



MODELS OF SUPPORTED ACCOMMODATION

A Response to the DADHC Discussion Paper

'Models of Supported Accommodation for People with a Disability'

Carers NSW

April 2005

1. Background

This submission in response to the DADHC discussion paper 'Models of Supported Accommodation for People with a Disability' has been prepared by Carers NSW representing the estimated 750,000 family carers in NSW¹. Carers provide care to family members and friends with disability, mental illness, chronic conditions or who are frail aged.

Supported accommodation is one aspect of support that should be available to family carers and people with disabilities. Finding appropriate models is critical for many carers of people with disabilities for several reasons. Knowing that there are suitable places where their child or family member can live once they are no longer in an active caring role is extremely important for the entire family. People with disabilities and their carers should also have choices about where they live at various life stages.

Family carers provide the foundation for policies of deinstitutionalisation and a community care system. They are heavily relied upon to provide the majority of essential support for people with disabilities living in the community. Frequently the transition to supported accommodation follows a crisis of some sort and therefore further support needs to be provided to family carers from the beginning of their caring role for planning, advice and assistance².

The evidence on which this submission is based comes from several sources. Primary data has been obtained from the Commonwealth Carer Resource Centre located in Carers NSW, from a recent survey of Carers NSW members conducted through the newsletter, Carers News and from individual telephone or written interviews with twenty carers³. The findings are supported by research in the field that has been collated for this discussion.

The questions raised in the DADHC Discussion Paper will be addressed (although not in the same sequence) with a focus on components and models of supported accommodation that promote positive individual and community outcomes. It will look at the needs of different population groups and how these can be addressed and considers the interface of different services to provide a framework of support for people with disabilities and their carers throughout the caring relationship.

2. Carers in NSW

The Australian Bureau of Statistics (ABS) estimated in 2003 that there were around 750,000 family carers in NSW. One in five of those (or 150,000) were primary carers meaning they provided the most informal assistance to a person requiring care. Of those primary carers, almost three-quarters were female, almost 30% were providing care to their son or daughter and 40% to a partner and 45% provided care for 40 hours or more per week.

Financially primary carers are disadvantaged compared with the rest of the population.

- 76% are workforce age,
- 64% are not in the labour force,
- 55% receive a government pension or allowance as their main source of income,
- Primary carers have a median income of \$224 per week compared with \$435 for non-carers.

¹ ABS (2003) 'Survey of Ageing, Disability and Carers' NSW Tables, Australian Bureau of Statistics, Canberra.

² Bridge C et al (2002) 'Housing and care for younger and older adults with disabilities', Australian Housing and Urban Research Institute, Sydney.

³ All names in this submission have been changed.

It is also known that, while caring can be satisfying and rewarding, there are many negative affects that carers may experience. Australian data⁴ for 2003 reported that:

- 34% of primary carers felt weary and lacked energy;
- 29% felt their well-being had been effected;
- 29% frequently felt worried or depressed; and
- 10% had stress-related illnesses.

In total 72% of all primary carers reported some physical or emotional affect from their caring role.

Further to the evidence from the ABS, a survey conducted by the Carers Association of Australia⁵ found that, due to tasks associated with caring:

- 55% of carers surveyed reported tiredness or exhaustion;
- 34% reported upper body problems;
- 13% had high blood pressure and other heart problems; and
- 10% had arthritis.

The most commonly cited reasons for these conditions were the constant pressure of caring, stress, disturbed or lost sleep and providing mobility assistance (particularly for long-term carers and carers of children with disability).

Given these statistics it is indisputable that carers need breaks from caring and choices about continuing with care. In order for this to be achieved the appropriate services must be available at the stage of the caring relationship when they are needed. It is apparent from contributions to this submission by carers that supported accommodation services are frequently not available at the point when they are sought.

A Parliamentary inquiry into supported accommodation conducted in South Australia in 2003 found that there were high levels of poor mental and emotional health amongst carers. A great deal of anxiety from families was generated by their fears over what would happen to their son or daughter when they were no longer able to care for them.

It is the contention of this submission that supported accommodation services are a key element of support, both for carers and people with disability. It is critical that carers have choices about their caring role and do not feel that they must continue caring until they die at which time a crisis will take place. Supported accommodation services should not be seen solely as a service for the person with disability but as one choice that they, and their family, can make throughout the caring relationship.

3. The Need for More Accommodation Support Services

It is clear, both from the literature available and from reports by carers and people with disabilities, that there is not enough accommodation support available to reduce the pressure on carers. This includes both services that can assist people living at home and residential services such as group homes, both of which are in short supply.

