AFAO Briefing Paper - May 1997

Benefits of Community Based Care: Quality and Cost Effectiveness

Background

Care and support programs for people with HIV-related illness have operated since the beginning of the epidemic. The programs offered by AIDS councils are largely volunteer based and are consumer driven. The models offered by different AIDS councils vary slightly but most include the following services:

- home nursing care (personal care, bathing, administering drugs, etc)
- domestic assistance (shopping, cooking, cleaning etc)
- emotional & psychosocial support (counselling, support groups etc)
- transport (to medical appointments, hospitals, etc)
- 24 hour acute care.

The models of care adopted by HIV/AIDS community care services are based on the notion of a social health continuum, and are open to all people with HIV/AIDS in need of care and support, regardless of mode of transmission, beliefs, background or sexual orientation.

The Social Health Continuum

The framework of a social health continuum recognises the varying needs and experiences of people with HIV/AIDS from the point of diagnosis through to death and beyond. Changes in health, sexual and other personal relationships, employment, travel, diet, treatments, income and social status prompt a range of needs requiring a range of services. Some of the services needed may include shopping, meal preparation, financial counselling, transport, treatment information, housing, legal services, psychological support, job retraining, medical care, specialist health services (podiatry, physiotherapy, dentistry, etc.), income support, grief and bereavement counselling, and many more.

The social health continuum approach relies on the capacity of the parts of the health and social services system to work together in cooperation, ensuring lack of duplication and guarding against consumers ‘falling through gaps’.

Care and support services at AIDS councils, along with other AIDS council services like legal information and advice, treatment information and advice, financial assistance schemes and peer support groups, provide many services along the social health continuum. These care and support services also work with other care providers beyond AIDS councils to ensure that continuity and coordination are guaranteed for all consumers. This results in better health outcomes for individuals and a more cost-effective provision of service.

Complexity of Care

Significant and rapid developments in treatment for HIV illness have resulted in changes to the way care is provided to people with HIV/AIDS. People with HIV/AIDS are now living
longer, often in situations characterised by long term illness of a more chronic nature. Dual diagnosis, or diagnosis with a number of illnesses, is becoming more common. While there may be a reduced demand for acute and palliative care, there is likely to be a higher demand for intermittent and maintenance type care, of a less intensive type but over a much longer period of time.

In addition, new treatments involve sometimes complex dosing regimes which rely on rigorous adherence to ensure the treatments are effective. Peer support groups and counselling can play an important role in helping people develop effective dosing strategies, ensuring the quality use of medicine and getting the best outcome for people with HIV from the new treatments. Where people are ill or manifesting some behavioural symptoms (such as mania or dementia), volunteer carers can play a crucial role in ensuring that people take treatments regularly and as prescribed.

New treatments are also increasing the demand on counselling services and peer support groups, and legal advice centres, as significant numbers of people contemplate re-entry to the workforce. This is a new demand and our ability to provide appropriate supports for people through this process will clearly have indirect economic benefits.

**Volunteers Providing Care**

The level and quality of care provided by AIDS councils for people with HIV/AIDS is sustained by large numbers of dedicated and skilled volunteers. As a model of community development in action, volunteers from communities most affected by HIV/AIDS have, since the beginning of the Australian epidemic, organised home based care as a primary response to the needs arising from HIV illness and death. These services have been an essential part in ensuring that people with HIV do not “fall through the gaps” in existing home-based care services, most of whom are not funded to provide care for any population other than the frail aged or people with disabilities. Currently, these more traditional home care services are operating under great financial strain and are having difficulty meeting the needs of their primary target groups. Their ability to meet the needs of people with HIV/AIDS and other chronic illnesses therefore remains very limited.

HIV/AIDS volunteer care services have developed significantly over time and, with minimal funding, have cared for thousands of people with HIV/AIDS in a cost effective and quality manner. Care in the home ranges from 1 hour to 24 hours per day. Volunteers also provide essential emotional support to people with HIV, relatives and carers, reducing stress and burnout and preventing re-hospitalisation. In order to maintain levels of quality in care, training for volunteers has always been a priority of these services. While this represents a significant proportion of the costs of running these services, it ensures the delivery of quality, appropriate care and support. Adequate continued funding is essential to ensure a cost-effective quality service, rather than just a cheap one.
Cost benefits

I) Costs

The benefits of training and supporting volunteers to care for people with HIV/AIDS are not only evident in the standards of quality and progressive models that are present. The cost savings are also significant. Preliminary data from a range of AIDS council home care and support services from 1995 produced the following costs:

