

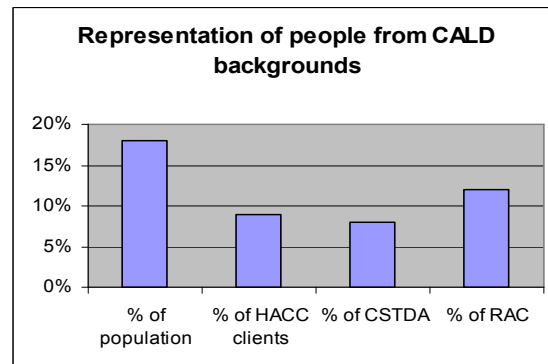
Accommodation options and the needs of carers

Carers NSW response to MDAA Discussion Paper 'Supported accommodation services for people from culturally and linguistically diverse backgrounds'

Carers NSW is the peak body representing carers in NSW. The majority of informal care that people with disabilities require is provided by family carers. These can be parents, partners, children of any age and other relatives or friends of the person with a disability. There may be several people involved in the support and assistance of a person with a disability.

There are an estimated 150,000 carers from culturally and linguistically diverse (CALD) backgrounds in NSW, based on 2001 Census data and estimates from the ABS Survey of Disability, Ageing and Carers 2003. It is also known that in many cultures the word 'carer' does not exist. Furthermore carers from CALD backgrounds are very diverse in their cultural practices, beliefs, religious backgrounds and conceptualisations of family, caring and disability. Therefore a varied and flexible approach is required when considering carers from CALD backgrounds.

Typically CALD population groups are less likely than others to use disability and community care services as shown in the graph opposite using NSW data¹:



Carers NSW submitted a response to the NSW Department of Ageing, Disability and Home Care (DADHC) in 2005 on its discussion paper entitled *Models of Supported Accommodation for People with a Disability*. In that response Carers NSW consulted with carers of people with disabilities about their supported accommodation requirements. The key findings included that:

- Supply of supported accommodation for families does not meet demand.
- Choice is important for families. Group homes are appropriate for some people but not everyone.
- Adequate information on accessing supported accommodation is needed.
- CALD carers have particular trouble accessing supported accommodation.
- Accommodation support for people with disabilities is just one aspect of support and will not be effective unless it is offered as one of a range of supports for families from an early stage in their caring relationship.

Carers NSW also cited statistics demonstrating the need for supported accommodation showing that, in NSW:

- Around 3% of the potential population of people with disabilities currently access accommodation support services (this is slightly lower than the national average)ⁱⁱ;
- The Australian Institute of Health and Welfareⁱⁱⁱ made a conservative estimate in 2003 that there were 12,500 people across Australia with an unmet need for accommodation and respite services.

- In 2003 the ABS estimated that 96% of people with profound or severe disability were living in private dwellings^{iv}.

This response builds on the submission made to the DADHC discussion paper in 2005. Specifically it addresses the need to identify transitional arrangements, carers' needs for support and models of support for CALD carers. While Carers NSW understands that MDAA is experienced in understanding CALD carers' needs, Carers NSW wishes to ensure that these issues remain central to MDAA's recommendations to DADHC on models of supported accommodation for people with intellectual disabilities from CALD backgrounds.

1. Transitional arrangements

Many of the carers who are caring for people with disabilities seeking supported accommodation are parent carers (who may be ageing themselves). They may have been caring for several decades and this will have affected their lives substantially. There is evidence to suggest that parent carers experience a range of issues when their son or daughter with a disability transitions into supported accommodation. While most studies of older parent carers in Australia do not include the CALD perspective, the findings that may be more generally applicable include:

- Uncertainty about the service system (particularly for those parent carers who have not typically used services);
- Feelings of loss and grief associated with ceasing an active caring role;
- Concerns about quality of care and ability of care workers'.

Carers therefore may require assistance throughout the transition of the person with a disability into supported accommodation and ongoing assistance thereafter.

The NSW Carers Coalition identified through a workshop the key issues facing ageing parent carers of people with disabilities^{vi}. These were:

- Physical and emotional health
- Social isolation and participation
- Access to appropriate services
- Financial limitations
- Planning for the future
- Accommodation

The report recommended that "structured forward planning is essential to reduce carer stress and address a range of practical issues including accommodation options, work and social support, guardianship arrangements and the role that siblings and other family members can play to support parents and the person with the disability". Therefore the report emphasised that carers require a range of supports as well as accommodation. This is further supported in the literature on older parent carers^{vii}.

2. Carer needs for support

It is important to acknowledge that parent carers of people with disabilities who are likely to be in need of supported accommodation are often not engaged in services to support them^{viii}. This is particularly important for carers from CALD backgrounds as they are less likely to be engaged in all community care and disability services.

In the Carers NSW response to the 2005 DADHC discussion paper on supported accommodation models the following elements of carer support were put forward as essential in considering supported accommodation options:

- 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;
- Effective and sufficient respite, and other community participation, employment and recreation services, for the person with a disability, to give the carers substantial breaks from caring responsibilities; and
- Financial assistance including financial planning and the development of a will.

3. Models of support for CALD families

While Carers NSW does not have a position on the preferred model of accommodation support for families from CALD backgrounds, there are some key principles that have emerged from practice wisdom and feedback from carers which affect the appropriateness of accommodation options for carers.