The 2005 Productivity Commission Report on Government services provides some information on people using accommodation support services. It shows that, in NSW:

⁴ ABS (2003) 'Disability, Ageing and Carers, Australia: Caring in the Community' Cat. No. 4430.0.55.003

⁵ Carers Association of Australia (2000) 'Warning – Caring is a Health Hazard: Results of the 1999 National Survey of Carer Health and Wellbeing'

- Around 3% of the potential population of people with disabilities currently access accommodation support services⁶ (this is slightly lower than the national average);
- Around 60% of these service users have profound limitations, 35% severe and 5% moderate to no limitations;
- The proportion of people living in outer regional and remote areas that access accommodation support services is lower in NSW than the national average.
- The proportion of Indigenous people accessing accommodation support services is higher than the proportion of the total population accessing them.
- The proportion of people from culturally and linguistically diverse backgrounds accessing accommodation support services is lower than the proportion of the total population accessing them.

In addition:

- The AIHW made a conservative estimate in 2003⁷ that there were 12,500 people across Australia with an unmet need for accommodation and respite services.
- In 2003 the ABS⁸ estimated that 96% of people with profound or severe disability were living in private dwellings with the other 4% living in cared accommodation or other non-private dwellings.

These figures demonstrate that family carers are currently providing the vast majority of support for people with severe and profound disabilities in NSW. They are under-supported by essential formal respite, accommodation and other services for which there is significant demand.

The devolution of large residential centres will create further need in the community. Currently this is occurring at a slow pace. As part of its goal to increase community participation for people with disabilities greater resources will need to be committed to the devolution process and supported accommodation options as well as accommodation services for people with disabilities.

4. Key Considerations for Supported Accommodation Models

There are several key components of all models of supported accommodation that are most important for carers and their family members with disability. These include a range of available service models, appropriate and safe accommodation, improved community involvement, reliable and inclusive staff and appropriate support throughout the continuity of care.

4.1 Information and support for families

Carers NSW contends that families and carers of people with disabilities need a range of supports throughout the caring relationship. They can be provided either by formal services or by family and friends. A comprehensive support framework for family carers should contain the following aspects:

- Timely, accessible and relevant information that is culturally and linguistically appropriate and targeted to people who it will reach;
- Emotional support to assist carers dealing with a range of changing emotions including guilt, fear, frustration, isolation, loss, anger, depression and anxiety;
- Education and training to equip carers with practical skills for management of the disability or condition, communication and coping skills;

⁶ Funded under the CSTDA, excludes psychiatric services.

⁷ Australian Institute of Health and Welfare (2003) 'Australia's Welfare', AIHW Canberra.

⁸ ABS (2003) 'Disability, Ageing and Carers: Summary Tables, NSW', Cat No 4430.1.40.001

- Effective and sufficient respite to give the carers substantial breaks from caring responsibilities; and
- Financial assistance.

For support and services to be effective they must be offered, and available at the time when the family needs them. For many people trying to access supported accommodation (and other services such as respite and home care assistance) this does not occur.

The response from all the carers contributing to this submission who had tried accessing supported accommodation was that it was a very difficult process and there was very little available. However the frustration carers felt was amplified by the lack of information they had received about supported accommodation and the process of accessing it.

When asked how their experience of accessing supported accommodation had been, all carers responded negatively. They commented that it had been hard or impossible and often based on luck and timing if they had eventually been successful. They found it difficult to get information about how to access supported accommodation and once they were on a waiting list there was no advice given about how long they could expect to be on the waiting list or any other information. Respite is a key service to support carers while they are caring for someone at home. Effective respite, when linked with other key support services for carers can prevent crises from happening. The case study below demonstrates this point.

Renee was driven to crisis point because she could not access supported accommodation for her daughter and her respite care was continually cancelled at short notice. This meant she could never have a break from caring for 33-year-old Lucy with high support needs, severe challenging behaviour and complex health care needs. On one occasion respite was cancelled at short notice but Renee took her daughter to the centre anyway which then admitted Lucy to hospital on the grounds that she had been abandoned.

In response to this an arrangement was made between the family and the respite centre that Lucy could have a place made permanently available if Renee paid a high proportion of her daughter's pension to the service provider. Effectively she now has supported accommodation but it's in a respite home. It is not ideal but the carer feels it is all she could get.

It is not uncommon for carers to feel this level of despair when they do not receive necessary support over an extended period of time. The South Australian inquiry into supported accommodation also referred to "numerous reports of cases in which families have threatened to relinquish their son or daughter or have abandoned them in centre-based respite facilities"⁹. It also acknowledges the strain that this places on the availability of respite care.

Many carers interviewed for this submission felt they had no choices when it came to supported accommodation and were forced to take what came up because they urgently needed supported accommodation. Alternatively carers found that there was nothing appropriate available. One carer of a son with intellectual disability, psychiatric illness and epilepsy now believes that there is no supported accommodation available because they have been trying for years and have been on waiting lists for "a very long time".

Highlighting the urgent need for additional resources and improved options for supported accommodation were the carers contributing to this submission in their 50's and 60's and still supporting a son or daughter in their 30's because they have not been able to find any supported

⁹ Social Development Committee of the Parliament of South Australia "Inquiry into Supported Accommodation" November 2003.

accommodation. They do not have any indication of how much longer they will need to continue their active caring role. One such carer of her two sons is currently facing this frustration that she is unable to access services prior to a crisis occurring.

