COMMUNITIES RESPOND TO HIV

Experiences of Perspective Building on HIV

SAMRAKSHA
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Adding Life To Years

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Acknowledgement

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Preface

This document captures the different ways in which the village communities in Kumta, in Uttara Kannada District of Karnataka, India have evolved a local response to HIV. About 85 village communities have engaged with Samraksha and gained a perspective on HIV through a series of discussions and reflections. They have taken forward the action in their own ways. In this document, we share the process of engaging communities in the HIV response and the different initiatives taken by them in the areas of prevention, stigma reduction and care.

Background

A fundamental principle of community empowerment is that when the onus of change is on the community, then the social capital in the community propels the change process. This change, being internally driven, is much more sustainable. However, in the context of the HIV response, the potential of the communities - especially geographical ones - has been largely unrecognized. The approaches have been either external expert-driven or disease-centered.

Samraksha, an HIV specific development organization in Karnataka with over 16 years of work in this field, became convinced that communities have the potential to respond to the HIV epidemic just as they have responded to other issues in the past. It recognized that their deep involvement is crucial because an effective HIV response needs changes in behaviors which, despite being intimate and individual, are largely shaped by social norms. Samraksha was also convinced that when the communities are involved in the response, they themselves constitute norms, such as safe behavior practices or acceptance and care of people living with HIV. They also demand compliance with these norms from all members of the community.

Involvement of the general community gradually normalizes HIV and promotes social cohesion, so that people no longer see HIV as the issue of the socially undesirable 'other' but as their own issue. The people affected by HIV who are living in those communities, then, become a part of that community and benefit from the social supports and resources that exist within it.

What is critical in this engagement with the community is that it does not become a didactic process of giving information or awareness, but a reflective, dialogic process. This facilitates communities to think through the issue of HIV and to develop a perspective on this.

Samraksha started this programme in 2002, in the villages of Raichur and Koppal with the firm belief that once this perspective on HIV is developed, communities can start

responding to it in their own way, from a position of their strength. The responses in these communities were amazing (Gunnal et.al, 2007).

Samraksha decided to try this approach in an entirely different cultural context. In 2007, this programme was started in the villages of Kumta Taluk, in the district of Uttara Kannada. This differed from Raichur and Koppal on many fronts: geography, human development, culture and tradition (Samraksha 2005).

Kumta Taluk

Kumta is a coastal *taluk*,[1] spread over 582 sq km with 119 villages, 4 *hoblis*[2] and 1 town. According to the 2001 census, it has a population of 134144.

The settlement pattern in Kumta is characterized by small habitations separated by long distances. Many of the villages have fewer than 500 households; a few settlements have lesser than 100 households. The villages are distantly situated; not always connected to each other by road and frequently separated by backwaters and rivers.

The major occupations are fishing and agriculture. Tourism is also a major industry and the attractions include Gokarna and the world famous OM Beach. There is a high degree of migration, both into and out of the region, primarily north to Goa and south to Mangalore.

Literacy levels in the region are high at about 70 percent, although the male literacy rate at 80 percent is substantially higher than the female literacy rate at 59 percent.

In terms of the HIV scenario, the district of Uttar Kannada has, in recent years, recorded an ante-natal prevalence of about 1 percent, indicating that the epidemic is no longer confined to specific risk groups. However, the issue of HIV is not frequently talked about in the communities. An in-depth ethnographic situational needs assessment, undertaken by Samraksha across five districts of Raichur, Koppal, Haveri, Gadag and Uttar Kannada in 2005 showed that of the five districts, sexual networks were least visible and most closed in Uttar Kannada. Many of the respondents either denied the existence of commercial/transactional sex in their communities or reported strong social disapproval of such behaviour (Samraksha 2005).

1 In Karnataka State, the main administrative units are districts, which may be divided into divisions. Each division consists of talukas, which are headed by a tahsildar.

2 Talukas can be fdivided into 'hoblis', clusters of villages forming a revenue circle, and headed by revenue inspectors. Number of hoblis in a taluk, and number of villages in the hobli vary depending on the clustering of the villages

It became all the more necessary to get communities in Kumta to confront their own risk and vulnerability. Critically, communities needed to open up and discuss the issue so that stigma and discrimination could reduce and those living with HIV could access services. This led Samraksha to engage with communities in Kumta, through the '*NamBaduku*'[3] approach of perspective building in communities through discussions and reflections.

3. Samraksha's stream of intervention which works with geographical communities is called NamBaduku (our living).

The Process

The village perspective building process is a flexible one, with a series of activities designed to involve all the community members in a reflective discussion on the issue of HIV/AIDS. This was done over a period of 3 to 5 days during which the Samraksha team stayed in the village, and the community hosted them.

