Absolutely Ours

The importance of community-owned responses to HIV in India

Men who have sex with men (MSM), *hijras* and transgender communities across India are doing something considered by many to be audacious: they are demanding legitimacy from their local governments. To support their efforts to protect the health and wellbeing of their communities, they are registering as organisations under the Societies Registration Act 1860, a law that was created by the British around the same time as India's antisodomy statute Indian Penal Code (IPC) Section 377. Although the anti-sodomy section was read down by the Delhi High Court in July 2009, MSM, transgenders and *hijras* continue to face regular discrimination and violence. Despite this and in some cases as a result of it, many MSM and transgender groups are exercising their right to organise. Groups that used to meet informally in public parks and bus stands now have bylaws, elected office bearers, accounting systems, and the other necessary organisational machinery to support their work. As one community member commented, "I used to feel threatened by local rowdies in my area. Now I walk in the streets of my town with confidence knowing I have my organisation to back me."

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Why does this matter? First, marginalised groups have been afforded legitimacy by a system that typically treated them with abhorrence and disrespect, and in some cases even denied their existence. Second, it enables groups to work officially: protests, World AIDS Day events, support group meetings, condom distribution and other critical HIV prevention activities become a possibility only when groups have a recognised legal status. Third, it is a first step towards becoming eligible for funding from government and other donors, which is essential if these organisations and their work is to be sustained. Last and certainly not least, registration can be an act of tremendous personal courage, as it requires registers to write their names and addresses on their application; for many, this is their first instance of associating themselves formally with their sexuality or gender identity. Over time, we have even seen instances of government registrars and other officials who are part of the process develop friendships with community members. Registration is an ultimate expression of "we're here, get used to it," and it is remarkably good news that so many communities across the country are doing it.

Through the Global Fund-supported Pehchān programme, Alliance India and six implementing partners are developing the capacity of 200 community-based organisations in 17 states to provide services to promote the health and wellbeing of their communities. Pehchān is focused on community systems strengthening. Increased community participation in the HIV response has been accompanied by a marked increase the reach and uptake of services, both within and outside MSM, transgender and *hijra* communities. There are many examples of community-driven work that has achieved the relevance and reach that other approaches cannot: after all, who knows community needs better than community themselves? We have seen groups performing street theatre in village squares filled with people of all ages sitting on empty oil cans, tree logs, and dusty rocks watching stories of men loving men. Crisis and violence response teams have organised briskly in the face of harassment and other defamation, assisting and protecting community member rights and helping them to avoid future threats.

Communities are assisting State AIDS Control Societies to train police and health officials on their specific needs and concerns. It is not uncommon during police trainings for sari-clad *hijras* and MSM to lead sessions on why and how police services can be made more friendly and inclusive for the community. Media advocacy has yielded results, and instances of stories that accurately and respectfully portray sexuality and gender identity differences are penetrating into the homes and minds of the media-consuming public. The richness and value of the results are evident on multiple levels: with the project implementers themselves; in the populations they target; and in society at large. The process of working on an HIV prevention project itself can increase community pride and self-esteem, helping them to see latent strengths and capacity they might have thought they didn't have. And a community that loves itself, protects itself.

Despite the success of such efforts, there still remains a lack of confidence in community ability to manage and run programming. While many implementers will claim "community involvement," the reality is less engaged and sometimes little more than a tokenistic nod to communities as part of

Box 7: Community Advisory Boards in Pehchān

Lack of accountability to beneficiary communities in HIV programme governance discourages the addressing of real community needs and leaves no check to ensure ethical programme implementation. Pehchān is committed to maintaining accountability to its beneficiary communities and has an in-built governance structure that does this. Community Advisory Boards (CABs) are a governance structure comprised exclusively of community members who participate in programme decision-making processes, provide technical inputs, and assist in conflict mediation at all levels of programme implementation. They also have the authority to raise issues and concerns, serving as a watchdog body to ensure the programme's ethical implementation. The Pehchān programme has formed six CABs, representing 17 states. CAB membership, which rotates on a yearly basis, is comprised of Pehchān's beneficiary groups: MSM, transgender, and hijras; at least one of whom should be PLHIV; and its members should have a minimum of 3-5 years' experience in HIV programmes. Key CAB responsibilities include:

- Providing technical inputs to inform programme functioning and policies
- Supporting relationship strengthening with State AIDS Control Societies
- Guiding and ensure action on priority issues of the community
- Advising best means to synergise with existing programmes and projects
- Assisting in conflict mediation, as needed

