

## **Carers NSW submission on Statewide issues in NSW for the Home and Community Care (HACC) Program 2006/07**

Carers NSW is pleased to have the opportunity to contribute statewide carer issues to the NSW HACC Statewide Planning Process for 2006/07. In the 2005/06 HACC planning process Carers NSW made a written submission as well as attending the Statewide Stakeholder Planning Forum that was held in February last year. Many of the issues relating to carers that we raised in that submission are still pertinent. We have therefore included our submission from last year as a point of reference for the 2006/07 planning process.

We welcome feedback on specific aspects of the planning process from DADHC, in particular how DADHC is responding or planning to respond to the issues and recommendations raised. For instance some of the short, medium and long-term priorities that were tabled at the last planning round that are of continued interest include:

- mapping the interface between HACC and other programs (short term),
- working with ATSI and CALD communities to ensure the continued availability of appropriate HACC services across NSW (medium term), and
- improvement of flexibility of care to increase the responsiveness of the HACC system to better meet the needs of clients with short-term or episodic care needs (medium - long term).

There are two broad areas of the HACC program and the HACC Statewide Planning process for 2006/07 on which Carers NSW wishes to make comments. These are carers in the HACC program and other issues relating to planning and development of the HACC program.

### **1. Carers in the HACC Program**

The HACC Program has three target groups, frail aged people, younger people with disabilities and the carers of these people. It remains of concern that carers constitute only a small percentage of HACC clients, despite being one of the HACC client groups. According to estimates provided by DADHC from the HACC MDS, in 2003-04 there were only 8,000 carers accessing HACC services (4% of all HACC clients)<sup>1</sup> out of 750,000 carers in NSW including 150,000 primary carers. This is despite the reported figure that 53% of clients classified as "care recipient" also received assistance from informal carers<sup>2</sup>. This indicates a potentially larger need for support from family carers in the community.

Family carers provide the vast majority of care and support for people in the community and there is a range of supports that they require, outlined in the Carers NSW Framework for Carer Support (forthcoming). HACC-funded services including case management, transport,

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<sup>1</sup> Although according to recent figures in Table A9 of the 2003-2004 HACC MDS Annual Bulletin, carers could constitute as little as 1.7% of HACC clients in NSW. This is less than half the average for Australian states and territories.

<sup>2</sup> Australian Government Department of Health and Ageing 2004, *Home and Community Care Program*, Australian Government Department of Health and Ageing, Canberra.

home maintenance, respite and other services, form a significant component of this support for carers.

Providing support to carers will help meet the stated aims of the HACC Program which are to provide comprehensive support to the client groups, increase independence of the target groups, thereby enhancing their quality of life and/ or preventing inappropriate admission to long term residential care and to provide flexible, timely and responsive services<sup>3</sup>.

Support for carers of people with disabilities, chronic conditions, mental illness/disorder or who are frail aged, will also create positive outcomes for the community. It has been demonstrated that effective carer support has long term cost benefits to government<sup>4</sup>.

Our key areas for comment on the HACC statewide planning process for 2006/07 include respite for carers, support for ageing carers and improved support for culturally and linguistically diverse carers, Aboriginal and Torres Strait Islander carers and carers in the Home Care Service of NSW.

### **a) Respite**

Although it is not the only support that carers require, respite is a very important service for carers and the main service for which carers are currently recorded as the client in the HACC Program.

Many carers have difficulty accessing respite or accessing a sufficient amount of respite through HACC-funded services. Furthermore for many carers who access respite through the HACC program they report that it does not meet their family's needs or is not sufficiently flexible.

Respite is narrowly defined as in-home or host family respite in the HACC Program. There are a number of emerging issues for carers trying to access in-home respite. For instance many carers find that they are required to have specialist equipment or to make modifications to their homes in order for them to be safe working places for HACC workers. This can entail long waiting times for carers to access other programs such as the Program of Appliances for Disabled People or Home Modifications.

Greater flexibility in HACC respite services is required so that carers and the people they support have more satisfactory **outcomes** from these services.

