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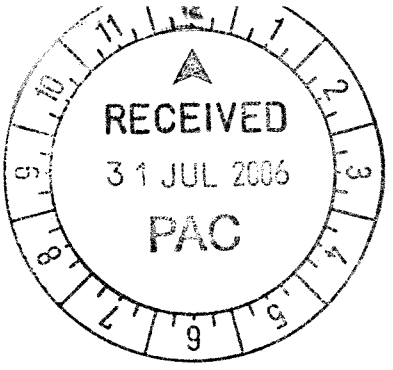

The Cancer Council NSW

The Cancer Council
New South Wales

Submission to the Public Accounts Committee

Home and Community Care Program Inquiry

July 2006

Introduction

The Cancer Council NSW (TCCN) is the leading cancer charity in New South Wales. Our mission is to defeat cancer. To achieve our mission we are working to build a cancer smart community by providing information and services, conducting research, and generating funds. The Cancer Council also aims to reduce the impact of cancer on communities by speaking up for the rights and interests of cancer patients and their carers and families. The TCCN welcomes this opportunity to provide comment on the Home and Community Care program and the Home Care Service.

The Home and Community Care (HACC) Program is a joint Commonwealth/ State initiative aimed at enhancing the independence of frail aged people and younger people with a disability and their carers, to avoid premature admission to long term residential care. Other groups, such as people with HIV/AIDS, can be classed as eligible for HACC services upon the agreement of the relevant Commonwealth and State Ministers.[1]

Many stakeholders have told TCCN that more practical support is required to provide home-based care for people with cancer. There has been an increase in home-based care of cancer patients due to the wishes of patients themselves, continuing pressure on the acute care system, early discharge policies and a lack of inpatient facilities or beds in some areas.

Cancer patients who require palliative care are a special needs group who often require urgent services via HACC-funded programs. Palliative care is any form of treatment that focuses on reducing the severity of the symptoms of a disease and improving the quality of life of patients, rather than providing a cure. The wish of many patients and their carers is for those in the end-stage of disease to be able to die at home. However, most deaths still occur in hospital due to difficulties in obtaining support and service in the home.

Home-based carers of people with cancer in NSW are often themselves technically eligible for a range of household support programs and services provided by the Home Care Service (HCS) and other HACC-funded services. In reality, cancer patients and their carers have problems accessing these services because of confusion about eligibility and the limited availability of respite, domestic assistance, support and transport to medical treatment.

Recognising the needs and eligibility of home-based cancer patients and their carers for HCS and other HACC services will fulfil the aims of the HACC program, including preventing inappropriate admission to long-term care and inpatient facilities.

Response to Terms of Reference

(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.

HACC and Home Care Service funding issues

There are around 700 HACC service providers in NSW, of which the **Home Care Service of NSW (HCS)** is the largest, consuming approximately one third of the allocated HACC funds. The HCS provides about 90% of all HACC domestic assistance and personal care services. The HCS, part of the NSW Department of Ageing, Disability and Home Care (DADHC), provides domestic assistance, personal care and respite care to clients who meet the HACC target group. Other HACC services are largely provided by community organisations and local government and include transport services, home maintenance, meals and other food services, nursing care and linen services. The Auditor-General's performance audit[2] of the Home Care Service revealed that up to **75%** of those deemed eligible were denied services due to the limited funding of the HCS program. In addition, about 85% of HCS clients receive less than 2 hours of domestic assistance per week.

Expenditure on HACC services in NSW has traditionally lagged behind that of other states. The Productivity Commission reported that in 2003-04, NSW had the lowest government real expenditure on HACC services per capita of eligible population.[3] This has since increased by about 8%. However, welfare groups such as the Council of Social Services of New South Wales (NCOSS) and Carers NSW have called for an injection of up to 30% in HACC funding in order to address current unmet needs.[4,5] In addition, Australia's ageing population will instigate ever-increasing needs for HACC services. This will require additional yearly increases to the HACC budget of at least 6% in addition to indexation.

At such a time of proven unmet need for HACC services, TCCN understands that HACC was underspent by almost $30 million in 2005/06.[6] The HCS budget was underspent by $4.58m in the same period. The State Budget has also shown that the hours of service plus the number of customers per year have actually been steadily *decreasing* in previous years despite increases to the HCS funding. No accountability explanations have been provided for this failure to meet projected service targets.

TCCN consultation with NCOSS and other community service organisations have revealed inordinate postponement in the release of the HACC State Plans every year delays access to much needed growth funds and causes uncertainty and inefficiencies for service providers. In addition, the yearly planning process is unrealistic and should be changed to triennial plans which incorporate projections for future need.

