

**NSW Legislative Assembly
Public Accounts Committee
Home and Community Care Inquiry**

Submission from Carers NSW



28 July 2006

Introduction

There are at least 750,000 carers in NSW. These are family members and friends providing care to people with disabilities, mental illness, chronic conditions or frail aged people in an unpaid capacity. Carers come from all walks of life, cultural backgrounds and age groups. Carers assist people with a range of activities including personal care, provision of transport, assistance with mobility and communication and supervision.

For many it is a 24 hour job that is emotionally, physically and financially stressful. There are documented impacts of caring which include financial disadvantage, reduced health and wellbeing and social isolation. Some of these are demonstrated in the statistics below.

Of the 750,000 carers in NSW (ABS 2004):

- 150,000 (20%) are primary carers, meaning they provide the majority of support to someone;
- 90,200 (12%) are young carers (aged under 25);
- 135,000 (18%) are ageing carers (aged 65 and over);
- 76% of carers are workforce age;
- 45% of primary carers spend 40 hours or more caring each week;
- 64% of primary carers and 45% of all carers are not in the labour force;
- the median gross personal income of primary carers is \$224 per week compared with \$435 for non-carers.

Carers themselves may require support. This may be in the form of services, financial assistance or informal support.

Carers NSW is the peak body representing carers in this state. We undertake a range of activities including education and training for carers and service providers; emotional support and counselling for carers; information and resource development; policy development, research and advocacy and sector development.

Our submission to the Public Accounts Committee Inquiry into the Home and Community Care Program is founded on feedback that we receive directly from carers through the range of activities we undertake, Home and Community Care program data, organisational knowledge about the needs of carers and the impacts of this program and the Home Care Service on carers. Current research and literature regarding the needs of carers and the impacts of carer support also inform this submission.

The primary data on carers in this submission been collected by the Commonwealth Carer Resource Centre at Carers NSW. The issues reported, therefore, are those identified by carers themselves, rather than by service providers.

Home and Community Care Program

The Home and Community Care (HACC) Program is one of the key programs that delivers services to carers. However, despite being a target group of the HACC Program, carers constitute as few as 1.7% of HACC clients in NSW, compared with 12.6% in the ACT. Of the 'care recipients' 61.4% had a carer available (DoHA 2005).

In previous years Carers NSW has participated in consultations for the annual statewide HACC plan. Our submissions to these processes for the last two years are attached to this submission as appendices for the Committee's information. They include recommendations for improving access to the HACC program for carers and targeting specific groups of carers that are in need of support.

1. The efficiency and effectiveness of the joint arrangements by the Commonwealth and NSW State Government for approval of the annual expenditure plan for the HACC program, with a focus on the timeliness of agreement of the plan and discharging of grants

In our capacity as a consumer peak body, Carers NSW is able to comment on the effect that Commonwealth/State arrangements may have on carers. It is our understanding that there is frequently a significant delay in the signing of HACC State Plans resulting in significant unspent monies (around \$25 - \$30 million annually) that would otherwise be put into direct service delivery. Our primary concern is that due to these delays many carers and people requiring support who could be receiving services are not. Furthermore the lapse in time between the planning process in which unmet need is identified and the rollout of funds for services to address those needs is problematic. The approval process is currently unclear, lengthy and not effectively communicated.

We suggest that, within the current arrangements, a more efficient system could be implemented. It is our expectation that from one year to the next there is a certain degree of predictability in the HACC State Plan. Therefore a large proportion of the plan could be agreed to prior to July 1 each year. In addition we question whether a yearly planning process is necessary and suggest that a triennial planning process, in line with the triennial HACC Agreement may be more effective. Greater consistency of local and regional planning processes would also contribute to a more effective planning mechanism.

Carers NSW recommends that the Public Accounts Committee:

1. Investigates the effectiveness and efficiency of a triennial planning process and mechanisms for the Commonwealth and NSW Governments to develop and agree to plans prior to the annual budget process.