Michelle has two sons who she provides care for, Tony and Marc. Tony is in his 30's and has Autism and Stickler Syndrome. He lives in a group home that he and his family are very satisfied with. He entered the home when the family was in crisis. Marc is in his 20's and has the same condition and similar support needs however he is unable to gain access to supported accommodation of any sort because, as Michelle was told, he is not "homeless or abused" (ie there is no crisis currently).

4.2 Appropriate and safe accommodation

Appropriateness and safety of services is often the primary concern for carers. Some responses from the 2004 Carers News survey¹⁰ highlight this important factor. To demonstrate the need for appropriate services and the need for a choice of services, below are some of the suggestions made by carers about what they felt was necessary:

- "A place for younger people to go other than nursing homes"
- "More premises or residences for people who need one on one residential care"
- "Residential care for my severely disabled daughter if not earlier at least when she's 18"
- "Supported accommodation with right amount of individual support"
- "Housing for the mentally ill with supervision"

Carers NSW also hears occasional reports of abuse in group homes and supported accommodation arrangements of people with disabilities. In addition inappropriate placement in group homes can lead to assault and abuse, both by staff members and by other residents. These issues create a great source of anxiety for carers.

Another source of stress for carers and people with disabilities is inappropriate placement of **younger people in nursing homes** and other aged care residential facilities. One carer contributing to this submission was distressed that her 64-year-old husband (and younger people) with Multiple Sclerosis had been placed in a nursing home because his care needs were too high for community care and there was no supported accommodation for younger people available.

"They get put in with dementia and dying elderly people and it's absolutely terrible. There are no other options available". Jill, who is the wife and carer of 64-year-old Dennis hopes that one day there will be a separate living area from the nursing home - where her husband now lives - for younger people with high support needs. She is unaware of any such services in her area.

Jill goes to the nursing home every day to visit and feed Dennis. The staff are supportive of her visiting and being involved but Dennis has not been able to have any therapy services since he moved in there as this was discouraged by the nursing home. Dennis has been living in a four-person room in which, Jill estimates, up to eight of his room mates have died since he's been there. Most of the other residents are frail aged people with dementia and cannot converse with Dennis. Jill also knows of two other younger people (one is only in her 40's) in a similar situation in her area.

Supported accommodation should be available to people of all ages including flexible options for people who still wish to live independently or with their partner but have complex health care or high support needs.

¹⁰ In 2004 a survey was sent to members of Carers NSW through the monthly newsletter, the Carers News.

Part of having appropriate and safe supported accommodation options is ensuring there are enough services for people with high support needs. A report by the Australian Housing and Urban Research Institute¹¹ in 2002 found that people with high support needs were at the highest risk of being institutionalised.

4.3 Facilitating community involvement

The introduction to the DADHC discussion paper poses the question: How best can we support people with a range of disabilities to live within their communities in ways that as far as possible offer choices that reflect the lifestyle of other people in the community? There are several key issues that have been raised by carers regarding this question. Individualised service plans that are developed between families, people with disabilities and services are critical during every phase of caring.

Carers involved in the survey for this submission identified many different services that are important to promote community participation for the person they support. The key services, in addition to personal and home care support, that were identified by carers were one or a combination of transport, recreation, social support, employment, therapy and day programs, depending on the individual care situation. As one carer said in her telephone interview **“bricks and mortar aren’t the issue – support services are the crucial issue”**. The following case studies illustrate the issues raised by carers.

Rhonda cares for her 22-year-old son who has an intellectual disability, some challenging behaviours and moderate to high support needs. He attends an employment program that keeps him occupied during the day. However Rhonda is finding that as he gets older he wants to go out and do things but relies on his parents to take him. This is not suitable for the parents and does not allow him to have choices that other people his age in the community have. The recreation group that used to take him out was de-funded but this is the type of service he needs to keep active in the community once he has transitioned to supported accommodation.

Continuity of services and lifestyle need to be maintained throughout the transition process. One of the carers contributing to this submission commented that her daughter, who has high support needs will have positive community involvement if she can continue to receive support to go to the local coffee shop and library and keep doing local activities where she has already built networks.

Community education is also vital to the successful participation of people with disabilities living in supported accommodation in their local community. This is significant for all groups of people with disabilities including those with mental illness and challenging behaviours to reduce stigma and social isolation. Many people with disabilities grow up being involved in the local community and it would be unnatural for them to move into supported accommodation and find that they became isolated.

Peter, the sole carer of his 12-year-old son Rupert, who has Aspergers and ADHD, has always received support from community members and neighbours in his town. It is very important to both of them that Rupert is familiar with and trusts the people that live around him and should be no different when he moves out of home into supported accommodation.

¹¹ Bridge C et al (2002) ‘Housing and care for younger and older adults with disabilities’, Australian Housing and Urban Research Institute’, Sydney.

4.4 Positive Community Outcomes

The need to maximise positive community involvement of people with disabilities in Australia is set out in the Disability Services Act 1993. The objects of this Act clearly state the role that adequate and innovative services should play in ensuring positive outcomes in the community for people with disabilities.