The process itself can be seen in three phases: social mapping, perspective building and social action.

In the social mapping phase, the village was involved through various participatory mapping methodologies in mapping the village, mainly its physical and social resources. This allowed the team to get familiar with the village and helped the community members to fully recognize the extent of their own resources.

In the perspective building phase, different one to one and one to group strategies were used to reach all the groups in the village in spaces and times which were convenient to them. The process went beyond awareness and information giving. It gave the community an opportunity to get to know about HIV in an interactive way. There was space for questioning and clarification of doubts; for the community to think through different aspects of the issue and understand what constituted risk, and vulnerability. They could also explore the factors which accentuated their own risk and vulnerability, understand stigma and discrimination and its effect on the families affected by HIV. The process typically culminated in a street play put up by village volunteers, with support from Samraksha. This activity usually ended up as a powerful statement against stigma. It became an opportunity for the community to come together on this issue and commit to take action for HIV prevention and care and support.

The social action phase usually began with different individuals and groups planning specific actions which they would subsequently take in response to HIV. Different community members would volunteer to take responsibility for the different tasks

involved in the action planned. As the public commitment to action happened in a village meeting, it created a social pressure on the individuals to complete the proposed activities.

In Kumta, follow-up visits were made to the village, once in three months, in order to observe and understand the changes in the community after the perspective building process. These visits were not a monitoring process, since it was clear that the communities were not accountable to anyone other than themselves for the actions. It was more of a support visit to document the community actions. Very often, the communities themselves had never perceived the changes in their attitudes and behaviors as anything significant. It was only when they were facilitated to think about this, did they appreciate the extent of changes they had already effected and their capacity for much more.

Even the process of selecting the villages was aimed at promoting community ownership. Samraksha took the initiative to enter only about ¼ of the villages on its own. In the remaining villages, the communities invited the team after hearing about the process in a neighboring village. At other times, a *Gram Panchayat* member (member of local self government body)/village elder recommended that the team cover the other villages in the areas which would benefit from the process and initiated the contact with the other villages. Thus, most of the processes started with an invitation letter from the village to the team to come and interact with them.

The process itself was given the initial momentum through the involvement of the opinion leaders in the village. Typically, it started with the *Prathama Sabhe* or 'First Council', which tried to involve all the different groups in the village. In the villages of Kumta, the communities themselves suggested different ways in which people could be mobilized to attend the Sabhe. In many villages the *Gram Panchayat* members themselves invited all members of the community.

In other villages, youth groups went about inviting people for the event, printing pamphlets about the meeting in advance so that the community members were aware of it. In a few other villages, the School Development and Management Committee (SDMC) invited the team to use the occasion of parent-teacher meeting in schools where most of the community members would be present, to start the meeting. In this way, right from the initial meeting, communities started opening up to the issue and volunteering their own structures and resources for the benefit of the process.

Coverage and Statistics

In the last three years, 85 villages in Kumta were involved in this process and through this 48,174 men, 42,446 women and 8,461 children were involved in discussions on the issue of HIV. As a result of this, these community members developed at least a basic level of understanding on this subject. However in many cases, there was more intensive discussion and a deeper level of understanding.

Condom demonstrations were done in every village, and there were more than 4000 instances of re-demonstrations (re-demo) which were done by the community members themselves during this period. This included demonstrations from men, women and young people, all of whom did the re-demo in public.

491 men and 459 women emerged as volunteers for the programme, who not only supported the process in the villages, but also continued to promote community ownership of the issue.

The Impact of the Programme

Keeping the Awareness Alive

One major impact of the programme has been the ways in which the communities have opened up to the issue of HIV, owned it as something for which they will all have to take action. In all villages where there was a follow-up, the different groups reported discussions on HIV, frequently among their own peers. This included men and women, of all ages. Also, the community members found ways of keeping the issue alive in the community consciousness, using various local communication channels.

Thirty villages have written HIV related messages on the walls of common village spaces, to continue spreading awareness on the issue and getting people to talk about it. While all villages have been interested in circulating the information pamphlets provided by Samraksha, in 5 villages, communities have incurred the cost of getting additional pamphlets printed for circulation. In 25 villages, the youth groups are attempting to keep the discussion alive through chain letters and mobile text messages. In 20 villages, the Gram Panchayats now keep books and other material on HIV in their library.

Sports and competitions are becoming a popular space for speaking on HIV related issues. In 19 villages, youth have used these competitions to put up a banner on HIV, distribute pamphlets or play songs encouraging care and support for people living with HIV.

