HIV/AIDS

At a glance

At the February 2000 Technical Seminar Series, Ian Campbell, Bram Bailey, and Alison Rader of the Salvation Army facilitated a workshop on Community Approaches to HIV/AIDS. While health care professionals play key roles in the fight against HIV/AIDS, NGOs need to find ways to build the capacity of communities to respond to the epidemic. This workshop focused on strategies to help communities address HIV/AIDS in a healthy way, which means avoiding stigma and sharing confidentiality rather than creating secrecy.

The "Outsider" Problem

At the heart of the community approach is a formidable obstacle: the health care worker usually comes from *outside* the community and therefore lacks the credibility and/or legitimacy so essential to bring about changes in attitude and behavior. Ian Campbell explained that AIDS workers need to find "a way into" the community, a point of entry or access that will make it possible for them sooner or later to become identified as one of "us" rather than one of "them." Fortunately, for those who work in HIV/AIDS, such an entry point is readily at hand: the home care they regularly provide to patients and their families. Their regular presence in the home and their eventual identification with the family and, by extension, with the neighborhood help create that connection to the community essential for any kind of effective advocacy.

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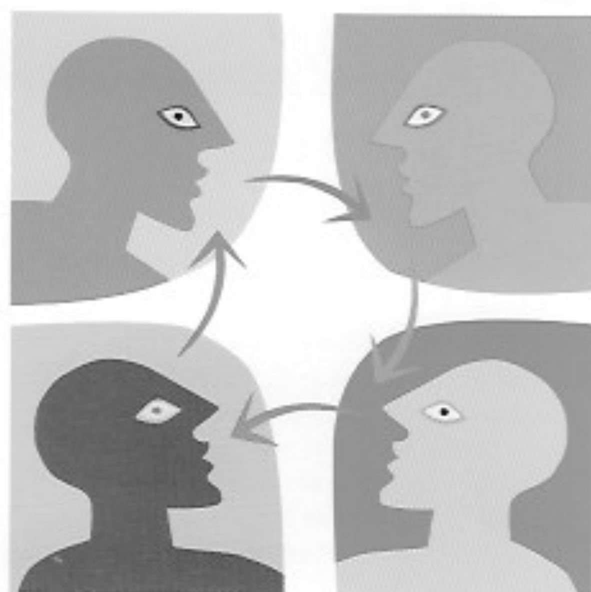
The Care-to-Prevention Link

There is another kind of care, Ian Campbell noted, that is also essential to effective community engagement, and that is the care the provider feels for the community. By demonstrating care or concern for the people in the community and for their welfare, the health care worker gains the trust of community members. And trust is essential for convincing the community to take up the cause of preventing HIV/AIDS. When families and neighborhoods are mobilized in this way, then they themselves are able to function as agents of change. This is known as the care-to-prevention link.

The Confidentiality Trap

Once we change our focus from caring for the individual in the home to engaging people in the community, we come up against another major obstacle: the issue of confidentiality. Respecting confidentiality is a cornerstone of the health professions, but at the same time being open and forthcoming is important for winning the trust of the community. When health care workers refuse or hesitate to answer questions about what they're doing in the neighborhood, for example, or about the patients they visit, they run the risk of coming across as guarded, closed, and untrusting. At the same time, by not opening up and talking



> By not opening up and talking about HIV/AIDS, health care workers may add to the already deep-seated reluctance and fear of many segments of the community even to acknowledge the problem.

about HIV/AIDS, they may add to the already deep-seated reluctance and fear of many segments of the community even to acknowledge the problem—to say nothing of talking about how to address it. One of the tools of building community capacity, after all, is opening up a discussion and dialogue about AIDS, beginning the process of informing and educating that is the essential first step in mobilizing a community, but if the health care worker seems uncomfortable talking openly about the subject, how can he/she expect the community to?

Ian pointed out that in one way or another the community eventually finds out what is going on whether the health care professional tells them or not. In that case, by adhering to strict standards of confidentiality, we may actually end up stigmatizing the patient and the problem. "At this point," Ian believes, "we need to be self reflective and question our assumptions. Perhaps we need to change how we, as professionals, look at the concept of confidentiality." We are trained to respond the way we do because western medicine and thought assume individuals take responsibility for their own actions. However, this is not usually the situation in traditional cultures where the individual—especially a woman—has to defer to the opinions of others in their family circles, clans, and wider community. In this context, the western notion of individual confidentiality may not be appropriate and

DISCUSSION QUESTIONS

How do we design approaches that avoid stigma?

How do we elicit the local standards of confidentiality?

How do we establish safe boundaries between the rights of the individual and the need to share concerns?

How do we discover where the community is with regard to the issue so that we can open up a dialogue?

What is adequate information (in order to prevent HIV/AIDS)?

How do we validate that people are informed?