Some of the issues that carers of people with intellectual disabilities face have been highlighted by the Down Syndrome Association of NSW. They include cultural barriers surrounding intellectual disability; the lack of up to date information that is translated into a number of community languages; and limited access to bilingual workers with specific knowledge and experience of people with Down Syndrome and their carers^x.

There are some additional issues specific to the accommodation models identified by MDAA. In terms of in-home accommodation support, for instance, it is important that staff and managers are cognisant and respectful of cultural practices upon entering a person's home to deliver services. This may require cultural competence training specifically relating to carer responsiveness, as well as responsiveness to the needs of the person with a disability.

■ Group homes

In terms of the group home model, Carers NSW understands that people from CALD backgrounds have particular difficulty accessing this type of supported accommodation. There is little information available regarding CALD carers' needs in terms of group homes. However Carers NSW anticipates that those needs would reflect mainstream carers' needs. As identified in the Carers NSW response to the 2005 DADHC discussion paper on supported accommodation models, where appropriate, carers should be encouraged to have ongoing involvement in many aspects of a person's life once they have transitioned into a group home.

Many carers also experience guilt and anxiety when placing their children at a group home. CALD carers in particular may experience pressure from the family as well as friends in relation to their decision. In addition there is generally little information available to CALD communities about group homes in terms of the options and what to expect of the service.

Additional issues may include lack of cultural or ethno specific group homes (some carers feel that the cultural, language and spiritual needs of the children cannot be met by generic group homes) and concerns that carers have placing their children in a mixed gender group home.

■ Institutions

In terms of institutions, Carers NSW supports the perspective of other disability peak bodies that institutional settings do not provide adequate quality of life and are not an appropriate model of housing people with disabilities.

■ DHASI Model

The DHASI model is an adaptation of the HASI model for people with mental illness. One finding from the HASI evaluation was that accessibility to family and other social networks was an important factor

in the satisfaction of service users with the program. Geographical dislocation from family and social networks was an identified factor in the dissatisfaction with the model.

There are likely to be other factors of the HASI program that could apply to the DHASI model. For example the level of satisfaction with family relationships was considered high in the HASI evaluation and for some participants it improved including comments that their relationship with parents had moved from a child-adult relationship to an adult-adult relationship^x.

Carers NSW would therefore be interested in this model being further developed to respond to the needs of diverse cultural communities.

■ Other issues

There are a number of other cross agency issues implicated in the need for accommodation models for people with disabilities. In summary they include:

- Access to appropriate, affordable housing for carers and those they support.
- Access to employment and education for carers and those they support;
- Need for accommodation and support options to enable and encourage community participation and involvement of people with disabilities and their carers.

4. Summary and conclusions

The following recommendations were made in the Carers NSW submission to DADHC:

- An increase of resources to develop improved accommodation options for people with disabilities.
- 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.
- 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.
- Sufficient and flexible funding should be allocated for people or community groups presenting innovative models of accommodation that address local issues.
- 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.

These recommendations remain relevant and pertinent in the consultation being carried out by MDAA regarding the accommodation needs of people with intellectual disability from CALD backgrounds and their families.

Carers from CALD backgrounds are likely to have many of the same issues and needs regarding supported accommodation as other carers. In addition, however, greater attention must be paid to reaching out to CALD carers and engaging them in services and supports from an early point in the caring relationship.

Endnotes

ⁱ Source: Carers NSW & Down Syndrome NSW (2007) 'Making it work: The theory and practice of partnering with carers from CALD backgrounds', in Partnerships for better health outcomes: Carers and professionals working together: Conference Proceedings, Carers NSW. Note: RAC – Residential Aged Care; HACC – Home and Community Care program; CSTDA – Commonwealth, State and Territory Disability Agreement services.

ⁱⁱ Productivity Commission (2005) Report on Government Services, Australian Government, Canberra.

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

^{iv} ABS (2004) Survey of Disability, Ageing and Carers 2003, Australian Bureau of Statistics.

^v See, for example: Llewellyn G et al (2003) 'Invisible carers facing an uncertain future', A report of a study conducted with funding from the National Health and Medical Research Council 2000-2002.

^{vi} Cranny & Associates (2004) 'Needs of Ageing Parent Carers of Younger People with a Long Term Disability: Report of the Carers Coalition Workshop, Carers NSW.

^{vii} See, for example: Bigby C & Ozanne E (1999) 'Older Carers of Adults with Intellectual Disability, Characteristics and Service Provision Issues: A Literature Review', La Trobe University, Melbourne.

^{viii} Carers Australia (2006) Ageing Carers: Succession planning and long term needs - A response to the Federal Government's Budget Initiative 2005-09. Available at www.carersaustralia.com.au

^{ix} Carers NSW & Down Syndrome NSW (2007) 'Making it work: The theory and practice of partnering with carers from CALD backgrounds', in Partnerships for better health outcomes: Carers and professionals working together: Conference Proceedings, Carers NSW.

^x Muir K, Dadich A, Abelló D, Bleasdale M & Fisher K (2006) Housing and Accommodation Support Initiative: Report III, Summary, report prepared for the NSW Department of Health.