MODELS OF COMMUNITY-BASED HIV/AIDS CARE AND SUPPORT IN SOUTH AFRICA

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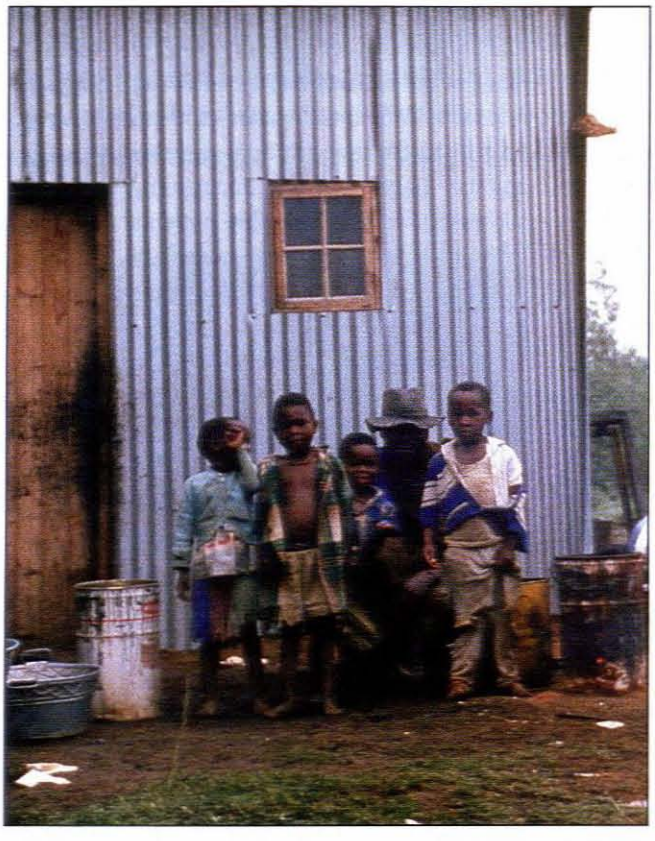

Over the past few years, the previously largely silent HIV epidemic in South Africa has shifted to a visible AIDS epidemic. The impact on health services, families and communities is emerging rapidly. In 1997, 20% of all patients admitted to the paediatric wards at Chris Hani Baragwanath Hospital were HIV-infected,[1] and in 1998, more than half (54%) of the admissions to the medical wards at King Edward VIII Hospital in Durban were HIV-related.[2] By the year 2005, conservative predictions are that there will be nearly 1 million children orphaned by AIDS in the country,[3] clearly overwhelming the current capacity of the welfare system.

In an attempt to deal with impacts, it is common practice for healthcare facilities to ration services to people with HIV. Much of the burden of HIV care in developing countries is now falling onto households and communities, and in South Africa home-based care has become a national policy priority.

Any discussion of AIDS care and support therefore inevitably turns to a consideration of how to achieve greater community participation, both in minimising impacts on the formal health sector and in meeting the needs of people infected and affected by HIV. Community mobilisation is often described as the key to the sustainability and success of care and support strategies.[4]

However, decades of experience in implementing primary health care have shown that meaningful community involvement in health services is not easy to develop and sustain, and is especially hard to institutionalise on a wide scale. Communities are often assumed to be homogeneous and unproblematic entities, while little thought is given to the tasks involved in mobilising them. This is especially so in South Africa, where households and communities have been systematically disrupted by Apartheid. Moreover, evaluations in various southern African countries have dispelled the idea that home-based care is necessarily a quick fix and a cheap alternative to hospital-based care.[5]

Despite these considerable challenges, a number of non-governmental organisation (NGO), community and religious-based projects, attempting to grapple with HIV/AIDS care and support needs at community level, have emerged across South Africa. A review of these projects was conducted during the latter half of 1999, the aim of which was to identify the models of community-based HIV/AIDS activities being implemented, the challenges facing them and the possible role of government in promoting such activities.
This article gives findings from the review.

The review methods included a literature review, 68 key informant interviews, and visits to 20 projects across the country. Key informants and projects were identified through a snowball sampling strategy, starting with a list of 15 contacts known to the researchers.

We defined AIDS community-based care and support as being all AIDS activities that are based outside conventional health facilities (hospital, clinic, health centre), but which may have linkages with the formal health and welfare sector; and all AIDS activities that address any aspect of the 'continuum of care and support', from time of infection through to death and impact on survivors.

Models of care and support in South Africa

Although it was not possible to quantify the presence of community-based services across the country, it was very evident from discussions and visits that coverage by community care and support for people with AIDS (PWAs) is very patchy, and most often lacking. However, in almost all parts of the country evidence could be found of attempts to initiate activities and programmes. Many initiatives did not refer to themselves as 'AIDS' organisations, but rather as 'palliative care' projects, and many were still in their infancy, operating with little external support and with uncertain prospects of sustainability. Some have benefited from contact with, and the materials of, projects in other parts of southern Africa, such as the Family AIDS Caring Trust (FACT) in Mutare, Zimbabwe,[6] and the AIDS Support Organisation (TASO) in Uganda.[7]

Five 'general' and four orphan care and support models were identified and are summarised in Table I.