<table>
<thead>
<tr>
<th>State</th>
<th>No. of Clients</th>
<th>Hours of Care Provided</th>
<th>Cost of Care per hour</th>
<th>Volunteer Cost per hour</th>
</tr>
</thead>
<tbody>
<tr>
<td>NSW*</td>
<td>977</td>
<td>70,348</td>
<td>$12.14</td>
<td>$1.54</td>
</tr>
<tr>
<td>Vic AIDS Council</td>
<td>451</td>
<td>59,000</td>
<td>$6.36</td>
<td>$1.05</td>
</tr>
<tr>
<td>Qu AIDS Council</td>
<td>369</td>
<td>40,500</td>
<td>$14.88</td>
<td>$0.65</td>
</tr>
<tr>
<td>WA AIDS Council</td>
<td>65</td>
<td>13,845</td>
<td>$14.29</td>
<td>$2.29</td>
</tr>
</tbody>
</table>

*NSW figures includes the following services: Central Care and Support Network, Ankali, Illawarra, Hunter Valley and Western Sydney.

Note that these costs include overheads such as travel, training and paid staff costs. The volunteer costs are included in the cost of care per hour.

Finding an appropriate model for comparison is very difficult, as other services are only just beginning the process of gathering data and costing services. Nonetheless, some sense of relative cost-effectiveness can be gained, as well as a much clearer picture of the amount of money saved as a result of community-based care allowing people to be cared for and to die at home rather than in hospitals or other institutional settings (such as hospices and nursing homes).

An obvious point to make is that if these services were not provided by volunteers, the cost would be significantly higher. Overhead costs such as training and travel would not decrease, while the “wage cost” of providing attendant care ranges from $14 per hour to $20 per hour. This would add at least 100% to the cost of providing this care. Comparisons with other home care services are difficult as unit costings for HACC funded services, the most appropriate comparison, are still being finalised and will not be available publicly until July at the earliest.

ii) Cost & Client Benefits

The Report on the Australian Community Home Nursing Casemix Development Project (that's ACHNCDP for short) states that “One key trend related to more efficient use of institutional health care resources is towards changing modes of health care. These changes enable people to remain at home, to be discharged earlier following an operation or illness...or to be treated at home rather than in an institution. Home nursing is one element of a range of co-ordinated services required to enable a person to return home. as soon as possible. Home nursing services also contribute to the prevention and reduction of premature readmission of the chronically ill to hospital”. While community based organisations’ (CBO) care and support services are not a substitute for home nursing, they are a central element of the “range of co-ordinated services” required to keep a person at home and out of institutional care. The report also notes that non-nursing care is an important component of palliative, post-acute and maintenance care., and that “nurse clinicians generally agree that carer availability is an important determinant of the amount of home nursing resources used by clients".
In other words, the provision of volunteer carers can help reduce hospital admissions through making home nursing more viable, and reduce the costs of home nursing as well.

Case Studies

a) Palliative Care.

In the ACHNCDP report, the total episode cost for a three month period of palliative care ranged from $776.38 to $1699.87\(^1\). Hospice care in NSW has been costed at a minimum of $400 per day\(^2\), or $36 000 for a three month period. This, however, involves 24 hour supervision. The community home nursing figure would represent a fairly low level intervention and assumes the availability of carers. If we factor in the cost of volunteer carers to supplement or substitute for family/partners, we get something like this;

1. **Worst Case scenario.** 24 hour care, using NSW figures.

   **Per patient:**
   
   - 24 hr volunteer care  24 x $12.14 = $291.36
   - plus 2x nursing visits @ $20 per visit = $40.00\(^3\)
   - **Total** $331.36 per day
   - **Saving** $68.64 per day

2. **Realistic scenario.** A maximum of 8 hours volunteer care per day, with family/partners staying overnight.

   **Per patient:**
   
   - 8hr volunteer care  8 x $12.14 = $97.12
   - plus 2x nursing visits @ $20 per visit = $40.00
   - **Total** $137.12
   - **Saving** $262.98 per day

Scenario 2 is the more likely case - if a person requires 24 hour care CBO care services will only be able to meet this need for a short time before this is reduced or the client referred to a hospice. The majority of palliative care clients require only 4-8 hours care per day.

*In 1995, there were 314 deaths from AIDS in NSW*.\(^4\) *Even if only half of the people who died accessed community based palliative care services for a period of four weeks, the savings would have been in the order of $1.16 million for that year in NSW alone.*

b) Post Acute Care

This refers to care following hospitalisation for an acute episode requiring surgery and/or treatment. It has been shown that the availability of community home nursing allows for early

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1 Note that these are national figures. However, variance from state to state was not significant. The mean was $776, with a standard deviation of $923. The highest figure of $1699 has been applied.