We frequently hear that respite provision is service-focussed, rather than carer-focussed. Given that respite is a service to give carers breaks from their caring role, as much as possible, these services should be provided according to the needs of the carer. One of the main concerns that carers raise is the lack of appropriately trained staff to support people with complex care or medical needs.

The lack of appropriate respite options for carers of young people with disabilities has been raised with Carers NSW as a particular gap in respite services. Both carers and service providers have highlighted this as an issue across the state through a recent online survey conducted by Carers NSW. The HACC program is well positioned to provide appropriate respite for this target group.

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<sup>3</sup> Australian Government Department of Health and Ageing 2004, *Home and Community Care Program*, Australian Government Department of Health and Ageing, Canberra.

<sup>4</sup> Carers NSW (2005) Carers NSW State Budget Submission 2006-07, p11, available at [www.carersnsw.asn.au](http://www.carersnsw.asn.au)

Carers NSW is currently undertaking research into what constitutes effective respite for carers (forthcoming). According to this research, the key principles of effective respite are:

1. Timely, relevant and culturally appropriate information and referral
2. Emotional support and assistance with access
3. Flexible service delivery that is appropriate to individual cultural and lifestyle needs
4. Appropriately trained staff for the needs of the care recipient
5. High quality, reliable care and support
6. Affordable
7. Appropriate length of time
8. Planned and developed in consultation with carer
9. Choice of options for the carer and the person they support

## **b) Ageing Carers**

The carer population is ageing and, as stipulated in our 2005 submission to the HACC planning process, this is likely to lead to a 'carer crunch' over the coming decades (with a reduction in the number of informal carers compared with the number of people requiring care).

The implications of the ageing population for the HACC Program are likely to be pronounced, particularly given the current age focus of the program, with the average age of HACC clients in NSW being 73.6 years. Many HACC clients will also have informal carers. Recent ABS<sup>5</sup> data shows that there are around 280,000 ageing people in NSW who currently receive assistance from informal providers.

A long term plan should be developed for the role of the HACC program in supporting ageing carers and others requiring care and support in the community.

A significant number of ageing parent carers<sup>6</sup> are supporting their adult sons and daughters with disabilities. There are estimated to be at least 2000 ageing carers supporting an adult son or daughter with a disability in NSW. These carers have immediate support needs and many of them currently do not access any services.

A recent report on the support needs of ageing parent carers by Carers Australia<sup>7</sup> shows that they have a need, not only for respite, but for other supports including case management and succession planning. In particular there should be immediate planning on how the HACC program can support ageing parent carers through outreach and in coordination with other community care programs.

Not only do ageing parent carers present a current service delivery and planning issue but it is likely to be increasingly significant as the population ages over the coming decades and will present new challenges for the HACC program amongst others. A coordinated response is required across programs and the HACC program should be central to this.

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<sup>5</sup> ABS (2003) 'Survey of Disability, Ageing and Carers: Summary Tables, NSW', Cat. No. 4430.1.40.001, Australian Bureau of Statistics, Canberra.

<sup>6</sup> The NSW Carers Coalition defines ageing parent carers as parent carers aged 65 or over (or Aboriginal and Torres Strait Islander parent carers younger than 45 years) who care for an adult son or daughter with a disability; parent carers younger than 65 years of age whose caring relationship is of 30 years duration (10 years for ATSI carers) or more.

<sup>7</sup> CA (2005) 'Ageing Carers: Succession planning and long term needs', Carers Association of Australia. Available at [www.carersaustralia.com.au](http://www.carersaustralia.com.au)

### **c) CALD Carers**

There is a small percentage of people from culturally and linguistically diverse (CALD) backgrounds accessing services funded under the HACC program. Only 8.6% of HACC clients in NSW have a main language spoken at home other than English. The DADHC Annual Report shows that on average only 9% of people from CALD backgrounds access the Home Care Service of NSW, whereas it is estimated that 20% of the total population in NSW is from a CALD background.

The survey of Carers NSW members conducted in 2004 showed that CALD carers were more likely to report a need for information than other carers and just as likely to report a need for essential services such as respite. While these results are based on a small sample size and therefore are not truly representative, they do indicate that there is still a low level of information about services reaching CALD communities despite their level of need being significant. Improved cultural awareness in assessment is a vital component of this.