GENERAL MODELS	TYPE OF ACTIVITY
1. Funding, technical assistance and support programmes	Umbrella structures channelling funds, providing technical assistance and monitoring and evaluating functions
2. Advocacy and community mobilisation	Community structures to protect the rights of individuals and facilitate access to health and welfare services and schooling
3. Drop-in centres/support groups	Physical facility that provides a space to run support group and income - generating activities
4. Home visiting programmes	Home visiting, assistance with chores and psychological support
5. Comprehensive home-based care	Package involving palliative care and well-developed referral network to health facilities and welfare agencies
MODELS FOR PLACEMENT OF ORPHANS	
Extended family Child-headed households 'Create a Family' or 'Cluster Foster Care' Placing responsible adults in the homes of orphaned children	

FUNDING, TECHNICAL ASSISTANCE AND SUPPORT PROGRAMMES

Two examples of funding, technical assistance and support programmes encountered in the review were the AIDS Foundation in KwaZulu-Natal and the Mpumalanga Project Support Association (MPSA). These organisations are NGOs providing a support function to community-based organisations (CBOs) with regard to mobilising and channelling funds, providing technical assistance and training for home-based care, project management, report writing, and project monitoring and evaluation. Such structures could be one vehicle for public-NGO partnerships to promote the development of community-based action, and could also play a co-ordination and standard-setting role.

ADVOCACY AND COMMUNITY MOBILISATION PROJECTS

An example of this is the Thandanani Project in Pietermaritzburg. Thandanani has created Community Child Care Committees (CCCCs) comprised of community leaders and residents, whose task is to identify children who are abandoned, abused or at risk of being orphaned. The CCCC will not only protect the rights of the child but will also help in accessing child welfare grants, medical and home-based care and schooling. The CCCCs do not themselves provide services, but have created linkages and referral relationships with social, medical, nutritional, child welfare and other support service providers.

Community mobilisation programmes are often perceived as being easy to develop. However, they are a time-consuming endeavour requiring specific skills in the areas of motivating and sustaining community involvement, developing partnerships and linkages, and creating opportunities where all participants feel equally respected and able to make a valued contribution.

DROP-IN CENTRES/SUPPORT GROUPS

This model is perhaps the most common form of community-based care and support. It consists of a simple facility where people can receive HIV counselling and education, and can participate in support group activities. Most providers felt that the traditional support group model centred on verbal problem exploration and psychosocial counselling was not sufficient, and combined it with an income-generating activity (IGA). This has a twofold benefit - participants are engaged in an activity that facilitates conversation, and the activity has the potential to generate some income. The IGA activities included beaded ribbons, paper bowls, hats from plastic bags, tablecloths, gardening, chicken farming and making foodstuffs. In practice very few projects actually manage to generate income, and as one person put it, 'I have a room full of things people have made but we can't sell them. They're just packed in there.' One project had acquired maize-grinding and fence-making machines, an oven for baking bread, juice-making equipment and battery-recharging facilities. With the income generated they were able to fund the activities of the drop-in centre.

Support groups were reported to build self-confidence, help people cope with their diagnosis, overcome depression and create social networks for people who are isolated. Bonds formed outside of the group often result in sick members being assisted with small chores. Through support group activities, HIV-infected adults can also be engaged in discussions about the future placement of their

children, and can acquire the documentation necessary to access welfare grants.

HOME VISITING

Drop-in centre activities may include a home or 'friendly' visiting service. Volunteers visit patients in their homes and spend time talking and educating patients and their family about basic care needs. They also provide support with cooking, cleaning and helping with errands, including accompanying patients to health facilities. They may also arrange access to food parcels and other material support.

COMPREHENSIVE HOME-BASED CARE

In addition to the above, comprehensive home-based care programmes provide varying degrees of palliative care. These programmes tend to be run by more established NGOs (such as Hospice, the Red Cross Society and church-linked groups). A number of such relatively large projects, catering for hundreds as opposed to tens of clients, were identified in the review.

Training of caregivers includes supportive counselling, cleaning and dressing of wounds, oral hygiene, supervision of drug taking and in certain instances necrotic wound care, pain management and diagnosis of opportunistic infections. The package of services also often includes DOTS (directly observed treatment, short-course) for tuberculosis. At least two projects had been trained in and adopted the Zimbabwean 'FACT' model. This has a strong spiritual component, and many of the volunteers are recruited from the church.

All projects had invested considerable energy in creating partnerships and referral networks. Relationships are formed with the local welfare department, schools, businesses, hospitals, respite care facilities and clinics. Building these partnerships is time-consuming. However, once created, the package of services that can be offered to clients is comprehensive.

Care of orphans

Many community-based HIV/AIDS care and support programmes visited had been confronted with the needs of orphaned children, and felt they had no option but to address these needs.