Home Care Service

The Home Care Service (HCS) of NSW provides vital assistance to family carers providing support for people in the community through its personal care, domestic assistance and respite services. The HCS is particularly important as it is the largest provider of these HACC services in NSW.

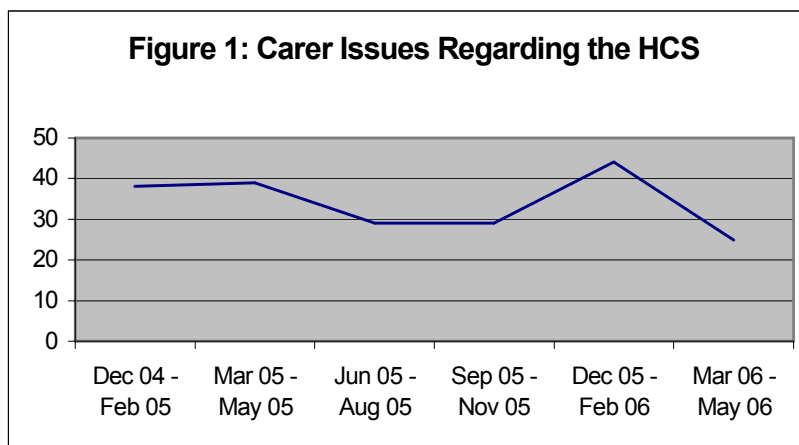
Carers NSW is in contact with carers across the state through the Commonwealth Carer Resource Centre¹ and various programs, projects and education and training sessions that we run including the Mental Health Project and the Young Carers Project. Through our community development work we have a broad understanding of issues that Aboriginal and Torres Strait Islander carers and carers from culturally and linguistically diverse populations face.

Access to, and issues regarding the HCS are continually raised by carers through these channels. Data from the Commonwealth Carer Resource Centre (Figure 1, below) shows that

¹ Carers NSW is the auspice body for the Commonwealth Carer Resource Centre which provides information, emotional support and referral to carers by telephone.

there has been a slight decrease in the number of issues raised by carers about the HCS² with the exception of increases in the end-of year-holiday period.

Analysis of Commonwealth Carer Resource Centre data demonstrates that the number of calls received about the HCS in the six months from November 2004 to April 2005 was 85% higher than the number of calls received in the same period a year earlier. Thus overall we have seen a significant growth in the number of phone calls received from carers regarding difficulties with the HCS.



The types of issues raised by carers have remained consistent. The key issues raised in the last year include:

1. Eligibility/Access

- Carers can't access Home Care or any other services (because services are full)
- There are long waiting times for Home Care (for assessment and/or between assessment and commencement of service)
- Carers can't get through on the 1800 number, or are put on hold for extended periods or leave messages which aren't returned

2. Flexibility

- Home Care service is inflexible (either in terms of timing or how the service is delivered)
- Carers require increased hours of service (when needs change) but Home Care cannot provide any additional service

3. Reliability

- Home Care is unreliable (in terms of timing, continuity of workers, turning up for agreed shift)
- No service received because Home Care workers do not undertake certain personal care and domestic assistance tasks (due to OHS or other requirements) or are not suitably qualified to handle certain conditions or needs (eg incontinence)

A snapshot of HCS issues raised by carers in 2003 reveals similar issues regarding access, flexibility, the impact of internal policy changes on service delivery and reliability of the HCS.

² Figure 1 shows the number of carers that have contacted the Resource Centre to raise an issue or complaint about the HCS. Many more carers call each month with general enquiries about the HCS.

2. A follow-up inquiry of the Auditor-General's review of the NSW Home Care Service in terms of:

a) Strategies for addressing unmet need in the context of growing demand for services from eligible parties

The demand for services for carers and the people they support is projected to grow over the coming decades. The impact of population change is likely to be felt by carers as a gap between those requiring care and those available to provide it increases.

A recent report by the National Centre for Social and Economic Modelling (NATSEM 2004) made a projection that the number of people over 65 in Australia requiring assistance would increase by 160% from 2001 to 2031. Over this period, it was projected that the number of informal carers would increase by only 57%. Furthermore carers themselves will be ageing, hence requiring more support in their roles.