When considering options for supported accommodation models community outcomes must not be compromised in the interest of cost-effectiveness. Risks are present for many models of supported accommodation, particularly clustered accommodation and medium to high density housing options for people with disabilities, that old style institutional living will be replicated in the community setting. This danger exists with some group home models too, particularly those that house too many residents and are removed from the rest of the community. One carer made the comment that "we need to get away from (favouring) group housing because of the cost factor and look at varying models to address individual needs more carefully".

4.5 Service providers, staff and family inclusion

A study carried out in Victoria in 2002 assessed some available literature on models of supported accommodation. It reported that there are many factors that influence the integration of people with disabilities into the community and cited Australian research by Ralph and Usher (1997) that "merely closing the institutions and transferring clients and staff into community-based settings will not ensure successful integration. Staff need new skills, new values and new goals if they are to succeed".

According to this report families were previously discouraged from visiting people with disabilities in institutional settings, as it would disrupt their care patterns. It is therefore important that consideration is made in future planning of supported accommodation to include families and carers in the daily lives of people with disabilities living in supported accommodation. In addition it is a requirement of the NSW Disability Services Act (1993) that support for people with disabilities includes valuing the importance of their relationships with friends and family.

Carers NSW often receives reports that families are not involved enough or encouraged by service providers to be part of the care process after their family member leaves their care at home. One in ten respondents to the Carers News survey in 2004 felt that greater inclusion by health professionals and service providers in all areas of the care situation would be a practical way that carers could be recognised. It is important to many carers that staff understand the ongoing needs of family support once a person requiring care has moved out of the family home.

Reliable and consistent staff and inclusive management of facilities are extremely important to achieving positive outcomes for families and people with disabilities. Staff issues were repeatedly raised in carer contributions to this submission. For many it is *the* most important issue rather than design or location of supported accommodation models. As acknowledged in the DADHC Discussion Paper the quality, reliability and availability of support and clinical staff is extremely fundamental to the success of any community care model. One carer recommended that families should be given the opportunity to get to know staff prior to the transition to supported accommodation.

The most effective models of supported accommodation are those that allow flexibility in the delivery of care services to cater for the different lifestyles and needs of people with disabilities and their families and carers. For supported accommodation to be effective family or carer involvement must be incorporated in the provision of support.

For Michelle, whose son is in his 30's, has Autism and Stickler Syndrome and is living in a group home a change in management made a remarkable difference to her and her son's lives. Moving to one key support worker for the family meant that, rather than dealing with

a different person each time she contacted the home, she was able to develop a relationship with one worker. Michelle reported that this not only improved her own experience with the group home but that her son's condition also improved due to better management because the key worker could benefit from Michelle's knowledge and expertise as a carer.

4.6 The continuity of care

Every person's care needs change throughout different stages of their life. For some this will be associated with the ageing process and for others it will depend on their disability or condition. For instance a carer of a boy with Aspergers and ADHD commented that when his son is ready to move into supported accommodation the type that he requires will depend on his condition at that time and how he is interacting with other people. There must therefore be different levels of support and different models of accommodation available for people at different life stages.

Of the carers contributing to this submission most had only recently tried to access supported accommodation so the care needs of their family members had not changed significantly in that time. However it is critical that families do not feel that, because they had difficulty accessing supported accommodation in the first place, they must keep their place, even when it is no longer appropriate for the care, support and social needs of their family member.

Integration and linking of services is fundamental to addressing changing care needs. A person's support needs can increase and decrease during their lifetime and various different support services should be available when needed. For many a case manager or key worker will be needed to ensure the care needs and social needs of a person are met. These relationships should be established while a person with disability is still living with their primary family carer.

5. Population Groups

Some consideration must be given to population groups with specific needs. In particular these are families where the person receiving support has a mental illness, families from culturally and linguistically diverse backgrounds and Indigenous families.

5.1 People with mental illness and their carers

Supported accommodation is critically needed for people with mental illness in NSW. The issues for carers are considerably different to those associated with other disabilities and support needs of people with mental illness vary greatly given its episodic nature.

Reports from Carers NSW Mental Health Project staff regarding supported accommodation for people with mental illness highlight several key barriers. Firstly many carers do not know what options they have. Additional problems arise from the specific support needs of people with mental illness who may require, for instance, daily or frequent visits during periods of "wellness" when they seem to be coping very well and more intense support when necessary.

Often carers of people with mental illness find that they are called upon frequently to provide support, sometimes even more often than they were when they were the primary carer at home. An additional concern is for carers of people with dual diagnosis who have extreme difficulty finding accommodation, particularly with the right level of support.

A carer of her daughter with depression highlighted the need for her to live somewhere where she could have moral support and some supervision throughout the day and assistance with keeping medical and other appointments. She also indicated that crisis accommodation would be useful in their situation. This was typical of other responses from carers of people with mental illness (often in combination with other disabilities or conditions).