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otherwise top-down approaches. It is all too easy to make assumptions of what constitutes "support" for communities and what interventions make the most sense to achieve improved HIV outcomes. We may want to rely on logic, or what is most measurable, or most achievable within a given set of circumstances. Programming for communities can be compromised, irrespective of how wise or viable it may seem, unless it is informed by the communities who may benefit. Addressing this from the start, from programme conception through planning and implementation ensures interventions outlive funding streams. This is crucial to building effective and sustainable interventions with communities, and programmes should be structured to support this process. Pehchān's Community Advisory Boards (CABs) are one example of how this can be accomplished. (See Box 7.) As one CAB member commented, "A Community Advisory Board brings to the project the priorities of the community and keeps the project aligned with the true needs of the community. It serves as a bridge that links the project with the community it serves."

Here it might be useful to go a bit deeper into what we mean exactly by "community." One NGO leader who works with an Alliance India observed jokingly that she wished she could put a sponge against her head to suck out all the NGO jargon; in the same spirit, she even proposed a rule at her organisation that the word "awareness" should never be used in order to promote greater specificity. Jesting aside, there is truth in these statements. "Community," like many words in the NGO lexicon, is warm and embracing, but also vague and imprecise. The concept of community may differentiate one group from another, while simultaneously recognising the integral connection between them. As important as it is recognise the status of certain groups as marginalised, this should be done in an affirmative way. Otherwise, we can compound stigma and instead increase the barriers we are trying to overcome.

The relevance of the type of work that the Alliance does with communities to overall epidemiological impact is increasingly undeniable. For example, Dr. Chris Beyrer from Johns Hopkins University has recently shown in research in four low and middle-income countries that MSM-specific interventions had a statistically significant impact on new infections in both MSM and general populations.[1] While it would be expedient to consider these populations distinct, MSM are part of general populations, and the difficulty we face in reaching MSM due to their marginalised status represents a serious challenge for the effectiveness of HIV prevention programming.

In India as elsewhere, most men who have sex with other men do not make an identity claim based on this sexual behaviour. While in the epidemiological sense these men are MSM, they lack any associated identity or community: so how can we effectively engage them in HIV prevention interventions? There are no easy answers, but we can start by reaching out to and supporting those MSM who embrace some sense of identity and

[1] Beyrer C. *The global epidemics of HIV among MSM in 2010: Epidemiology, responses, and human rights.* Paper presented at The Global Forum on MSM and HIV Pre-Conference (July, 2010). Vienna, Austria.

Box 8: Operations research in Pehchān

While the National AIDS Control Organisation (NACO) has done significant research relating to MSM, transgender and hijra communities, knowledge gaps remain about these communities and the HIV epidemiology within them. Pehchān has dedicated funding for seven operations research projects in five key areas, which will assist in generating knowledge that can be used to enrich programme implementation, support advocacy, and contribute to global dialogues. For example, in a national BSS study, 31 percent of MSM surveyed said they had sex with female partners in the six months prior to the survey. Our understanding of MSM and their female partners is inadequate if we are to develop responsive programming, and operations research will be used to inform the design of interventions to reach these groups.

community, and through them, we may be able to reach some of the men who remain hidden and unserved by programming. It's easy enough to see how the task of building programmes that are relevant and responsive is a challenge, but we should not shy away from this complexity and have the courage to admit there are still questions even as we move forward with the work. (See Box 8.)

Communities are constructed, contested, overlapping and constantly changing. India understands the key role that community plays in HIV programming. It is a guiding principle of the National AIDS Control Programme III, which is committed to "promoting social ownership and community involvement."[2] As part of civil society, it is our duty to engage with government policy and programme approaches to ensure they are sufficiently broad, flexible, relevant and accessible to meet community needs. By building informed programmes and delivering on results, we also have the opportunity to demonstrate priorities to policy makers.

In the end, our goal is to serve as a catalyst, enabling action without residing at its centre. As Alliance India works with communities through our Linking Organisations, and other implementing partners to strengthen their ability to plan, execute and evaluate their own programmes, we seek to become unnecessary. This is a good thing and, in fact, a real mark of our success. We need to work toward being able to pull away from communities that have achieved sufficient strength. And it doesn't stop here; there is a multiplier effect. Community members become advocates, leaders, and teachers who in turn go on to support others. In the words of one community member, commenting on the process of engaging in a community-owned and managed initiative: "I see a ray of light in community eyes when they see me as a manager; it is as if they realise, if she can do it, so can I!"

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[2] Government of India Ministry of Health and Family Welfare (2010). *Department of AIDS Control Annual Report: 2009-10.* New Delhi, India.