### **d) ATSI Carers**

While the HACC MDS reports show that the proportion of service users who are Aboriginal or Torres Strait Islanders (ATSI) is representative of the proportion of the general community, higher rates of disability and illness in ATSI communities, compared with the mainstream population, lend particular need for the HACC program to support these communities. Most importantly HACC planning should address the needs of ATSI people. For carers in particular there is a great need to deliver flexible services and supports.

As identified in the planning forum for 2005/06, HACC statewide planning should include strategies for engaging ATSI communities and delivering appropriate and flexible services to these people. In particular, regarding ATSI carers, there will need to be a greater focus on information about the supports that are available to assist carers to self-identify.

Improved partnership between mainstream and ATSI-specific community care services would assist as well as better awareness in mainstream services of the specific issues and needs of ATSI communities. This is an important priority in the planning of HACC workforce development.

### **e) Home Care Service**

The Home Care Service (HCS) of NSW is the largest single provider of services funded under the HACC program in NSW. For this reason the HCS is often the first (and only) point of contact for families requiring support. Carers NSW continues to hear from carers about the lack of availability of services through the HCS, including respite.

It is our understanding that the HCS is developing a number of responses to the recommendations made in the Auditor-General's Performance Audit of the HCS in 2004. However we continue to hear from carers about the difficulties they face in accessing the HCS.

Carers NSW receives many calls from carers regarding access to the HCS in NSW. Key issues include no availability of services and long waiting times between assessment and commencement of service. One example that illustrates these problems from the last six months is:

- Family member calling on behalf of a young carer who is caring for her mother with Huntington's Disease. She was complaining about the lack of action from Home Care to help. They contacted Home Care the first time and were told to call back in 3 months.

They called again after this period and they were told the same thing all over again. (September, 2005).

Carers NSW would like to see a larger number of carers accessing the HCS in 2006-07. Respite for carers, although it is one of the three main service types provided under by the HCS, only comprises 13% of the total hours of care provided by the HCS.

## **2. HACC planning and development issues**

It is anticipated that the HACC MDS Version 2 will collect more data on care recipients who have carers, including whether the carer provides care and support for more than one person and the gender of carers. While this is to be welcome, there is still an issue in NSW regarding compliance by service providers in submitting their data. The recent report on government services by the Productivity Commission (2006) showed that NSW had the lowest percentage of services funded under the HACC program returning their MDS data to the Department of Ageing, Disability and Home Care.

Data collection on the extent of waiting lists for people who are eligible for HACC services to receive assistance would greatly improve the capacity for planning. We understand that in some areas these waiting times are significant (up to several years according to some service providers). Coordinated collection of this data would give a better picture of the level of unmet need in NSW and would assist with planning and service delivery to address these needs.

A major gap in services that has become increasingly apparent to Carers over the last year is the lack of community transport options. This presents a particular problem for carers for whom provision of transport is a costly exercise. Increased funding is required for community transport services given that these services enable more appropriate use of other services.

Other issues and gaps in services that were identified at the planning forum last year and that are still of major concern include services for people with mental illness (and other deteriorating conditions such as HIV/AIDS) and their carers. HACC workforce development issues and equity across the state are also important areas for planning.

## **3. Recommendations**

Carers NSW recommends that, as part of the NSW 2006-07 HACC statewide planning process, the NSW Department of Ageing, Disability and Home Care:

1. Develop strategies for better supporting carers in the Home and Community Care program.
2. Work towards greater flexibility in carer-focused services, particularly respite.
3. Address gaps in service including lack of respite for carers of young people with disability, lack of transport, lack of service delivery to people with mental illness and other episodic conditions and their carers across the state.
4. Consider strategies for better supporting ageing carers and in particular ageing parent carers of people with disabilities.
5. Improved service provision to ATSI carers.
6. Improved access to services of CALD carers.
7. Commits to feed back progress and outcomes for short-term, medium-term and long-term activities that form the yearly plan.
8. Improved access of carers to the Home Care Service of NSW.
9. Improved data collection on unmet need across the state.