5.2 Culturally appropriate services

Carers from culturally and linguistically diverse backgrounds and Indigenous carers have raised a set of issues that are unique from the general carer population when accessing or trying to access accommodation services for family members with disability.

The first barrier is often lack of knowledge about the options due to lack of understanding about how to access information and lack of linguistically appropriate information. There can also be limited communication about how the carer and family can be involved in the arrangement of support services. Families from CALD backgrounds may also question the benefits of supported accommodation or independent living for their family member with a disability.

All these questions should be addressed as part of a comprehensive support package for families of people with disabilities from CALD backgrounds. Throughout various transitions families will need further information and support as changes take place.

Once their family member is in supported accommodation there are additional complications that may arise for families from CALD backgrounds. Communication between service providers and families is often poor and there is uncertainty around what to do when the person's support needs change. Reportedly changes tend to take place only when a crisis occurs.

Some key considerations must be made for Indigenous families accessing services. Autonomy and self-determination principles command that carers and families have the right to choose the services they access and have input into those services. It is essential that culturally appropriate services are made available for Indigenous people and that service providers receive training on the specific needs of Indigenous families.

6. Models of Supported Accommodation

This submission is not promoting any one model of supported accommodation. As previously noted, it is essential that a range of models is available to provide families with choice. They should also have choices about when in the caring relationship the person with disability moves into supported accommodation and when they live at home with support from a combination of formal providers and family carers.

The following discussion is informed by the twenty carers who have contributed directly to this submission¹² and is therefore not an exhaustive discussion of supported accommodation models. These carers either have been successful in accessing supported accommodation and are content or displeased with their current situation or they have been unsuccessful or are looking to access supported accommodation in the future and have ideas about the type of accommodation that would best suit their family situation.

The main commonality amongst all carers was that they felt accommodation should be for small numbers of people and that staff and services were key ingredients in successful outcomes. There was agreement that institutional accommodation is inappropriate for people with disabilities. The people these carers support have a range of support needs, disabilities and conditions, health care needs and behaviours. The models to be commented on here are primarily the group home model, cluster model and innovative models that have been raised by carers, many of which could be adapted from the sample models in the Discussion Paper.

Interestingly there was not an identifiable link between the model of accommodation thought to be preferable by the carer and the type of disability of the person they support. There was some link between the level of support and care required and the type of accommodation.

¹² All names in this submission have been changed.

Many innovative local solutions have been put forward by carers contributing to this submission and by other community and carer groups that are sending their own submissions to DADHC. It is the recommendation of Carers NSW that DADHC carefully consider these local models that respond directly to local need.

6.1 Group home model

Seven of the 20 carers identified the group home model as the best, or the only, model that would work for the person they support. Some identified with the term "group home" and others described a home-type environment with a couple of other companions with similar needs and 24-hour support. No carers felt that a house with more than four residents would produce positive outcomes. It must be noted that for many carers this was the only model they knew of, which may have influenced their preference for this model.

Strengths and Weaknesses

Carers who favoured the group home model generally felt it provided safety, security, live-in staff, social interaction and a high level of care or supervision. There was a fear amongst some carers that people with limited physical, cognitive or communication abilities could easily be taken advantage of and that, with reliable staff, this may be less likely to occur in a group home setting.

On the other hand, the group home model does have some weaknesses. One of the issues is that there are few other options in many areas and as a result people who are not suited to the group home model are inappropriately housed, as demonstrated in the following case.

*Rebecca has a 24-year-old daughter, Jackie, who is currently living in a group home. Rebecca reports that in the process of accessing supported accommodation they **had no choices** and had to take what they could get. They are not happy and Jackie is considering moving back home. Jackie has moderate support needs and requires supervision from staff for safety reasons and guidance with finances and other living skills. She has moderate intellectual disability, mild physical disability and Obsessive Compulsive Disorder. They would prefer to find a small cluster of units where she could live independently but with a fairly high level of support and would need to continue her day Post School Options program and recreation service to maintain community participation.*

There is an inherent risk in the group home model for people accessing day programs which was raised by one carer contributing to this submission. In many cases day programs are attached to residential services. This means that the residents end up doing everything together, which does not promote community involvement. Therefore people in supported accommodation should be encouraged and enabled to participate in generic services as well as those organised for the group home.

The next case study highlights the need for people to be placed appropriately in housing with other people who have similar support needs and behaviours. It is distressing, not only for the person accessing supported accommodation, but also for their carer or family to feel that they are not safe.

June and her husband care for their 35 year old son with polyarteritis nodosa who lives close to them in a Department of Housing home. They are effectively on call 24 hours a day to provide him with assistance as they are the primary contact for his "Constant Companion" device (similar to Vitalcall) and are frequently called to attend to him at all hours of the day.

*Previously he had lived in a group home with a "roaming population" where another **resident physically assaulted** him. Furthermore the house was in such serious degradation that his father went around to do maintenance himself. June and her husband*

hope that they will be able to find suitable supported accommodation for the future as their son's condition worsens.