Integrating HIV into the Cultural Fabric

Festivals with religious and cultural significance have become another platform for HIV related discussions. In 29 villages, volunteers used the *Ganesha Habba* to talk to the community about HIV, in 9 other villages, they used the *Navratri* festival. Village level *jatres* (fairs) in 9 villages and the taluka level jatres were another occasion for such discussion. The ability to look at HIV without prejudice or stigma is what has enabled this integration. The moralizing of the early days is rarely to be seen.

People have also adapted HIV relted messages into their indigenous art form. The community was involved in writing a script for a *Yakshagana*[4] performance focusing on HIV and this has been used by artistes in many ways. In 6 villages, artistes have written songs about HIV to form part of the *SuggiKunitha*[5] performances. In other villages, artisans have crafted HIV messages using bamboo.

The openness to talk on this issue is specially striking among women who have typically been perceived as reluctant to discuss issues of HIV or sex and sexuality. In all the villages where there was a follow-up, women's groups reported that they were discussing these issues regularly in their meetings and also distributing the information pamphlets to other women. Women get together and speak about the issue in different ways, amongst each other, as well as in public spaces. In one village, Nadamaskeri, one of the women sang a song on HIV; in another, Hosakatte, a well known woman leader personally shared her experience of having gone for HIV testing.

Renewing Commitments to Care

The International Candle Light Memorial day is observed every year in May, in memory of the people who have succumbed to HIV and to reaffirm the commitment to ensure care and support for those who are still living with HIV. In the villages of Kumta thirty village communities have been involved in organizing this event, and nearly 1300 people have participated in these events.

What is really remarkable is the way the communities have accepted and adapted this event. In Devana and Moolikeri villages, some people have lit earthen lamps in

4 Yakshagana is one of the most popular classical dance drama's in coastal districts of Karnataka.

5 Suggi Kunitha is a festival dance, usually performed by the Hallakki Vokkaliga community of Uttar Kannada. It is performed on full moon nights, and the dance procession visits each house in the village.

memory of the dead. In Moolikeri, the women observed this event in a traditional way, with a *kalasha*, a pot filled with water with mango leaves and a coconut at the top. This is a traditional practice which signifies a full, green and useful life and through this, the women prayed for such a life for the people living with HIV.

In another village, Taribagilu, there was initially some opposition for observing the event in public. But as the community members got to understand the significance of the event, they insisted that it should be observed publicly so that the entire community could be a part of it.

The observation of this day has deeply touched people, some of whom have faced their own personal losses. For instance, in the village of Dareshwara Mata, an elderly man spoke amidst tears of the son he had lost earlier in the year, in an accident. This event, he said, helped him to understand the sorrow of all those fathers who had lost their sons to HIV. In this way, just the involvement in the event helped the general community understand and empathize with the people affected by HIV. The psychosocial impact of HIV was highlighted.

Reviving Basic Human Responses to Care

When a HIV positive widow was thrown out of her house, the entire village, which had recently been through the community process, came to her support. They tried to convince her family to accept her. When the family refused, the women adopted her as one of their own. One of the older women offered to give her shelter; the entire village contributed resources to support her medical and daily living expenses. The community also helped her reach the district hospital, about 150 kms away, for a safe and attended childbirth.

A family was keeping a young girl, a niece who was HIV positive, outside the house after she contracted TB. She was asked to stay in the toilet, given food there and not allowed to come out. During the perspective building process,

the family had a chance to talk about her illness, and understand it better. They immediately brought her into the house. She also started taking TB medication and recovering.

A young man was touched by the plight of his HIV positive friend, whose wife was keeping him in a separate room and not allowing him to even see his children. He visited his home, personally helped him wash and shave to show HIV is not contagious. He was also able to offer his friend support and companionship in his last days.

These are just a few instances of individuals, families, and entire communities understanding and empathizing with people affected by HIV and reaching out to them. In some instances, people have demonstrated positive action to support people with HIV. In others, they have understood the negative impact of their own discriminatory behavior and changed it.

Such changes are very critical in creating a more supportive environment for people affected by HIV, in their own communities. Within such an environment, the resources and the existing social capital is available for their support. With community support, affected people are more likely to access the services which are available to them within the health systems.

Recognizing Risk and Moving to Prevention

After the perspective building process, all the villages have reported that they have identified a community condom stockist who ensures condom availability in the village. Besides this, in 18 villages, communities have set up condom outlet boxes, with certain individuals and groups in the community-typically the young people- taking responsibility for keeping it stocked. In 18 other villages, women Self Help Groups stock condoms and distribute it to their members.