The Productivity Commission (2005) confirms that the ageing population will also lead to a significant increase in demand for aged care services. This is likely to be skewed towards community care as people are most likely to choose to remain at home, rather than enter residential aged care.

This projection must be contextualised by the existing unmet need for Home Care and population trends demonstrate that this need is likely to increase substantially in the coming years. Significant proportions of older people (aged 60 years and over) had unmet need for assistance in 2003. Nationally, sixty-five percent of people who required assistance had their needs partially met while 6% had none of their needs met (AIHW 2005).

The Australian Bureau of Statistics estimated in 2003 (ABS 2004a) that 37% of all primary carers did not have their support needs met. The low participation of carers in the labour force and other health and wellbeing characteristics of carers (previously described) are indicative of existing unmet need. For example, of all primary carers who were unemployed or not in the labour force in 2003, nearly one-third of those who would like to work cited 'no alternative care arrangements available' as the main barrier to employment.

Our contact with carers indicates that many carers who require assistance and contact the HCS currently are not able to have their needs met (due to eligibility or access issues identified above). Examples from the last year are provided below:

- A 25 year old carer who was assisting her mother with feeding, toileting and medication contacted the Home Care Service and the Commonwealth Carer Respite Centre and other services to find that no help was available (May, 2005).
- Person unable to get Home Care services even though they were blind (September 2005).

Carers are often told that they cannot access a service at the time they call and there are waiting times. In some cases there is a wait for assessment, in other cases a wait between assessment and service commencement. Examples where this has been the case include:

- Carer of two daughters with disabilities has been waiting 6 years for Home Care and was taken off the Carer Payment (March 2006).

- Carer of two grandchildren with ADHD has recently had an operation on her arm and cannot take it out of the sling for 3 months. It will take a year before she can use it again. She was told that there is a 12-18 month wait for Home Care (November 2005).

Many of the carers who are unsuccessful accessing the HCS also report to us that they are unable to get any other services. As identified in the Auditor General's Performance Audit (2004), the HCS is often the first (and only) service that carers contact and in many regional areas it is the only service available.

In addition there need to be appropriate services available for different CALD communities. Provision of training to HCS staff may be necessary in order to facilitate better service delivery.

In order for the HCS to effectively address unmet need, the extent of that need must be systematically recorded and measured against services being provided. The 2004 Audit Office's Report on Home Care recommended that waiting lists be maintained by the HCS in order to do this. To our knowledge however there is no consistent measure for maintaining waiting lists by the HCS.

Additional funding of the HCS will be one aspect of addressing unmet need. While a significant funding increase was made to the HCS in 2005-06 (6% or \$10.5m), the budget was underspent by \$4.8m in that financial year. The 2006-07 budget is \$186.4m, a decrease of 0.5% on the previous years' budget. Hours of service are estimated to remain similar to previous years (NSW Treasury 2005; NSW Treasury 2006).

It is a further concern that the HCS does not reach many NSW communities at all, particularly culturally and linguistically diverse (CALD) communities. The Department of Ageing, Disability and Home Care annual report 2004-05 (DADHC 2005) reveals that only 9% of HCS clients are from CALD backgrounds. In comparison nearly 20% of the NSW population are in this category (ABS 2001).

It is our understanding that CALD carers have similar needs to other carers for services such as personal care, domestic assistance and respite. However there is a greater need for accessible and available information and for outreach to people from CALD backgrounds in order to facilitate timely access to services.

Carers NSW recommends that the Public Accounts Committee:

2. Investigates the need for the HCS to improve mechanisms for recording and measuring unmet need (through waiting lists) in order to address need.
3. Investigates the ability of the HCS to meet the needs of people from CALD backgrounds.
4. Investigates departmental processes to periodically assess budget underspending on services through the financial year.

b) The effectiveness of Home Care Service processes for managing access to services, across service types

Carers NSW has some understanding of the effectiveness of HCS processes for managing access to services across service types from our contact with carers and from information received from other organisations in community forums that we attend. Where carers are concerned there are a number of issues to be considered here, primarily flexibility across service delivery areas and carer assessment and access to respite.