Suitability of model to different groups

Carers supported the group home model for people with all different types of disability. They all had high support needs, leading parents to feel that companionship and 24-hour support and consistent staff would be the best aspects of a group home environment. However individual space, care planning and small group numbers were equally important.

The following case studies demonstrate that the group home model can be appropriate for people with complex health care needs and for people with challenging behaviours. Individual care and support plans need to be made to provide the appropriate support.

The group home model for a person with complex health care needs:

*Janice is the carer of her 14-year-old daughter Fiona who has severe intellectual and physical delay, high support and **complex health care needs** and is legally blind. She feels that the group home model would be most appropriate when Fiona turns 18. Fiona should have her own room and a couple of housemates. She will need regular visits from health professionals and an individually designed day program would be needed to help Fiona access and maintain involvement in the community.*

The group home model for a person with challenging behaviours:

*Melita supports her 27-year-old son who has both **challenging behaviours** and high support needs and requires 24-hour support. He has intellectual disability, psychiatric illness and epilepsy. He needs support there all the time and needs to be with residents who have similar support needs to him. Melita believes her son could not participate in the running of the household (including activities such as organising maintenance, cooking and cleaning).*

Carers of people with developmental disabilities and mental illness also identified the group home model as their preference. However, highlighting the point that not all people with the same disability are suited to the same accommodation type, two carers of people with similar conditions (developmental disability) described entirely different accommodation for their sons. One wanted a group home model and the other felt that living in individual apartment-style supported accommodation would be the only option.

Most carers felt that group homes should be located in residential areas although one carer identified a group home she knew of which was just out of town (in a regional area). She feels it would be a good model for people such as her son who has Autism as it provides plenty of outdoor space to do various activities such as gardening. It is most important that supported accommodation options are located in areas that people would choose to live in if they had no disability.

From these case studies it appears that the group home model (with live in or 24 hour support) is more suitable for people with high support needs. An important factor is the number of people in a group home and the level of involvement of staff in supporting residents to participate in the running of the home. It was also apparent from discussions with carers that individual planning and support within a group situation is essential. The example was raised twice that people who practice religion should be enabled to continue practicing it, both at the church they attend, and in their own home. Similarly people with disabilities should be supported to continue with all activities, education and social or other groups they accessed prior to their transition to supported accommodation.

Meeting changing community expectations

There is evidence to suggest that group models may hinder outcomes for people with disabilities in the community as the group needs take priority over individual needs. In 1999 a study¹³ was conducted comparing outcomes for people living in group homes and people living in semi-independent arrangements. It found that those living in semi independent accommodation (2 to 3 people with minimal support with access to emergency support) used community facilities more frequently and had more choice and control over their lives. They were not found to be more at risk of loneliness or poor personal care, money management or personal safety. It also suggested that people living in group homes can be over-supported for their needs.

The group home model of supported accommodation can provide positive community outcomes with the **right** level of support for the individual. However the model may be changed to reflect changing community expectations. Future planning for group homes should consider carer feedback that:

- Smaller units are more effective (up to 4 people rather than 5 or 6).
- People in the house should be able to participate in community activities separately and not do all activities together, to maintain more active community involvement.
- It is important that residents and their families are given choices about all aspects of group home living and that the right amount of support is given to support decisions made.

In terms of positive outcomes for people with disabilities, most carers felt staff quality was vital and that in the home environment residents should be encouraged and supported to be as active as possible in activities such as cooking, cleaning and organising maintenance. Individualised support packages were also raised by many carers as being fundamental to positive outcomes.

6.2 Small clustered accommodation model

For six of the twenty carers a small, supported cluster of units (with 2 to 5 units) was a preferable model for their family situation although few knew of such accommodation service in their area and none had been able to access them. All the carers who identified this model were supporting people with low to moderate support needs. Among them several supported people with challenging behaviours although none with complex health care needs, perhaps owing to concerns that they could not receive enough clinical support and also maintain independence.

When questioned further about the physical design of a cluster model and availability of support staff carers generally described something similar to the St Martin's Court Project outlined in the Discussion Paper however most carers felt that fewer than 13 units would be more appropriate.

Strengths and Weaknesses

The main strengths of the model relate to maintaining independence while having support needs met. There was a feeling amongst carers supporting this model that their family member would have opportunities for social interaction with other residents. A few carers described "retirement village style" accommodation for people with disabilities where they could receive varying levels of assistance and care depending on their changing needs.

None of the carers who contributed to this submission were actually accessing this style of accommodation and few knew of suitable models that existed in their area. It was seen by many as a better alternative to group homes for people who needed a significant amount of support and some social interaction but their own space to live and independence as well.

¹³ Stancliffe, R. J., & Keane, S. (1999) 'Matched comparison of group home and semi-independent living'. CDDS Sydney, NSW Centre for Developmental Disabilities Studies. Cited in Community Services Commission (2001) 'Living Arrangements'.

For some families clustering independent units together is the most appropriate option. However for others it is seen as the only alternative to group homes. Careful consideration must be made around this model as it has the potential to promote segregation and isolation of people with disabilities from their communities. Families need to have more options available to them than group homes or clusters of units so they can make true decisions about what is appropriate.