In one village, a man shared that after the perspective building process, he realized that his friend had died due to HIV. He was worried about his friend's wife and wanted to get her to test. In order to fully understand about the test, he himself got tested, before going to his friend's wife and encouraging her to get tested.

Across all the villages, nearly 400 people have shared with the team that they have gone for HIV testing. There have also been 80 referrals for STI services from the community members. In this way, the involvement of the communities in the perspective building process has spurred certain behavioral changes. At the community level, this has increased acceptance of HIV prevention services and promoted community access of these services. These are significant steps which will gradually lead to the creation of community norms around safe sex practices, which will ensure that HIV prevention sustains across generations.

At another level, there has been discussion on mobility and migration and inter-generational discussions on how to be safe when away from home. Open discussion of tabooed topics of sex and sexuality in the community has also opened up issues of vulnerability of young girls, single women and widows. Issues of gender and patriarchy that contribute to this vulnerability have been raised although not yet addressed. It is a beginning.

Mechanisms to Sustain Community Responses

AIDS Action Committees

The process has inspired the formation of community based groups identifying themselves as AIDS Action Committees. These committees, through their regular meetings and discussions, continue to engage the community on the issue of HIV and AIDS and also become the support for the people affected by HIV in their community.

Village level AIDS Action Committees consisting of opinion leaders in the village

including the *Gram Panchayat* (local self-government body) members, group leaders have been formed in 12 villages. In most villages, these have been initiated and led by women, including one in the village of Hagal, where the AIDS Action Committee comprises only of women. This group is specifically interested in looking at the impact of HIV on women. Existing groups in the community, especially the women's groups, have taken up the issue of HIV seriously and frequently discuss it in their meetings.

Community Volunteers

The community volunteers, about 900 men and women from different villages, have been the strongest forces giving momentum to the community actions. Whether it is in ensuring condom supply, making an informed or accompanied referral for services, or organizing events around HIV, these volunteers have been in the forefront of community actions. Most of all, they have been the agents of change in their communities; allowing sisters and daughters to attend sex and sexuality sessions; allowing them to talk about HIV in their college; taking the awareness into the next village through a cycle jatha; not allowing an episode of discrimination within their village; not allowing quacks to exploit people with magic remedies; helping people to shed self stigma . The examples are innumerable.

Volunteers have also benefited from the periodic volunteer meetings and sharings. Five volunteers from the villages were part of the inspiration sharing *Spoorti Yatre* (Inspirational Journey), where volunteers from Samraksha's different programmes across six districts came together to share their stories.

Trainings have also been organized for the volunteers, when they have felt the need for it. These focus on basics of HIV prevention, care and support. Volunteers have reported a greater sense of competence in responding to issues in the community following the training. After one such training, 28 of the 50 volunteers voluntarily went for an HIV test, and committed to sharing their own experiences, and encouraging others to go for testing.

Community Members as Catalysts

When Samraksha had initiated a similar programme in the villages of Raichur and Koppal in 2002, the programme was carried forward through community catalysts, people from within the communities, who could kindle the spark in these communities to take action and change. These community catalysts had been through a rigorous selection and induction process and had acquired the skills for community engagement through field practice and cross learning from a large cohort. When the programme was started in Kumta in May 2007, the idea was to use a similar approach. But this was a little challenging in Uttara Kannada which was more conservative and also in denial about HIV risk and vulnerability. It was difficult to find appropriate people within the communities, who could believe in and be comfortable with such an approach.

In the initial period, senior community facilitators from other Samraksha interventions were involved in the programme. They modified and adapted the processes to the Kumta context. Gradually, a local team of facilitators emerged. Many members of this team were actually volunteers from the community, who had been part of the village processes and had also attended volunteer training. Their involvement with Samraksha helped develop their interests and skills to work in this field. They were eventually selected through a competitive process and became part of the implementation team.

Another major challenge was the small strength of the team, which made cross learning through a variety of shared experiences limited. So, the Kumta team went out to work with other community teams in Raichur, Koppal and Dharwad. This gave them greater exposure and a wider range of experiences. In fact, it helped them to build their own perspectives on community potential and ways of facilitating the communities to realize this potential.

Community Contributions

Over the three years, in these 85 villages, communities have contributed significantly towards the cost of the programme, not just with human resources but also with material ones.

The communities hosted the Samraksha team whenever they visited the village for the perspective building or for subsequent follow-up processes. As a community, they provided food and accomodation to the team during this period., contributing to the direct operational cost of the process. This was also important in establishing and promoting community ownership. The team was in the village at the behest of the community and as such were treated as guests to be welcomed into the community.

