# Community mobilization and the UNAIDS Investment Framework

# Trends, gaps and opportunities in mobilizing the community response to HIV

#### A new framework for the global HIV response

In June 2011 a policy paper published in *The Lancet* lays out a new framework for investment for the global HIV response. It was developed by an international panel of experts and is intended to facilitate more focused and strategic use of scarce resources.<sup>1</sup>

The investment framework takes as its starting point a human rights approach to the HIV response, and makes a distinction between basic programme activities that have a direct effect on HIV risk, transmission, morbidity and mortality; the critical enablers that are crucial to the success of HIV programmes; and synergies with development sectors.

Critical enablers fall into two categories: social enablers that create environments conducive to rational HIV responses, and programme enablers that create demand for programmes and improve their performance. Examples of social enablers are outreach for HIV testing, stigma reduction, human rights advocacy, and also community mobilization, which has been recognized as a cornerstone of HIV programmes.

#### The crucial role of community mobilization

In the UNAIDS Investment Framework, community mobilization is defined as "...when a particular group of people becomes aware of a shared concern or common need, and together decides to take action in order to create shared benefits." Community mobilization is a key element of the investment framework because it leads to improved uptake of HIV programmes and promotes local-level advocacy, transparency and accountability.¹

Community-based organizations are uniquely placed to address scale-up of HIV treatment and prevention and are already providing many services. Indeed, community-level initiatives are widespread in every area of the global HIV response.

Recently a number of literature reviews have examined elements of community mobilization in the context of the UNAIDS Investment framework.<sup>2-10</sup> The common themes and key findings of those reviews are summarized here.

**1. Community mobilization is crucial.** Community mobilization as a critical enabler can be sub-divided into three parts: outreach and engagement, support,

and advocacy.<sup>2,3</sup> For it to be successful as a critical enabler, community mobilization requires an effective and strong community system that encourages a broad spectrum of community members to participate.<sup>2,3</sup>

- **2. Communities know their needs best.** Community-based HIV testing, prevention, treatment, care and support can be highly effective but there is no one-size-fits-all model and they must be adequately supported and resourced.<sup>2,4</sup>
- **3. People living with HIV play a special role.** PLHIV need to be at the forefront of community-based efforts, both as in civil society organizations' traditional role of advocacy, and increasingly as service providers.<sup>2,4</sup>
- **4. Community-based groups are for advocacy** *and* **service provision.** The monitoring and advocacy role of communities affected by HIV is just as important as service provision. However, there is also an inherent tension between the two- it can be difficult to openly criticize organizations and institutions that are also a source of funding for services.<sup>4,5</sup>
- **5. Peer groups are powerful.** Not only are peer groups one of the most popular means of community mobilization, they are also one of the most effective.<sup>2,3</sup> For key populations at risk of HIV, only community-based interventions can effectively reach their target audiences, be they men who have sex with men, sex workers or people who inject drugs.<sup>4</sup>
- **6. Task-shifting in needed.** Community-based organizations and community health workers can play a key role in task-shifting of, for example, HIV testing and counseling to improve efficiency in the health care system and remove service bottlenecks.<sup>4,5</sup>
- **7. Voluntary does not mean free.** There is extensive use of volunteers and unpaid community health workers for HIV-related interventions.<sup>3</sup> However, even volunteers incur costs, both for management and to the individual. Using unpaid community-based workers is fraught with challenges (including ethical challenges) and even using volunteer workers still requires an investment in training, and organizational support.<sup>5,6</sup> Women predominate in the voluntary sector, with voluntary duties often undertaken when aged 30 to 49, the life stage most burdened by other responsibilities. Increasing task-shifting to volunteers has implications for gender inequalities.<sup>7</sup>
- **8. There are many gaps and overlaps.** Community-based services are typically poorly coordinated between themselves and with other organizations. Coalitions of community groups can conduct mapping exercises to identify areas that are over-served and those that are neglected.<sup>4</sup>
- **9. There are common obstacles.** There is a lack of resources to ensure service community-based services are delivered on sufficient scale, particularly core funding that is not restricted to specific programmes.<sup>4</sup> Community-based interventions can be undermined or even completely prevented by legal and

social barriers to human rights, and stigmatizing behavior, even among health care workers.<sup>8</sup> Gender inequalities are a pervasive obstacle.<sup>4-6</sup>