Some carers raised concern with this model particularly around security issues (out of worry that people with disabilities could be taken advantage of or their units could be broken in to). One carer of her 35-year-old son with a degenerative physical condition expressed the need for her son to live with access to 24-hour support in apartment-style accommodation but not solely living around others people with disabilities. This case further supports the argument that, in addition to models that offer services to people with disabilities living together or in close proximity, services should be available to people with disabilities living in the community as well.

Suitability of model to different groups

The cluster model of housing was recommended by carers supporting people with a range of disabilities and conditions including mental illness, intellectual disability, developmental and physical disability, with varying support needs, health care needs and behaviours. They ranged in age from 11 years old (but not wishing to access until 18) to 35. It may be ascertained from this sample that the model of a small cluster of units could be applied to many different disability groups and to people requiring varying levels of support.

Improving community outcomes

Some suggestions that carers gave for ensuring that the cluster model of accommodation would foster positive community outcomes included:

- There should only be a few units in any cluster.
- Clusters should not be physically removed from residential areas.
- Units could face in towards each other so there is a central courtyard.
- Residents can receive support with cooking, cleaning, paying bills and rent etc from the same provider if needed.
- Accommodation should be within 50km radius of family home.
- Individually designed services should be available including day programs, recreation and transport for residents (rather than all residents doing all outings together).
- Support personnel should be there, nearby or on call 24 hours a day.

One carer advised of an existing cluster model in Armidale. She reported that there are 12 terrace houses on a residential street for people with disabilities. There is a community centre behind the houses where there is a support worker 24 hours a day. She felt this would be a good model for her son with Down Syndrome.

6.3 Medium/high density living models

With the challenges presented by higher density living in NSW, particularly in Sydney, a few carers that contributed to this submission presented innovative models for both inner city and other metropolitan areas. The following case studies demonstrate that a model such as Model 6 in the Discussion Paper (Matavai Ageing in Place initiative) could be adapted for other population groups and family situations.

Similar to cluster accommodation models there is a risk that people with disabilities will be isolated and segregated as a result of the cost-effectiveness of many people living in one large block and accessing the same services.

*Anne is the carer of her 33-year-old son, Robert, with undiagnosed developmental disorder and **very challenging behaviours**. They have moved to the inner city of Sydney as this is where his behaviours are most accepted (and Anne has been unsuccessful accessing supported accommodation for Robert). Anne insists that they must remain living in the city.*

Ideally they would like to live in an apartment block and where they could live in adjoining units so that he could live independently but still have the security of having Anne nearby. Currently Anne is providing all the care and support for Robert which is unsustainable for her as she can never have a break and he requires a high level of support.

This example also highlights the need for accommodation where people with disabilities and their carers have the choice to continue living together. This is also particularly relevant for carers who are also partners of the people they support.

Another scenario is outlined below.

Lindy lives in a metropolitan area supporting her 25-year-old daughter, Mel, who has intellectual disability and requires constant supervision and coaching with all activities. She feels that ideal accommodation for Mel would be group living in an apartment block where someone is available 24-hours a day. This would both enable independence and provide necessary support. It would also provide social opportunities. It is important to Lindy that the family has easy access to Mel and she commented that often parents don't get a say in the programs of the people who they support. Lindy identified services such as transport, personal care and home care as being important to Mel.

6.4 Privately owned/rented accommodation models

Some carers identified their wishes for the person they support to live in accommodation that they have bought or rented themselves. This requires funding for a disability service provider to provide the necessary support. Accommodation Model 5 in the Discussion Paper, 'Floating Care – Supported Accommodation Initiative for People with HIV/AIDS' could be modified for this group of people who require individualised funding packages and, due to high support needs, would need coordination by a case manager.

The Community Services Commission¹⁴ (now Community Services Division of Ombudsman's Office of NSW) refers to this type of accommodation as 'supported living' whereby one or more people with disabilities live in accommodation that is owned or leased privately. It features tailor made supports for the individual residents.

It seems that carers and parent groups are finding innovative solutions such as the following two to address the current shortage and limited options of available supported accommodation. In both cases the carers have had great difficulty dealing with DADHC having been advised first that they could get funding and later informed that they could not.

*Carmen supports her 31-year-old son, Tasman, who has an Acquired Brain Injury. He has high support needs, **challenging behaviour** and requires 24-hour care or supervision. Carmen and her husband have bought a house that is suitable for Tasman to live in. It is entirely set up with three bedrooms and a workers room. There is another person in the area, also with ABI who would like to live there. All that is required is some flexible funding for the provision of services to the home. With the difficulty they have faced so far, Carmen fears that Tasman will end up in one of the existing group homes in the area. However she feels that there are inadequate services for people with ABI in her area and, as they have*

¹⁴ CSC (2001) 'Living Arrangements: A guide to supported accommodation for people with disabilities', Community Services Commission, Sydney.

unique support and other needs, her proposal would provide a very needed service, not only for her son but for others as well.