Certain communities have also made additional contributions for additional activities including printing material for Information, Education and Communication (IEC) and procuring books on HIV and other issues, whenever they have felt a need for them.

Thus, in terms of the costs of the programme, Samraksha's direct operational costs have mainly been limited to the salaries for the staff, programme related travel and training costs.

Conclusion

In 2002, when Samraksha decided to work with entire village communities in Raichur and Koppal districts to evolve local responses to HIV, there was a lot of skepticism. The approach conceptualized was so different from the conventional model of expertise from outside taken into communities through different types of training. There were many questions: who would be the technical resource; who would develop the modules; what would be the training model; and most frequent of all, who would supervise and who would monitor? Village communities were seen as amorphous and large and unlikely to engage collectively on any action of this nature. The concept, it was felt, would be difficult to implement and even more difficult to sustain.

However, the overwhelming response of the communities in Raichur and Koppal districts put paid to any doubts and affirmed Samraksha's belief in the potential of communities to act individually and collectively on the HIV issue. Yet, there were other questions. Was it the high prevalence and visibility of HIV in these areas that had helped to stimulate these responses? Could the relative openness of the society in these districts or the visibility of the sexual networks be factors that aided this? Could it be replicated in different contexts?

Samraksha decided to examine those questions by taking the programme to Kumta, in Uttara Kannada, a district with higher human development indicators, higher levels of literacy and greater geographical dispersion. The culture, tradition and community organization here was also very different from that in Raichur and Koppal. It was a more conservative society, less open and far less permissive with invisible sexual networks (Samraksha, 2005). The enthusiastic response from these communities proved that the approach has wider possibilities. It was replicable in different settings.

The core strength of this approach lies in its inclusiveness and drive towards collective action. It is not based on blaming, stigmatizing or segregating any individual or group. In fact, it has applicability beyond HIV. Gender justice, human rights or communal harmony are difficult social change areas where this approach could be of value.

It also promotes people to people learning. In 2007, *Zilla Panchayat* (district level local self-government) leaders from Gujarat and Rajasthan, having heard about some of these communities through Solution Exchange, a knowledge sharing network, came all the way to Koppal to meet and learn from them.

In 2006, there was a posting on South East Asia AIDS Network, another knowledge sharing network, of an HIV care centre in Taiwan being forced to close down as the neighbouring communities protested against it. AIDS Action Committee members from Kushtagi, a rural province in North Karnataka wrote an open letter to those communities sharing their experience about how their support to a local care centre had helped not just people living with HIV but enriched the community itself. They felt the spirit of humanism and equality within them had been strengthened and appealed for support to the Taiwan Centre.

In the last three years, community catalysts in Samraksha have helped to build community knowledge assets in the form of stories of inspirational action by community members in response to HIV. Spurred by these, people are reaching out to others physically, travelling to other communities or sharing their testimonies through videos and even through blogs[5] and mobile text messages. Video clippings of personal testimonies through YouTube and MMS are not far away.

This non-didactic approach radically re-organizes power hierarchies, no longer dividing people based on levels of knowledge /skills or expertise. Rather it allows for members within communities, across communities and all relevant stakeholders to realize their connectedness with a social network. It promotes interaction on equal terms within this. It helps people to be a part of each other's experiences and appreciate and learn from them. This approach is breaking away from the conventional health education models to a contemporary network society model that promotes people to people learning for social change. It is the way of the future.

5 Experiences and stories from the community are shared with other communities through different blogs like www.samrakshainspirations.wordpress.com and www.aidscompetence.ning.com, a networking site, connecting individuals and communities across the worlds, who believe in the community potential.

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Samraksha started in 1993 as the HIV/AIDS sector of larger development organization, Samuha. Now an independent charitable trust, its goal continues to be to prevent the transmission of HIV and reduce its impact on the people vulnerable to and affected by it. Its current areas of operation are Raichur, Koppal, Gadag, Haveri, Dharwad and Uttara Kannada districts of Karnataka.

Samraksha believes that individuals and communities, if armed with information and power, can and will take responsibility to halt the spread of the epidemic. It believes that it is critical to empower entire communities to act.

It also believes that it is the right of every person living with HIV and AIDS to access care and support services in public, private and social sector. Similarly, it is the responsibility of individuals, communities, private sector and the state to ensure this. Its belief in a prevention to care continuum has led to a range of initiatives across this spectrum.

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SBM Colony, Anand Nagar, Bangalore-560024. Karnataka.
Phone: +91-80-23545161
e-mail:samraksha@samraksha.org www.samraksha.org