- **10. More data and evidence is needed.** Although there is much anecdotal evidence on the effectiveness of community engagement in the HIV response, more empirical evidence is needed, as is better and more regularly up-dated data on HIV prevalence and the impact of interventions.<sup>4</sup>
- **11. Community mobilization can turn synergies into partnerships.** Making use of synergies with other development sectors is a key component of the Investment Framework.¹ Community-based organizations play a crucial role in exploiting those synergies, in particular within the health sector.² Community mobilization can be crucial to building partnerships and links with service providers in, for example, sexual, reproductive, maternal, newborn and child health.
- **12. The benefits of community mobilization go beyond HIV.** The crucial role of community mobilization in the HIV response is very clearly stated in the Investment Framework. However, it also has benefits beyond HIV, such as empowering citizens and improving economic productivity due to better health.<sup>2</sup>

## Community mobilization and the six programme activities of the UNAIDS Investment Framework

#### Programme Activity 1: Focused programmes for key populations at higher risk

Key populations, including sex workers and their clients, men who have sex with men, and people who inject drugs, are engaged in a wide range of community mobilization activities at all levels, from interpersonal and group levels to community structural and environmental-level interventions. These include training, peer leadership, outreach behavior change activities. At a community level interventions are typically delivered at drop-in centres and include community-based HIV testing, counseling and treatment. Community-level activities engaging key populations are not necessarily small-scale, and include, e.g., national policies on condom availability, or working with authority figures such as the police and government officials.

Although community initiatives occur at all levels of service delivery for key populations, they are rarely offered on a large enough scale, and there are many examples of underserved groups, such as females who inject drugs and transgender people.<sup>2,5</sup> They are also subject to social factors, e.g., legal barriers to key populations seeking help, and stigma and discrimination. There is a widespread lack of capacity and what is offered is often fragmented poorly coordinated.<sup>5</sup> Moreover, there needs to be better linkage between community-based programmes and public health and social welfare systems.<sup>4</sup>

#### Programme Activity 2: Elimination of new HIV infections in children

Community-based interventions for prevention of mother-to-child transmission (PMTCT) range from outreach by paid or unpaid community health workers and peer support groups to community-based testing and integration of PMTCT with other medical services such as antenatal care or sexually transmitted infection clinics.<sup>2,5</sup> Community-driven communication about PMTCT can help overcome common concerns such as early attendance for ante-natal care, male involvement and follow-up of infants exposed to HIV.<sup>2,8</sup>

Engaging community health workers, traditional birth attendants and women living with HIV, is seen as an important means to scale up PMTCT services, but there a numerous social and structural factors that leave gaps in community based services. They include low knowledge in the population of mother-to-child transmission, lack of support from family members and stigmatizing attitudes among health care workers. Services are often inaccessible too, due to cost or time factors, and a lack of health care workers.<sup>4</sup> Although PMTCT is an achievable goal, it can only be attained by sustained engagement with women living with HIV and communities from informal and grassroots levels up to global coalitions.<sup>2,8</sup>

### Programme Activity 3: Reduction of risk of HIV exposure through changing behavior and social norms

Peer-group interventions, condom provision, outreach and behavior change programs at the point of health service delivery are all ways in which the community plays a role in behavior change efforts. They also occur at the community level, e.g., via street theatre and other public events; and structurally through HIV policies and schools-based HIV education. Peer education is a particularly popular community-based intervention.<sup>5</sup>

However, prevention of HIV transmission through behavior change is complex and subject to unique social, cultural and epidemiological forces in different countries. Moreover, interventions are not of sufficient scale to reach the point of universal access. As well as insufficient funding there is a lack of consensus on what are the priority issues and poor coordination between different service providers.<sup>5</sup>