Some feedback from carers suggests that the HCS lacks flexibility and does not enable carers and the people they support to access the appropriate service at the appropriate time. This matter relates to the provision of ongoing reassessment of the caring situation, recognising that the support needs of both the person requiring care and their carer change constantly. One such issue raised by a carer in April 2005 demonstrated this inability to manage access across services:

- Carer for her mother-in-law with advanced dementia is receiving 3.5 hours a week of service from Home Care. Mother-in-law will only allow the carer to attend to her needs and becomes very aggressive and abusive towards workers or other family and friends. The carer is happy to continue to attend to mother-in-law's needs but would like Home Care to assist her with her house work etc. Home Care will not change service from personal care to domestic help as the funding is to provide service to cared-for.

There is now a growing body of literature indicating that, where a person requiring support has an informal carer, the 'dyadic' relationship should be considered as well as the needs of the individuals within that relationship (Coeling et al 2003; Schofield et al 1998). This emphasises the importance for services to be flexible and responsive to the needs of the caring dyad rather than taking a restrictive service delivery-focused approach to meeting the needs of their clients.

The care dyad must be recognised in HCS assessment processes. It must also be noted that carers and the people they support often have separate needs that require different service responses. Thus holistic assessment is required.

The Referral and Assessment Centre (RAC) carries out the majority of assessment by phone according to the RAC factsheet³. However, one disadvantage with a phone-based assessment tool is that assessors may not pick up the needs of a carer that may be additional to the needs of a care recipient in the same household or relationship. As demonstrated by the case below, it is important that assessment of the carers' needs as well as those of the care recipients are assessed.

- Home Care have started providing services to carers' parents (1 hour showering per week) but say that 1 hour per week is all they can spare and refuse to include 1 hour respite each week even though this is much needed by carer's mother (November 2004).

Carers NSW recommends that the Public Accounts Committee:

5. Investigates the ability of the Referral and Assessment Centre to adequately identify the support needs of carers (independently of care recipients).

c) The extent of consumer input to Home Care Service design, management or delivery of programs and other mechanisms for accessing service quality

Representation and participation of consumers, including carers, is of high importance in terms of ensuring the responsiveness and appropriateness of services, policies and programs that directly influence those people.

It is our understanding that there are two key avenues through which consumers including carers can potentially provide input into the HCS design, management and delivery of

³ Factsheet accessed from www.dadhc.nsw.gov.au

services and provide feedback on quality of services. These are the Home Care Service Advisory Board and the complaints mechanism.

The HCS Advisory Board was established in 2004 and currently is comprised of seven part-time Board members. Many of these individuals would be aware of the needs of carers and have a good understanding of carers' issues. Most are skilled professionals and academics working the field of community care or business.

We note however that there is no representative on the HCS Advisory Board who is appointed to directly represent carers' interests and there appear to be no consumers on this Board. We raised this concern in previous correspondence with the Director General of DADHC and feel strongly that there should be carer representation on this Board considering that carers are one of the three HACC target groups. It is not clear to us to what extent the Board is apprised of HCS activities and progress towards addressing the Audit Office's recommendations or what provisions exist for Board members to feed their expertise and experience into these processes.

It is our suggestion that one avenue through which the HCS could gain more input from consumers is through this Board and that, by expanding its membership and its role, a broader diversity of people could be represented by Board members.

The second avenue through which consumers can provide input into the HCS design and feedback on HCS services is through its complaints mechanism. Carers NSW provides information to carers on how to make complaints through provision of our 'Action Pack for Carers'. However we understand that making a complaint can be a daunting task for any service user, particularly in areas where they know there are no other services that can support them.

Many carers and others requiring services fear retribution from making complaints and Carers NSW is sometimes contacted by carers in NSW who believe this has been the case, as exemplified below:

- Carer feels victimised by Home Care because he has complained about them and they are now refusing to provide services to him (March 2005).

