



## Community engagement in HIV prevention in Asia: going from 'for the community' to 'by the community'—must we wait for more evidence?

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the provision of antiretroviral treatment—for humanitarian reasons in the first place, but perhaps also because of their theoretical potential to reduce infectiousness at the population level, making sex workers and other high-risk communities a priority for antiretroviral treatment access on epidemiological grounds.

In this time of global financial and economic crisis, one of the strongest messages coming out of Avahan is that not focussing HIV prevention programmes where HIV is primarily spreading, and not investing in solid multi-prong monitoring

and evaluation, are no longer acceptable. In that sense as well, Avahan has set new standards for HIV prevention.

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# Community engagement in HIV prevention in Asia: going from 'for the community' to 'by the community'—must we wait for more evidence?

Swarup Sarkar

The HIV epidemic in Asia is predominantly defined within the marginalised communities and their partners. The term 'communities' here refers to people who are living with HIV or injecting-drug users (IDUs), sex workers and clients, men who have sex with men (MSM), transgender population and intimate sexual partners, essentially population groups predisposed to higher risks of HIV.<sup>1 2</sup> The prevention of HIV among these communities is considered crucial to a successful HIV intervention response in Asia. Although any behaviour change programme must be addressed and tailored to these communities, the rationale, purpose, extent and means of engagement of these communi-

ties have often been debated.<sup>2–5</sup> However, despite recent rhetoric about the role of the affected communities in the response to HIV, significant involvement of the community has rarely been the mainstream practice. Instead, community involvement has been described as minimalistic, tokenistic and incomplete.<sup>2 3 6</sup>

One of the most common characteristics of these communities is that they are socially marginalised and often criminalised, even if their behaviour or actions are not illegal by law or immoral by belief. This makes it difficult to reach out to such high-risk population groups through existing health or social services, either because the services are not available or accessible to the marginalised community members, or because of the perceived or actual judgemental attitude, stigma and discrimination by healthcare workers and those associated with the field.<sup>7</sup> For example, STI clinics are not open in the evening time when sex workers actually work. Similarly, physicians do not examine for anal STIs.<sup>5</sup> This has led to the concept of 'community friendly' clinics and services which would be run by a range of service providers like private practitioners,

community organisations, NGOs and even government bodies.<sup>8</sup>

While engagement and community ownership of intervention would seem simple, logical and humane, its acceptance has not been simple. Part of the reason lies in the current social, political and legal contexts and structures whereby these populations/communities are marginalised. For example, politicians might often avoid a discussion of issues and rights of these communities, especially when the view is unfavourable among the public. Interestingly, another dimension stems from the previous successes of HIV prevention itself, such as in the early days of Thailand and Cambodia.<sup>9–11</sup> In these examples, HIV prevalence was controlled and reversed successfully through the involvement of the brothel owners and power structures, with minimal involvement of the sex workers themselves in the design and implementation of interventions.<sup>6 9</sup> Following the stunning success of these two countries, several large funding agencies in Asia provided funds for STI services and condom programmes without sufficient attention to factors affecting utilisation or uptake, and in turn effectiveness of the services. An important lesson was that unless services were people-driven rather than target-driven, sustained changes in behaviours were not achieved.

Soon, another stream of programmes emerged from the now well-known Sonagachi project that provided evidence of community mobilisation, self organisation, and overall tolerance and acceptance of these interventions and services. This eventually resulted in a high level of condom use and consequently lowered levels of HIV infection among these groups, as compared with other parts of the country.<sup>12 13</sup>

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Since the middle of the 1990s, two divergent approaches to HIV-prevention programmes have been refined, one led by the community and the other largely through structural interventions. This has left a space for a wide range of services to be provided by international and/or national NGOs. In these services, approaches that are more centred on community acceptance are starting to be adopted, such as 'friendly clinics' that operate at appropriate times, and offer outreach educational support. Some of these community-friendly projects run by national or international NGOs could actually record declining HIV rates as well.<sup>14</sup>

An initiative on scaling up a community-led strategy has been launched by AVAHAN, whose funding from the Bill and Melinda Gates Foundation has created the largest HIV-prevention programme for a single country in the world. Avahan provides funding and support to targeted HIV prevention programmes in the six Indian states with the highest HIV prevalence, and along the nation's major trucking routes. Avahan-supported programmes serve the groups that are most vulnerable to HIV infection, including sex workers, their clients and partners, high-risk MSM and IDUs. They have taken a pragmatic approach by developing a framework where the programmes would range from a 'for the community' to a 'by the community' programme, depending on the preparedness of the community. Some early data from Avahan have shown that the programme outcome is better—for example, there is increased condom use and reductions in STI when the community is engaged.<sup>2 15</sup>

Regardless of the debate on the design and leadership of the programme, certain types of activity are now widely recognised as within the role of community organisations. For example, sufficiently strong evidence supports the notion that community organisations should be the main provider of services for peer outreach, condom or needle and syringe distribution, the running of HIV testing networks, enrolment of HIV-positive people into appropriate treatment programmes, treatment-adherence counselling and management of impact-mitigation programmes for affected women.<sup>2 3 16–19</sup>

The genuine involvement of affected communities in planning and implementing HIV programmes is also regarded as one of the best ways to tackle stigma and discrimination.<sup>2 3</sup> Other key community roles include organising support groups, that is, 'self-help groups,' and contributing to the development of the policy and strategy agenda. Additionally,

conversely, the role of referring people to other services (eg, oral substitution treatment, STI diagnosis, antiretroviral treatment, TB, prevention of mother to child transmission, etc) is those that are generally not provided by community organisations could be crucial in successful community engagement.

In spite of their important role, donors and governments do not currently earmark funding for core capacity development of community organisations very often. As a result, participation of communities in HIV responses is held back by a lack of capacity. Recognition of these organisations by INGOs and NGOs and/or UN organisations which simply do not have the necessary time-bound approach to transition the services to community organisations continue to deliver through their own organisations. This may be linked to a lack of evidence. Indeed, data-collection system and data gaps are enormous on the roles and effectiveness of the community organisations.<sup>2 3</sup> Disaggregated data are not available on levels of funding for core capacity building of community organisations for HIV projects in Asia. Reasons for this data gap may lie in the fact that monitoring for most community-level HIV projects is built into national scale programmes that often rely on costly behavioural surveillance systems. Valuable information is missed possibly because simple, inexpensive and user-friendly monitoring tools are not available. There is clearly a need for such tools to guide front-line workers in decisions on mid-course programme correction—and to complete the evidence basis for community-led services.

Without doubt, a thorough systematic analysis of the nature, intensity, duration and outcome of community-engagement programmes is essential. Since most of the evidence behind community engagement in Asia is associated with programmes among sex workers, further research can be conducted among MSM and IDU communities. The Avahan project is a promising step towards a more complete picture and will hopefully succeed in providing such invaluable data from its own study.

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