### Programme Activity 4: Procurement, distribution and marketing of male and female condoms

Peer group and social networks are an important way in which community mobilization supports the promotion and distribution of condoms, As well as interpersonal-level interventions, there are also community-level actions to distribute condoms and promote their acceptance and correct use,<sup>2</sup> and in some

settings this has also been done at a structural level mandating the availability of condoms in bathhouses frequented by men who have sex with men, for example.<sup>5</sup>

Despite the fact that there is strong evidence in support of condom use for HIV prevention, there is a lack of availability of low-cost, good-quality condoms as well as a lack of demand and other barriers such as religious, legal and gender issues.<sup>5</sup>

### Programme Activity 5: Treatment, care and support for people living with HIV

The involvement of people living with HIV (PLHIV) in delivering care and as peer educators is one of the most significant means of community-based interventions.<sup>2,4,5</sup> Other small-scale interventions include microfinance, nutritional support for PLHIV and helping families affected by HIV and AIDS. Community-health workers also play a part in the process of task-shifting to make optimal use of health care human resources, through home- and community-based HIV testing and counseling, and increasing adherence in antiretroviral therapy.<sup>4</sup>

However, this is an area where the lack of human resources, capacity and funding creates striking gaps in service provision, and efforts are undermined by stigma, discrimination and gender inequalities. Also, services are particularly inadequate for certain groups, notably key populations and those living in rural areas.<sup>5</sup> The needs of PLHIV have changed over time, the most notable shift being the impact of availability of HIV treatment which has, when available, transformed HIV from a terminal illness to a chronic disease.<sup>6</sup>

## Programme Activity 6. Voluntary medical male circumcision in countries with high HIV prevalence

Community mobilization is an important means to promote male circumcision and recruit, screen and schedule men for the procedure. Although this programme activity is targeted at populations with low rates of male circumcision, there is also a need for engagement with communities practicing traditional make circumcision to ensure all men have access to safe and effective circumcision.

Despite the fact that engaging volunteers to help scale up male circumcision, these community-based interventions are also undermined by the same gaps as other programmes: lack of human resources, lack of infrastructure support and unreliable funding.<sup>4</sup>

#### The costs of community mobilization

Because the UNAIDS Investment Framework anticipates community mobilization will be one of the means to ensure efficiency gains, it is important to consider the cost implications for community mobilization, not just for programmes, but for the community. In the framework, task-shifting downwards will result in cost savings for the health care system. However, it is important that funding for community mobilization is increased, in line with the Investment Framework proposal, so that costs are not simply shifted from donors to the communities themselves.<sup>2</sup>

For communities, this process of task-shifting can bring gains, but it also entails opportunity costs. These can be calculated in monetary terms, but they also include ethical and social implications, e.g., of shifting the AIDS response from paid professionals to volunteers in the community.<sup>3,7</sup>

The costing methodology developed by UNAIDS for used in facilities-based healthcare was adopted in a costing study for non-facilities based social care interventions.<sup>3</sup> It was subsequently field-tested in studies in Cambodia, Kenya and Zambia.<sup>3,9,10</sup> The methodology calculates the costs to an NGO of including community mobilization in a particular intervention, as well as the opportunity costs and financial benefits to the community concerned.

The studies conclude that community mobilization can and should be costed, but that most in-country organizations will need external support to do this. 10 Rather than seeing the cost to the community as an obstacle to community mobilization, it should be used as an incentive to bring in new funding sources and incorporate a broader range of stakeholders, such as employers and unions, to support national AIDS programmes. 9

A costing study in Cambodia identified the costs of community mobilization for an intervention with key populations. It calculated that the cost to the community of participating in prevention program activities for men who have sex with men, sex workers and people who inject drugs, was equivalent to over 52 days' income per year. Similarly a study on the unit cost of including community mobilization in a PMTCT programme in Zambia found that there was a net benefit to participation in activities to strengthen community pathways of referral, but a significant cost to participation in awareness-raising activities.

The studies are the first step towards testing the UNAIDS Investment Framework's thesis that task-shifting to the community can increase efficiency in national HIV responses.<sup>9</sup>

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