Making a complaint is particularly an issue for Aboriginal and Torres Strait Islander carers who generally prefer anonymity due to concern about retribution from services. Culturally and linguistically diverse carers may also require language assistance to make a complaint.

We recognise that DADHC has a complaints policy and process in place and that, in the case of Home Care, complainants are not required to make a complaint directly to the person or branch providing the service. However in light of the above comments it is probable that the complaints process is not the most effective means of service user input into management of the HCS. Our suggestion is that the HCS considers other mechanisms for feedback perhaps involving improved communication strategies with key consumer and service provider networks in NSW.

It is our understanding that 'satisfaction surveys' have been undertaken in the past by the Home Care Service. We question the validity and methodology used to gain responses from service users about their satisfaction with the service.

Carers NSW recommends that the Public Accounts Committee:

6. Seeks information and makes recommendations on the governance structure of the HCS Advisory Board and how it could be used more effectively to provide the Department with information and feedback.
7. Considers the possibilities for expanded membership on the Board to represent consumers' and carers' needs.
8. Investigates the effectiveness of existing complaints mechanisms as a means of ensuring consumer input into service delivery.

d) The implementation by DADHC and Home Care Service of systems and processes to plan, monitor, report on and improve accountability of the service

In our capacity as a consumer peak body, Carers NSW does not have the knowledge or evidence to comment on DADHC's and the HCS's implementation of systems and processes to plan, monitor, report on and improve service accountability across the state. However, as outlined in our response to section 2a of the terms of reference for this inquiry, in order to better plan for services there must be documentation of need and unmet need as well as evidence-based population planning strategies. The extent to which these are employed by the HCS in planning for services is unclear.

3. Any other relevant matters

There are a number of other relevant matters that Carers NSW wishes to draw to the attention of the Committee.

a) Home Care's Response to Performance Audit Report

In response to the Auditor-General's Report on the HCS in 2004, the Director General of DADHC Brendan O'Reilly, made a commitment that five measures would be implemented immediately. We understand that, while a number of these measures have been implemented, there remains no information in the public domain about other measures, including the Home Care Advisory Board's position on the HCS as a provider in the community care continuum. The HCS also reported during 2005 that it was undertaking work on a statewide fees policy which is, as yet, unavailable.

The Report made a number of other pertinent recommendations to which there has as yet been no public response from DADHC, other than the initial response provided by Brendan O'Reilly, Director General, in the opening pages of the report.

Additional recommendations made by the Auditor-General's report that could address some of the issues raised in this submission include:

- Development of needs-based eligibility criteria,
- Maintain a waiting list for eligible applicants most at risk of not accessing services elsewhere;
- Regularly assess the quality of services in the home;
- Develop measures of effectiveness to monitor the impact of services;
- Develop and implement a common approach to determining consumer fees.

Further publicly available response on progress towards these recommendations is required in the public sphere to improve the transparency and accountability of the HCS.

Carers NSW recommends that the Public Accounts Committee:

9. Investigates the extent to which recommendations of the Auditor General's Performance Report on Home Care have been adopted by the HCS.

b) Effectiveness of HCS service delivery to specific target populations

One of the criteria of the Performance Report on the HCS was to review its effectiveness "in delivering services to specific target populations (ATSI, CALD, rural and remote populations, dementia and financially disadvantaged)". The report found that around 4% of HCS clients were ATSI, 15% lived in rural and remote areas and over 90% were financially disadvantaged. The 2004-05 DADHC Annual Report also indicated that 9% of HCS clients were from CALD backgrounds. The *effectiveness* of HCS services in meeting the needs of these groups, however, was not explored in the Report.

Further investigation is required to determine why people from CALD backgrounds and people living in regional and remote areas are under-represented in HCS client data. The effectiveness of HCS services and management arrangements for supporting ATSI families also needs further consideration.