The models of care and support for orphaned children included:

1. **The extended family approach:** a family member is identified to care for orphans after death of the parents. Often this family member is a grandmother.
2. **Child-headed households:** When parents die and there is a sibling 15 years or older, social services may work with that child to keep the family together. The younger siblings remain in their home, with the older sibling acting as a parent. They may receive support from volunteers who will visit the household to ensure that they are coping and to resolve problems.
3. **'Create a Family' or 'Cluster Foster Care.'** This intervention, based in Durban, involves identifying a surrogate mother, who is hired to care for six orphans in the community. She is provided with a home, in which they all live, and she raises the children as though they were her own. With the assistance of the Durban Child Welfare Society, foster care grants are accessed to pay for school fees and uniforms, and the foster parent receives a stipend. This model serves as a job creation opportunity for women.
4. **Placing adults (usually older women) in the homes of orphaned children:** This approach has worked successfully in the Masoyi Project (Mpumalanga). This approach benefits both the children and the adult, as often the latter lives in the poorest of housing (mud shacks) while the children tend to live in better quality brick houses.

The key tasks in child care and support programmes are accessing welfare benefits (child care and foster grants), including the documents required for grants, maintaining children in school, and ensuring that basic necessities, such as food and clothes, are provided.

Challenges to community-based care and support

MANAGING A VOLUNTEER BASE

With a few notable exceptions, most organisations had only one or two paid staff members, with the bulk of services provided by volunteers, who may or may not receive a stipend. Recruiting and maintaining commitment from volunteers is one of the main challenges facing projects and many programme managers admitted to struggling with this aspect. Interviewees reported high turnovers of volunteers who, once trained, moved on to other opportunities, dropped out, or were unreliable. Conversely, if a significant stipend was provided, a major concern was its sustainability over the long term.

Non-financial incentives, such as a sense of belonging a supportive work environment opportunities to gain skills and passing a rigorous screening process all appear to be crucial to maintaining volunteer commitment. As one project interviewee put it: 'The volunteers in these projects undergo a 4 to 6 month training, and not everyone makes it...'

ORGANISATIONAL STRUCTURE, STAFF CAPACITY AND ACCESS TO RESOURCES

Project readiness and ability to provide services differed widely among the projects visited. Programmes started by and within poor communities seemed to have the most difficulty developing strong and sustainable programmes. Although many of these community-based organisations had great intentions, they did not have sufficient internal capacity to implement those ideas. They also lacked

resources. In many cases, the project managers accessed some initial funding (such as pension payouts) to get started, but experienced difficulty as this money ran out. They did not have sufficient knowledge on how to maintain documentation and how to account for, or manage, funds. One retired nurse commented: 'I'm a nurse - not an administrator. I don't know about budgeting and administration. I know how to take care of people.' Another nurse voiced her frustration: 'We work from hand to mouth.'

The larger NGOs with a sizeable infrastructure, history of programme development, and connections with players locally and internationally, appeared to be in a much better position. They were able to provide services over a larger area, at a higher level, and possibly with greater efficiency (through economies of scale) than some of the smaller projects visited.

ABILITY TO FORM LINKAGES AND PARTNERSHIPS

Programmes that were able to develop partnerships or referral relationships with other service and care agencies were more successful than those that did not. Relationships with welfare agencies, hospitals and clinics were cited as being particularly important. Several projects had agreements with clinic and hospital providers, facilitating admissions to hospital or access to prescriptions and medications. In some cases, programmes also negotiated supplies of antiseptic solution, gloves, bandages and other home-based care necessities from hospital and clinic partners, in exchange for providing care to discharged patients in the community. Some projects were also able to engage local businesses to provide food parcels, soup kitchens, transport or office supplies.

LACK OF STANDARDISATION

There was little standardisation across projects with regard to training and the quality of services provided. Some programmes sent their volunteers and staff to formally established training programmes, while others conducted their own in-house training. Hence, the content and quality of care varied enormously.

Conclusions

While a rich base of experience in community-based care and support is being developed in South Africa, access to these services is still far from universal. Large-scale technical assistance and capacity-building programmes, networking and co-ordinating opportunities, development and dissemination of standards/guidelines, and the establishment of monitoring and evaluation systems are all essential to the creation of an effective and sustainable community-based care and support movement. There are still many unanswered questions as to the feasibility of extending community-based care and support activities to all parts of the country, both in terms of being able to mobilise activities on a wide scale and the costs of programmes.

It is clear that government has an important role to play in supporting and facilitating wider access to community-based care and support, and in ensuring a basic health and welfare safety net. Perhaps the biggest challenge will be the ability to form meaningful partnerships between government at all levels and the non-governmental sector. This may necessitate a paradigm shift in the minds of many health and welfare professionals, 'from the assumption that counselling, treatment and care of patients can only be done by highly technical personnel, to an appreciation that in every family and community there is some level of counselling and caring. Scientists must cease perceiving themselves as custodians but... rather as facilitators.'[10]

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