In the second scenario:

Dahlia is the primary carer of her 29-year-old daughter, Samantha, with Rett Syndrome, who has high support needs and is non-verbal. Dahlia would like her to be able to continue living in the family home with another friend who has similar support needs after she can no longer provide primary care for her. She would like flexible funding so that support services and management can be provided for the two women in a familiar environment.

Another carer of her 31-year-old daughter with mental illness also felt that private rental would be an option for them provided they could receive the necessary support from service providers and assistance with management of services.

Another model that should be further explored is low interest home loans for people with disabilities, such as the Home Adapt Loan in Queensland. This would assist people with disabilities to purchase their own homes.

6.5 Independent living – accommodation support

Some people with disabilities prefer to live on their own. These may be people who need assistance with personal care and other tasks or those with behavioural and social barriers to community living. For these people flexible support arrangements need to be facilitated to ensure that their needs are met.

Hannah currently supports her 18-year-old son, Ryan who has Aspergers, ADHD and Bipolar Disorder. He has challenging behaviours and requires supervision and prompting for personal care, medication and other daily living activities. Hannah believes that he will need to live on his own with “drop in” support to ensure that he is eating well and maintaining hygiene and a healthy lifestyle. He would need support to assist him with learning how to pay bills and do other household chores but Hannah believes this could be reduced over time. An employment service would help to keep him active in the community.

6.6 Crisis accommodation model

Many carers mentioned that crisis accommodation would be a useful service in their local area for the person they support. In most cases they were carers of people with behavioural problems and/or mental illness who are at risk of becoming homeless. One carer identified the need for crisis accommodation for her son with dual diagnosis¹⁵. Many of these people cannot gain access to mainstream services because of their disability and can end up homeless or, as demonstrated below, in prison.

Beth is a 60-year-old carer, living in a regional area, supporting her 30-year-old son with Schizophrenia. He has high support needs and requires constant supervision. He can no longer live at home because of his violent behaviour towards Beth and her husband and occasional alcohol abuse. Currently he is undergoing rehabilitation following his second term of imprisonment while the family waits for permanent accommodation to become available where he can have constant supervision and companionship.

Beth believes that, had crisis accommodation been available for men with mental illness and problems with substance abuse, he would have been saved from going to prison both

¹⁵ Mental illness and substance abuse.

times. She has been lobbying for shelter for men with mental illness and substance abuse issues to be established in their area for many years.

Accommodation Model 3, CAPII, in the discussion paper could be adapted for this group of people. It would be particularly effective if there was a system to assist people to move into longer-term accommodation, especially in cases such as Beth's, where the options appear to be homelessness or prison for her son if they cannot find appropriate accommodation.

Carers of people with complex care routines and physical support needs tended not to report a need for crisis accommodation. They felt that if the person they support was in a situation without accommodation they could not go into care where the support staff did not know them.

For these families a different approach for crisis prevention is needed. Families feel they need to get to know a service and its staff from early in their caring role so that they can be certain, if something happens to them, the person they support will continue to receive appropriate care and accommodation.

6.7 Other models

There are many existing models of supported accommodation, most of which have been developed by parent groups and carers of people with disabilities who need to find other options due to the lack of services available.

One such alternative exists in Victoria where a group of ageing parents formed a group that applied for funding through the Department of Human Services to fund their proposal. The proposal was for their sons and daughters, who were employees of the same business service, to live in a facility bought by the parents and receive living skills education (such as basic cooking, banking and housework skills) from the local TAFE college.

As the parents were not all in a financial position to contribute to the purchase of a home another model was considered. The parents rented a house near the business service and now it houses three residents who can travel to work together. The tenants, who all have an intellectual disability, pool their support packages to receive 4 hours service a day. With the skills they learnt at TAFE they are now able to do most things around the house.

Carers NSW has been informed of several other models of supported accommodation by community and carer groups that have created their own proposals to deal with the shortage of supported accommodation in their areas. By working with existing local groups DADHC can ensure that local needs are met in a cost-effective way.

7. Recommendations

The following recommendations are based on feedback from carers and the available literature regarding models of supported accommodation. In accordance with the specifications of the Discussion Paper issued by DADHC in 2004, they particularly address ways in which supported accommodation models can foster participation of people with disabilities in the local community and create positive outcomes for the whole community.

Any DADHC policy addressing community involvement of people with disabilities (in particular with complex health care needs and severe challenging behaviours) should incorporate the following:

1. Immediate increase of resources to develop improved accommodation options for people with disabilities.
2. Information about, and access to accommodation options are key elements of family support and should be introduced at an early stage in the caring relationship so that families are made aware of the options available and how to access them.
3. A range of accommodation models should be made available in all areas so that people with disabilities and their family carers have choices about where and how they live.
4. Sufficient and flexible funding should be allocated for people or community groups presenting innovative models of accommodation that address local issues.
5. Community education is needed to reduce stigma and isolation of people with disabilities living in the community and improve social outcomes for the entire community.

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