Taking Care of Their Own: Mysore Sex Workers Unite in Leading HIV/AIDS Prevention

By

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ABSTRACT

This paper discusses how commercial sex workers in Mysore, India have taken ownership of the monitoring and evaluation process in an HIV/AIDS prevention program focused on improving their health. The HIV prevention project was implemented in 2004 and its success has been largely due to the sex workers being in the forefront of the endeavor since its inception. The community has been actively involved in all levels of the process including planning, design, implementation and monitoring and evaluation. They have been empowered to make healthier choices and to assert their human and legal rights in the public domain. The project utilized the World Health Organization's effective strategies on empowerment and pioneered some new approaches as well. Community ownership will be taken to a new level when the project is handed over to them at the end of 2009 in order to become a fully sustainable community-based organization (CBO).

Key words: HIV/AIDS, Empowerment, Sex Workers, India, Monitoring and Evaluation, Community Ownership
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1. BACKGROUND

1.1 HIV/AIDS Prevention Project in Mysore

In 2003, the Bill and Melinda Gates Foundation established the AIDS initiative, known as Avahan, to prevent the spread of HIV/AIDS in India. They targeted the six states in India with the highest infection rates, working closely with the Indian government and the National AIDS Control Organization (NACO) in India. Over the last five years, they have donated over 258 million dollars to support this cause (Avahan, 2008). In 2004, they granted the University of Manitoba enough funding for a five-year HIV prevention program to be implemented in the city of Mysore, which is located in the southern state of Karnataka. The Karnataka Health Promotion Trust (KHPT) was the main implementing body for this endeavor (Reza-Paul et al., 2004).

The project was targeted at commercial sex workers in Mysore and the neighboring districts. The objective was to build the capacity and self-esteem of sex workers through mobilization, legal and human rights training, literacy classes and education on the consequences of HIV/AIDS and how it could be prevented. Root causes of their vulnerability were addressed simultaneously with health needs by targeting perpetrators of structural violence (Halli et al., 2006).

The project has taken a peer-based approach. Guides, elected by the community, are sex workers themselves and relay information to other sex workers about conflict resolution, HIV/AIDS and services provided by the collective. A peer-based approach is beneficial because sex workers are much more open to information and advice offered by someone in the profession who shares similar experiences (Asthana & Oostvogels, 1996).
Because of this, peers make much more effective educators than outsiders. Building the capacity of the sex workers and the social solidarity amongst them ensures sustainability of the project.

_An outsider doesn’t stand a chance. We haven’t been in their shoes or experienced their lives. We’ve realized that it’s impossible to identify the most vulnerable and bring them into clinics without having strong roots in the community._

(Dr. Sushena Reza-Paul. Director, Mysore, Karnataka Health Promotion Trust.)

An essential part of the project’s success is that from the outset, the community was placed in the forefront. The sex workers have taken ownership over every stage of the project. This paper focuses specifically on community ownership of the process of monitoring and evaluation, including enumeration and mapping, planning and conducting a surveillance survey, outreach assessment and peer appraisal. It was thought that a community-led project should not merely be a standardized template, but should be sensitive to local needs, as well as dynamic and constantly evolving as the project progresses. This has been achieved through community ownership and empowerment of the sex workers.

The sex workers in Mysore have been actively engaged in the process of HIV/AIDS prevention over the last 4 years. They have met and surpassed the required strategies of empowerment as set forth by the World Health Organization. By actively involving the community and teaching them the skills to carry out the prevention activities, it has led to a collective that is confident and capable. It has also prepared them for the transition to a community-based organization (CBO) so that these efforts are sustainable.
1.2 HIV/AIDS in India

India is one of the largest and most populated countries in the world with over one billion inhabitants. The HIV/AIDS epidemic emerged later in India than in other countries, but the rate of infection soared in the 1990's giving India the largest HIV/AIDS population in the world next to South Africa (Chattopadhyay & McKaige, 2004). Previously it was thought that 5 million people in India were living with HIV, which is more than any other country. This statistic could not be replicated and a national household survey in 2007 led to a major revision of the prevalence estimate. Currently, there is a conservative estimate of 2.4 million people infected with HIV in India (UNAIDS, 2008). This may be less than 0.3% of the population, but percentages mask the magnitude of the problem in a country as populated as India.

HIV was first documented in Chennai (Madras) in the southern state of Tamil Nadu in 1986 (Steinbrook, 2008). The first official case in the country was a female sex worker, which created the perception that HIV/AIDS was only a disease spread by sex workers and confined to certain high-risk groups. It was not recognized as a public health concern for the general population. It has only been in recent years that the epidemic has been reframed as an urgent public health problem (O'Neil et al., 2004). The government’s initial response to HIV/AIDS in India was denial, which resulted in people not getting the proper education they needed to protect themselves and a lack of treatment for those already infected. The delayed response to the public health crisis also allowed the epidemic to spread unchecked at a rapid rate (Venkataramana & Sarada, 2001).