2 BGF Supported Accommodation Funding Proposal. Figures sourced from Sacred Heart Hospice.

3 Figure derived from ACHNCDP Report. Mean visit cost of $16.41, standard deviation of $9.04

4 Australian HIV Surveillance Report April 1996
discharge from hospital following these episodes\(^5\). The maximum cost of a home nursing visit in these instances was around $21.73. Client needs on discharge will vary, but a high-cost example would be a person requiring twelve hours of volunteer care and two nurse visits on their first day out. This would result in a cost of $187.68 in NSW, $118.32 in Victoria, or $220.56 in Queensland. Compare this to a hospital “hotel” cost (ie beds, nursing and overhead, not including treatment and medical costs) of $585 per day in NSW\(^6\) and **a saving of nearly $300 per bed day is achieved**. Figures from Queensland suggest an even higher hospital bed cost. This is a conservative estimate as volunteer carers are generally able to meet client needs in less than 12 hours per day.

**Case Study**

In NSW in 1994/1995 there were 6724 hospital separations (ie people leaving hospital) following acute episodes relating to HIV. This represents an average number of admissions of 6 per person with AIDS per year. The average length of stay (ALOS) ranged from 7 to 16 days\(^7\). **If a funded volunteer carer service was able to reduce only half of these stays by just one day, then the cost saving would have been $2.02 million in NSW alone.**

It is difficult to extrapolate these figures with great confidence, but if we assume a hospital bed saving of $300 per admission per AIDS patient for all of the 1844\(^8\) people living with AIDS in Australia during 1995 community based care services would have saved around $3.3 million nationally in hospital costs.

c) **Support and Maintenance**

This is care which aims to support people with chronic conditions living at home. Community home nursing costs are similar to those for PostAcute care, while volunteer care costs would be significantly lower. This type of care is likely to be in increasing demand as the number of people surviving with AIDS increases as a result of new treatments.

If a 3 month period of care involving a volunteer carer for 2 hrs a day, four days a week (total cost $1250) and a nursing visit once every three days (total cost $600) saves just one episode of hospitalisation requiring a four day stay then around $500 is saved, before we even take into account the cost of home nursing which would have occurred on discharge from hospital.\(^9\)

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\(^5\) Moody H, *Continuity of Care Pilot Program A Joint Final Report* Geelong Hospital and Bellarine and Surfcoast Community Health Services 1994, quoted in ACHNCDP Report. Note that this study only involved 64 patients over 7 months.

\(^6\) BGF Supported Accommodation proposal, source St Vincent’s’ Hospital.

\(^7\) Source NSW Health Department.

\(^8\) Australian HIV Surveillance Report April 1996. Figure calculated by subtracting cumulative deaths from cumulative cases. This therefore doesn’t include people who died from AIDS during that year (592 deaths).
Based on these fairly conservative calculations, it’s clear that CBO care and support services have contributed significantly to reducing the costs of caring for people with HIV and AIDS. As a result of the contribution of volunteer care services, the savings realised in palliative and post-acute care in NSW in 1995 alone could range from $2 million to over $4 million. Nationally, CBO care and support agencies are saving millions of dollars a year in hospital and other institutional costs.

One other important benefit of volunteer carers is to reduce the burden on family and partners. Sometimes the availability of volunteer carers allows the client’s partner to remain in employment, with subsequent economic benefits to people with HIV and the community at large. The ability to remain at home and the reduced strain on personal relationships are other important benefits for people with HIV and AIDS.

Community home nursing can help keep people out of nursing homes and other medium to long term institutions. Respite care and supported accommodation will still be needed, and are usually more cost-effective and appropriate to clients’ needs than hospital care. Nonetheless, community based volunteer care services can reduce demands on these services and on hospital care.

Community based care services should not be seen as cheap nursing or alternatives to institutional care, but rather an alternative model of care which can minimise the unnecessary usage of more expensive services. They are an essential component of the continuum of care, providing information, support, referral and much-needed direct care. Most importantly, as services provided by and for the most affected communities, they offer a comprehensive and appropriate service which supports choice, dignity and independence for people with HIV and AIDS.
Appendix 1: cover letter to ED, Care & Support Manager

10 May 1997

TO: Executive Director
Care & Support Manager

RE: Briefing Paper
Benefits of Community Based Care;
Quality & Cost Effectiveness

Attached please find a copy of AFAO Briefing Paper #34, entitled “Benefits of Community Based Care: Quality and Cost Effectiveness”. This paper is intended to assist AFAO members in advocating for continued adequate funding of community based care services, a strategy identified in the AFAO Strategic Plan.

This briefing is part of a larger body of work to be developed over the year as part of the “Continuum of Care” policy project. Further work is planned in the areas of documenting current models of care, developing a more comprehensive economic evaluation of our work, and identifying an agreed national minimum data set for community-based care and support services.

AFAO will also be co-ordinating the First National Carers’ Conference in Sydney on September 20/21, which will bring together workers and volunteers from care and support services to discuss these and a range of other current issues in care and support for people with HIV/AIDS.

Please feel free to circulate this briefing as widely as possible. Any comments or feedback on the briefing would be greatly appreciated.

Yours sincerely,

Alan Brotherton
Policy Analyst (Care & Support)