What is the critical mass at which consent is said to have been made?

How can we ensure the community can withdraw if they wish to?

Who can provide consent?

Who is enfranchised?

we may have to rethink our paradigm. "In the end," Ian noted, "the circle of confidentiality is determined by the community, not us.

Ian suggested that we consider several questions (see discussion questions) and asked, "When people in the community ask us why we are visiting a family, shouldn't we explore the reasons for the question by asking them: "What is your concern about our visit?"

Community Consent

Like a patient who is provided with information and then gives his/her "informed consent" for a particular medical intervention, communities need to be informed and give their consent before they undertake any kind of joint effort. NGOs need to inform community members of the enormity of the AIDS epidemic, involving all sectors and all generations in a community, being careful not to stigmatize the issue.

Community to Community Transfer

In the best of all possible worlds, community action in one community will inspire/lead to community action in others. This process of community to community transfer typically happens through the members of various existing social networks, as well as via members of local elites, community health workers, women's groups and teachers' groups. Informal exchanges may also occur at community meeting points, such as churches, wells, markets, and funerals.

For further information about this topic, please see the NGO Networks for Health website (publications and presentations) at: **www.ngonetworks.org**

COPE: A Case Study

COPE (Community-based Options for Protection and Empowerment) is a program developed by Save the Children/Malawi to combat the impact of the HIV epidemic on communities in Malawi. COPE's approach is to mobilize community care coalitions to assist vulnerable children and adults in communities affected by AIDS. The coalitions manage a variety of initiatives including: 1) identification, monitoring, assistance, and protection of orphans and other vulnerable children; 2) home-based care training for caregivers of ill and aged community members; 3) community fundraising for an emergency assistance program; 4) community gardening as an income-generating activity; 5) distribution of agricultural inputs to orphan guardians; and 6) organization of youth clubs to promote HIV prevention and care.

Some of the many lessons learned from the COPE program are:

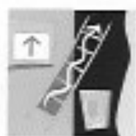
- Start with strengths of the community and build on these. Do a needs assessment to find out what the strengths and community resources are.
- Facilitate discussions in the community to find out what the community is most concerned about. In this way, the community chooses its own issues and comes up with its own solutions, using internal resources. Community members take on the responsibility of what can/will happen in the community.
- Try to ensure that activities are not only community based, but also community managed.
- Remember that NGO workers should act as catalysts not convenors.
- Work with the government at various levels, even though this may be frustrating.
- Remember that extension workers and religious groups are also part of the community and work with them/make sure they are involved.

Community Capacity Building

Dr. Campbell stated that successful community capacity building rests on four key principles:

1. *Care*—The health care worker has to genuinely care about people in the community, which is best demonstrated by being present in and a part of the community (such as identifying with the suffering in the home of AIDS patients).

2. *Community*—The health care worker needs to feel that he/she legitimately belongs to the community, even if it is not where the worker lives. This sense of belonging comes through developing personal relationships and is based on respect and trust.



3. *Change*—The health care worker must believe that change is possible and that it comes about through personal relationships within the community.

4. *Hope*—The health care worker must be hopeful about the future—which makes it possible for him/her and others to deal with a present that often seems hopeless.

For further reading

Campbell ID, Rader AR (1992) *A community development approach to AIDS care, prevention and control* Chapter 20 in Lankester (1992) Setting up Community Health Programmes Macmillan, London

Campbell ID, Rader AR (1999) *Community-informed consent for HIV testing and a continuum of confidentiality* Tropical Doctor **29**(4)194

Campbell, Ian D. "Loss, Hope, and Faith Through a Community Capacity Development Approach to HIV/AIDS: The Foundation to an Expanded Response", December 1999.

Campbell, Ian D., Rader, A.R., and Moodie, A.D., A Draft Paper on "Collaborative Processes Between Organizations: Sharing What We Do or Sharing Who We Are? (A Foundation to an Authentic Expanded Response to AIDS and HIV).

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Jones M (1999) *HIV Testing in developing world communities* Tropical Doctor **29**(4)193

Report (1999) *Coping with crisis : Mobilizing community response to the impact of AIDS in Malawi* Save the Children Federation (USA), Malawi Field Office

NGO Networks for Health (*Networks*) is an innovative five year global health partnership created to meet the burgeoning demand for quality family planning, reproductive health, child survival, and HIV/AIDS information and services around the world. Funded by the United States Agency for International Development (USAID), the project began operations in June 1998. For more information, contact:

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Networks Technical Support Group encourages and supports health policy makers, program managers, and service providers to:

- become aware of the need to consider related social issues in all aspects of their work.
- understand that individual's perceptions can affect policy making, program planning, and clinical practice.
- become comfortable in discussing a wide range of issues with colleagues, clients, and other persons at community levels as appropriate in their work.