From stakeholder consultation, the TCCN believes that inefficiencies in the HACC and HCS financial systems are resulting in delays in service provision for the cancer community.

TCCN supports

- Greater transparency and accountability of the HCS and HACC financial system, including the timely release of HACC State Plans.
- An injection of at least 20% to the HACC budget to address urgent issues of unmet need.
- HACC State Plans and NGO submissions be provided on a three-year basis, rather than annually, and to include projections regarding growth.
- Greater transparency regarding HCS spending, including providing explanations for the inability to meet forecast service targets.

(2) A follow-up inquiry of the Auditor-General's review of the NSW Home Care Service.

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

The NSW Auditor General's performance audit of the HCS in 2004, found that up to 75% of eligible applicants were unable to receive a service during the preceding year.[2] Contrary to predictions, the hours of service provided have not increased since this time. One of the major reasons cited for the excessive volume of unmet need was the low turnover of clients, with only 3.1% exiting the service over four years. Because HCS does not routinely review and refer existing clients to other programs that may provide more appropriate care, the Auditor-General suggested that the service may be masking demand for other care programs and preventing new clients from entering the system. The Auditor-General suggested the HCS develop an "exit policy" to ensure clients leave the service when appropriate.

To address unmet need, HCS services were "capped" to 28 hours per 4 weeks for all new clients (as compared to 59 hours per 4 weeks). The TCCN does not support capping of service hours as it believes that eligible clients should be allocated services as needed. In addition, clients with cancer and other diseases require intensive services for a short time, and are disadvantaged by this method of delivery. TCCN believes that the State and Commonwealth Governments should strive for excellence in service delivery; piecemeal allocation of services will not reduce client dissatisfaction or unmet need.

TCCN supports

- The audit recommendation that an exit policy with periodic re-assessment be developed to ensure fairer access to services and appropriate client turnover.

TCCN calls for

- Capping of services for new clients to be revoked and clients assessed on a needs basis.

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

Access to the Home Care Service for cancer patients and their carers is hampered by confusion regarding eligibility criteria, prioritisation of clients, and the absence of formal waiting lists.

Eligibility criteria for the Home Care Service

Consultation with stakeholders by TCCN indicated that there is confusion and inconsistency around the eligibility of palliative care patients and their carers for services from HCS. Stakeholders have brought up the following points:

- Unless a person with a serious illness or their carer is aged or has a disability, it is difficult to get services
- Staff undertaking HCS assessments may automatically assume that the condition of a palliative care patient is 'unstable' and their needs are outside the scope of HCS
- Even where the patient or carer are deemed eligible, waiting times of six to eight weeks mean that services will not be accessed by patients with advanced cancer and other terminal diseases.

While the receipt of palliative care services has been designated as a 'no growth' service area in the National HACC Program Guidelines[1], palliative care patients are still eligible to receive basic support and maintenance services including respite, if they are part of the HACC target group. The TCCN welcomes recent Commonwealth Government assurances to simplify entry and assessment processes for HACC-funded programs.[7] As part of these changes, TCCN would like the eligibility of *all* cancer patients who require services and their carers emphasised and these people formally recognised as a HACC target group. In the same way as the *HACC/HIV Liaison Project*, any person with a serious illness who is having difficulties performing the tasks of daily living should be eligible for HACC services. Information regarding eligibility of cancer patients needs to be disseminated amongst HACC providers.

Carers are also listed as a specific target group of the HACC program, which has acknowledged that carers need support, recognition and assistance in their role. A number of services specifically designed for carers, such as respite services, counselling and support services, receive funding through the HACC program. However, in 2003/04, of nearly 200,000 HACC clients in NSW, carers represented only 1.7% of HACC clients.[8] This indicates that carers also have problems accessing HACC services.

TCCN calls for

- Recognition that all home-based patients undergoing cancer treatment, including those designated as palliative care patients, are eligible for the HACC/HCS program.
- Recognition that carers are a target group of HACC-funded programs.
- Greater dissemination and standardisation regarding the HACC target groups and eligibility across service types.

Prioritisation of terminally ill clients and waiting lists

Appropriate and timely access to HCS and other HACC services must be enabled for people with advanced cancer and other terminal diseases who wish to remain at home. Long waiting times mean that the patient may die before the HCS service is provided.