ATSI service provision was excluded from the Auditor General's Performance Report which "focussed on mainstream, that is non ATSI, service provision" (p37). Therefore a further in-depth review of this service is required in order to make recommendations about improved effectiveness. Carers NSW understands that many of the issues regarding eligibility, access and flexibility of Home Care apply to the ATSI population as they apply to other groups.

Experience from Carers NSW also suggests that young carers (those aged up to 25 years) have additional and distinct issues that need to be addressed by services such as the HCS. In particular access to the HCS for this group is an issue.

Carers NSW recommends that the Public Accounts Committee:

10. Investigates the effectiveness of the HCS in meeting the needs of specific target populations including CALD, ATSI, rural and remote and financially disadvantaged groups, as well as young carers.

c) Equity of access to the HCS

The Auditor-General's Performance Report on Home Care found that the approach to allocating priority to clients was inequitable as it depended on "when the applicant calls and whether or not this coincides with service hours becoming available at the local branch". It appears from our contact with carers that this is still the current situation in many areas.

Equity of access to services is an important issue in NSW. It could in part be addressed by the recommendation listed above, to develop needs-based eligibility criteria. However additional measures are required to ensure that resources are distributed equitably across and within regions. As discussed in our response to 2a, service planning based on population statistics and evidence of need is required in order to ensure more equitable distribution of services.

Carers NSW recommends that the Public Accounts Committee:

11. Investigates equity if service delivery in line with evidence based needs analysis and population projections and planning.

d) Balancing quality services with other requirements

Increasingly Carers NSW hears from carers who report reduction or cessation of services due to insurance or occupational health and safety (OHS) reasons. An increased focus on community and in-home care (including many services provided by the HACC program) leads to increased provision of services in private residences. This presents an additional risk for service providers as they have less control of the workplace in which their employees operate. For many carers and people requiring support, however, risk management translates into reduced or inflexible services. A series of such complaints have been reported by carers including:

- HCS worker wouldn't reach up and dust furniture or move furniture to vacuum (May 2006).
- Carer of quadriplegic/bed-ridden son whose services have been withdrawn due to lack of equipment (mop and bucket) (May 2006).

The implications of services being withdrawn or reduced because of imbalance between responsible service delivery and other policy requirements include negative impact on carers (for example, resulting in injury or exhaustion). This is also a gap in the service system. The Young Carers Program at Carers NSW has identified this as a particular issue for young carers as they are put at risk when services cannot assist with lifting, moving and cleaning difficult areas.

There are also potential implications on other sectors of the service system, including inappropriate use of respite beds for ongoing accommodation and unnecessary use of generic emergency and health services.

Carers NSW recommends that the Public Accounts Committee:

12. Investigates the extent to which service effectiveness is jeopardised by risk management processes and to address the gap in services for clients where this is the case.

e) Other HACC Service Types

There are a number of other HACC service types that carers are in need of. Transport, in particular, is a vital service that enables use of other services including centre-based respite. The provision of transport by carers (where services are unable to provide transport) is not only costly to them but also reduces the 'respite effect' that they could benefit from. In 2004 a survey of Carers NSW members found that respite was the main service required by carers (64%), other community services were required by 58% of respondents and transport in particular was identified by one in ten carers as a service they required. This survey indicates a significant level of need for all service types offered by the HACC Program.

Summary of key points relating to carers in the HACC program:

- Carers are a legislated target group of the HACC program, yet they constitute only 1.7% of service users in NSW.
- The need to support 'care dyads' should be recognised in assessment and service delivery. Carers and the people they support often have distinct and separate needs.
- Carers benefit from and require a range of HACC services including, but not limited to, transport, centre-based respite, home modifications, home maintenance, social support, case management and goods and equipment. Carers NSW is contacted by carers regarding access to these and other services regularly.

- Carers NSW recommends in our submission to the State Budget that a significant increase (of 30%) to ongoing funding is made to the HACC program.

In summary

The HACC Program and the Home Care Service provide a vital source of support for many family carers living in the community. Effective services and programs benefit frail aged people, people with disabilities and other conditions and their carers. It is our hope that this inquiry results in improved systems and consequently in improved outcomes for those living in the community who depend on these services.

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