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Strategies for the Involvement of Civil Society in HIV Testing within the context of "3 by 5": Focus on NGOs

Defining the issue

Civil society groups have key strengths that make them critical actors in the scale up of HIV testing efforts within the context of the "3 by 5" initiative. Most social and health services are not delivered through government structures in developing countries. While in capital cities there may be decent public health infrastructures, private (often faith-based) clinics and hospitals are often the providers in the rest of the country. The majority of people receive their support from within their communities: NGOs, PWA groups, ASOs, etc. These services include HIV testing, education/counseling, direct support (meals, massage, family support, etc) and often medical treatment (drugs). There is an urgent need for well-educated and peer-led support workers from local organizations to provide services for the families and individuals affected and infected. This type of community involvement may be the least expensive and most sustainable systems required to increase the care and treatment components (including education about testing, treatment, peer support education for adherence, etc).

Central to making the "3 by 5" initiative work at the local level will be civil society leadership and involvement with HIV testing. Community groups (NGOS and ASOs) would be involved in all aspects of HIV testing, from education to providing the testing itself (in a secure, friendly non-judgmental environment). It makes more sense to invest in these communities and their organizations to deliver because there is very little hope that scaling up with a focus on government doctors and labs can take place in the short term. It simply takes too long, is too expensive, and can not even begin to deal with the numbers of people needing to access HIV testing and treatment services that currently exist in the highly affected regions, much less will be able to scale up.

Civil society includes these NGOs, ASOs, PWA groups, as well as unions and business. Thus the need to get businesses more involved seems like another aspect of the approach for the scale up. Currently in some cases they provide support and treatment directly to workers, at times also to their families. Increasing such corporate efforts on testing will be important; it makes sense to provide testing services to workers and their families through their places of work. Recent experience suggests that provisions need to be in place to ensure confidentiality is maintained in relation to testing, as well as to provision of care and treatment when employers are providing or supporting these services. Since businesses are already providing services such as treatment and support, this should provide access to employees who desire testing services. It may be more useful to now view these "business" clinics as providing services to the populations in general. For example, if there is a company clinic in some village, then why not expand it to deal with the entire community irrespective of whether the people are employees or are family members.

How to involve community groups

Specifically, NGOs/CBOs can be involved in the "3 by 5" strategy in several ways:

1. *Testing.* NGOs/CBOs must be key players in facilitating testing of individuals who may be candidates for treatment in the "3 by 5" initiative. This can include activities such as educating and raising awareness in the community around the benefits of knowing one's HIV status. Benefits must include those beyond access to treatment since not all HIV+ individuals will receive therapy through the "3 by 5" initiative. Other benefits publicized should include the ability to alter one's lifestyle in order to extend life expectancy, as well as the ability to take precautions to prevent infected others. NGOs/CBOs can also perform on-site testing at their premises. They can directly be involved in training medical personnel, including nurses, in their communities to perform testing. They can be involved in providing pre- and post-test counseling services. Further, they can be involved in the distribution of testing supplies. In all of these activities, the possibility exists for partnering with governments and international actors.
2. *Production of antiretrovirals*. NGOs/CBOs must participate in the debate around brand name vs. generics drugs thus also ensuring that quality generics are purchased for the "3 by 5" initiative (analyze and publicize world price date? → MSF). They may also be critical in identifying roles for the Global Fund since this will fund most of the scale up of treatment efforts in many countries. However, there are many setbacks and problems with the way the Fund is currently operating (millions of $ but no treatment yet: implementation of the Global Fund vis-à-vis the "3 by 5" initiative).
3. *Distribution of antiretrovirals* (from manufacturer to patients). NGOs can be key players in advocating for transportation times to be reduced, identifying obstacles and barriers in distribution efforts, and working with other stakeholders in addressing these obstacles.
4. *Selection of patients for treatment*. NGOs have to be included in discussions around setting up guidelines for testing and treatment, and they have to be involved in testing programs designed to identify recipients of increased supplies of antiretroviral drugs.
5. *Delivery of treatment to selected patients*. This includes:
    - training of community and health workers not only to provide treatment, but also counseling, follow up, education.
    - directly distributing and administrating ARVs to infected people (community clinics, PWA organizations, local NGOs)
    - encouraging sustained adherence to ART among those receiving ARVs (e.g., to prevent the development of resistance);
6. *Post treatment monitoring and assessment* (of the patient and of the initiative). NGOs have an important role to play in assessing the impact of "3 by 5" at country level (are efforts among the various partners coordinated or fragmented and inefficient?, is the quality of high standard?). They can also evaluate how 3x5 relates to other HIV/AIDS efforts (e.g., Global Fund; bilateral donor programs such as the U.S. Emergency Plan for AIDS Relief, small scale treatment initiatives). Thus, there needs to be detailed and measurable national targets to track progress.

7. *Advocacy at all levels and involvement*. This includes:

   - Making sure that ethics and human rights are central principles in scaling up ("3 by 5" has become a quantitative target that people will push to fulfill, perhaps at the expense of those individuals the effort is ostensibly to help. Thus, serious pressures to fudge informed consent and other ethical principles that affect testing, etc could (will) arise).
   - Advocating for the "3 by 5" initiative among affected communities (e.g., disseminating information; building bridges among other community groups) and governments (participation on Global Fund CCMs or other funding mechanisms, involvement with policy makers,).
   - Devising ways to use "3 by 5" to improve HIV/AIDS prevention programs at country level.
   - Encouraging global partnerships and mobilization of stakeholders (NGOs and CBOs that are already doing it in most developing countries).
   - Asking hard questions: who is paying? for how long? how are they paying?

All of the above will depend on building the capacity of civil society groups and ensuring their engagement not just providing lists of recommendations of how they can be involved.

This issue paper was prepared by Mary Ann Torres to facilitate discussion at the Reference Group's January 2004 meeting.