The TCCN understands that the HCS only maintains waiting lists for high-priority clients; other clients must repeatedly contact the HCS Referral and Assessment Centre to be offered a service when it becomes available. This situation is untenable and unnecessarily stressful for cancer patients and their carers. The establishment of a high-priority list would ensure that those in the end-stage of disease will receive treatment before they die. This will also ensure that those with serious illnesses receive services when most needed.

TCCN calls for

- Palliative care patients with advanced cancer and other terminal illnesses to be classed as high-priority clients for HCS and other HACC services.
- The HCS to keep waiting lists for *all* potential clients of the service. In addition, available capacity should be made public as soon as possible, through a centralised system. Data collection regarding waiting lists will also ensure that unmet needs are accounted for more systematically.

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

HCS does not currently keep waiting lists or routinely monitor unmet need for services. As part of any consumer-focused service, routine surveying of clients, including keeping adequate documentation of those who are waiting for services or who have not received services, will ensure that service provision can be continuously reviewed and improved.

TCCN calls for

- On-going assessment of client satisfaction with HCS services, including recording of unmet need and waiting lists.

(3) Any other relevant matters

Health-related Community Transport

Community transport aims to provide transport disadvantaged groups with access to recreation, shopping, education, medical care and social services, where conventional public transport systems are not viable nor appropriate. The Ministry of Transport administers the Home and Community Care (HACC) Transport Sub-program.

From a cancer perspective, some community transport issues include:

- Up to 90% of the HACC community transport program is skewed towards health-related transport
- In areas with limited or no access to transport services, cancer patients are unable to access treatment
- There is a need for most community transport providers to charge a fare due to service users due to inadequate funding.

Although the NSW State Government is about to implement a non-emergency health related transport policy framework (*Transport for Health*), this policy is not expected to replace HACC community transport schemes and will receive only minimal funding. HACC-funded community transport currently receives $26 million annually, however anecdotal evidence suggests that demand far exceeds supply. Concerns surrounding the *Transport for Health* program will be that clients with illnesses or disabilities will be forced to chase community transport and will be sent from one program to another. Open communication and liaison between these programs will ensure that the NSW Government retains responsibility for providing access to community transport.

TCCN is concerned that people may forego medical treatment as they are unable to organise adequate and timely transport. In addition, people of a low socioeconomic status may also forego medical treatment as some forms of health transport can be prohibitively expensive, especially if repeat trips are required, for example for chemotherapy or radiotherapy appointments. TCCN, the Community Transport Organisation and NCOSS have commissioned a study to investigate the proportion of health-related transport that is carried out by community transport organisations, and to gauge the extent of unmet need in this area.

TCCN calls for

- The HACC Community Transport Sub-program to assess and report unmet need for health-related transport services, in both rural and metropolitan areas. This should include mapping of areas where transport services are unavailable.
- Liaison and communication between HACC and the NSW Health *Transport for Health* program so that the responsibility for providing community transport lies with the government agencies.

Conclusion

Due to the lack of alternatives and confusion surrounding eligibility, cancer patients and their carers often miss out on much-needed services from the Home Care Service and other HACC-funded programs, especially in the last few weeks of life. Recognition that cancer patients, especially those in the end-stages of disease, form part of the HACC target group should result in a greater proportion of those with a terminal illness being able to obtain medical treatment in comfort at home, increase their quality of life, and reduce the number of hospitalisations. In addition, this will allow those with end-stage disease to die at home if they so wish.

In many areas of New South Wales, especially rural areas, the Home Care Service is the only provider of community care services. With recognition that the HCS is under-funded, a move towards greater accountability and transparency of the HCS program, including recording the unmet needs of clients, will go some way to ensuring a more flexible and efficient service.

References

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[4] Council of Social Service of New South Wales (NCOSS). Closing the gap. Social and economic priorities for a fair and sustainable community: 2006-2007 State Budget. Sydney: NCOSS; 2006.

[5] Carers NSW. Carers NSW submission for State Budget 2006-2007. Sydney: Carers NSW; 2005.

[6] NCOSS. NCOSS State Budget 2006-2007 analysis. Available from: www.ncoss.org.au/hot/budget2006/analysis-version-2.pdf. Accessed on: 1.07.06.

[7] COAG. 2006. Council of Australian Governments' Meeting 10 February 2006: Communiqué. Canberra: Commonwealth of Australia. Available from: www.coag.gov.au/meetings/100206/ coag100206.pdf. (Accessed 10.4.2006.)

[8] Australian Government Department of Health and Ageing (DoHA). Home and Community Care Program Minimum Data Set 2003-2004 annual bulletin. Canberra: DoHA; 2004b.