NDIS participants to live independently would not be sustainable for the NDIS. The economies of scale of having very high need participants supported in shared living arrangements, where staff and other resources can be brought together to support more than one participant, means that specialist disability accommodation is often the most cost effective option for supporting these participants.

This seems to be another indication that the NDIA SDA Pricing Framework will not support individual community living, or living with a housemate who does not have a disability.

Family Advocacy strongly recommends that the NDIA look to the SLF and parent-founded Community Housing Provider Homes West in Brisbane for an indication of just how successful and cost effective informal supports and independent living can be. However, it requires a willingness to provide some funding support for housing to people who want to develop such supports and independence.

Homes West Case Study: Mena needed 24-hour support and lived in her own home

Below is a story from Dr Margaret Ward, a parent associated with Family Advocacy, about her daughter, Mena. The story is told in 'The Homes West Experience', cited in Selected References below.

Introducing Mena

Mena is a very sociable young woman in her twenties. She has a wide circle of friends who visit regularly. She has the steely determination to succeed and achieve her goals. She has a wheelchair to get around. She needs 24-hour support from workers, family and friends.

Mena's story as told by Margaret, Mena's mother

Mena knew she wanted to move out of home. She named the date - her 19th birthday. The message was loud and clear – 'Mum, make it happen!' The family started with nothing but their enthusiasm. Mena had a few young friends who urged her on – blissfully unaware of all the pitfalls, costs and organisation required. This preparation time was very important, not only for Mena but also for her extended family who were trying to catch up with the idea.

Conclusion and recommendations

The advent of the NDIA and the pricing and payments Framework offers exciting possibilities for people's independence and control. We want to ensure the best outcomes possible from the Scheme.

Family Advocacy recommends:

- a) That the NDIA take heed of Dr Margaret Ward's expert and very practical advice on what the agency could do to make housing better, more affordable and available for more people with disability:

I argue that the National Disability Insurance Agency could take five practical steps to address the housing needs of most people with disability.

1. *It could advocate for a sustainable social housing system*
 2. *It could support the re-establishment of the [National Rental Affordability Scheme](#) and its commitment to equitable physical and financial access in future funding rounds*
 3. *It could expand home purchase assistance, especially shared-equity opportunities*
 4. *The NDIA has the opportunity to assure timely access and quality of home modification service*
 5. *The NDIA can influence the supply of accessible housing by calling for regulation of minimum access features in mainstream housing in the National Construction Code (2015).*
- b) That the NDIA look to the SLF in NSW, Homes West in Queensland and My Place in Western Australia for an indication of just how successful and cost effective informal supports and independent living can be.
- c) That the NDIA ensure that the SDA pricing and payments framework can enable people to live individually in the community in a ‘salt and pepper’ model rather than in congregate or cluster models, and that it enables informal supports and living with a housemate who does not have a disability.
- d) That the NDIA clarify their position on point c) above.

Selected References

Fisher, Karen et.al., 2008, *Effectiveness of Supported Living in Relation to Shared Accommodation*, available from

https://www.sprc.unsw.edu.au/media/SPRCFile/Report18_08_Effectiveness_of_Supported_Living.pdf

Hole, Jill with Homes West Families, 2007, *The Homes West Experience: Steps to Independent Living for Adults with a Disability*, available from <http://homeswest.org.au/The%20Homes%20West%20Experience.pdf>

My Place: My Life, My Choice available from <http://www.myplace.org.au/>

Ward, Margaret, 2015 *Everyone deserves to have a place called home – you can too*, available from <http://incharge.net.au/everyone-deserves-a-place-they-call-home-you-can-too/>