Although there are people living with HIV in all sectors of Indian society, all segments of the population are not at equal risk of infection. Demographic groups with
the highest risk of contracting the disease are sex workers, clients of sex workers, men
who engage in risky sex with men, and injection drug users (Evans & Lambert, 1997).
The role of commercial sex workers in perpetuating the spread of HIV in India is
inconclusive. However, mathematical modeling suggests that prevention interventions
targeted at female sex workers alone could halt the epidemic (Nagelkerke, Jha & de Vlas,
2002). The highest HIV prevalence rates are found in Maharashtra, Andhra Pradesh and
Karnataka and Manipur, Mizoram and Nagaland in the north-east. Four southern states
(Andhra Pradesh, Maharashtra, Tamil Nadu and Karnataka) account for around 63
percent of all people living with HIV in India (NACO, 2007).

The legal status of sex work in India is similar to that in Britain. The sale of sex
itself is not against the law, but all acts associated with it in the public domain, such as
soliciting, trafficking and pimping, are illegal (Evans & Lambert, 1997). Officially,
commercial sex workers do not exist as a professional entity or trade in India
(Chattopadhyay & McKaige, 2004). This acts to criminalize commercial sex workers and
makes them more vulnerable to structural violence from police, goondas or rowdies
(criminals), boyfriends, lodge owners, and brokers.

1.3 Sonagachi Project

One of the first efforts to develop an empowerment approach to an HIV/AIDS
prevention project targeting sex workers occurred in Kolkata (Calcutta). Sonagachi is one
of the oldest and largest red light districts in India (Gangopadhyay, 2005). The
HIV/AIDS initiative often referred to as the Sonagachi Project began there in 1991, along
with two other pioneer prevention programs in Mumbai (Bombay) and New Delhi. The
Sonagachi project was the only program of the three that achieved positive results. The founders Dr. Smarajit Jana and the All India Institute of Hygiene and Public Health (AIHAPH) framed the problem of HIV among sex workers in terms of improving occupational health. They included the sex workers in roles of power and decision-making, which was a novel approach at the time (Jana et al., 1999). They also established the short and long term results of condom use as being in the best interest of stakeholders (madams, police and political parties), as well as sex workers. The other two programs were unsuccessful. One of the failed programs mobilized police to force women to attend clinics, which fostered fear and stigma of the services. The other defined the problem in terms of sex workers alone and ignored the larger social structures that made these people more vulnerable to infection (Jana et al., 2004).

The Sonagachi project is internationally recognized as a success in preventing the spread of HIV and is a model of best practice approaches to other prevention efforts targeted at commercial sex workers throughout the world (Wallerstein, 2006). Condom use has greatly increased in Kolkata from 3% in 1992 to 90% in 1999. Despite having over 10,000 sex workers, the HIV prevalence rate in Kolkata has remained low (Jana et al., 2004; Basu et al., 2004). In 1999, the New York Times commented that, “it is the [sex workers] themselves who have become the leading crusaders against AIDS” (Dugger).

The Sonagachi project began as an STI clinic targeting sex workers. The project quickly became a community support structure for individuals to be empowered to demand safer sex practices and by doing so to reduce the risk of HIV/AIDS (Romero et al., 2006). The project employed sex workers as peer educators to propagate information on prevention and awareness. They created a collective called ‘Durbar Mahila
Samanwaya Committee’ to promote community solidarity and address problems that were faced (Gangopadhyay, 2005). The sex workers themselves currently own and run the Sonagachi project independently, thus making it a sustainable resource (Reza-Paul et al., 2004). This has been a best practices model from which the project in Mysore was shaped and developed.

2. METHODS

2.1 Research Methods

The data for this project was collected in Mysore, India over a three-month period. The researcher was there on practicum as a requirement for her Masters in Public Health, along with three other colleagues. Each student had a different research question from which to approach the project. ‘Ashodaya Samithi’ is the name of the sex worker collective in Mysore, which means ‘ray of hope’. It has been a successful project since its inception, but the community has not had the time or skills to document the work that has been done. They decided it would be beneficial to them if we were to produce a series of detailed, process documents about certain key aspects of the project such as mobilization, enabling environments, structural violence and monitoring and evaluation. They would then use these documents as learning tools at their training site. My process document focused specifically on community-based monitoring and outreach.

Interviews and focus groups were held at the drop in center with a translator. All interviews were recorded and one of my colleagues would transcribe directly onto the computer as I conducted the interview. Purposeful sampling was used to select the eleven people who would be interviewed.
interviewees who had knowledge or experience with community-based outreach and monitoring. Ashodaya, along with my key informant, Syed, helped to determine which sex workers and staff would be the most informative in regards to my research question. This capstone was written using information collected from all of the interviews and focus groups, key informants, participant observation and reviewing office documents.

2.2 Community Ownership of the Research Project

The community displayed ownership of the research process and results. The interview guidelines that we developed were reviewed and approved by the community (Ashodaya), the Project Director, Sushena Reza-Paul, and Dr. Rob Lorway before we commenced the interviewing process. The guidelines were revised based on the comments and suggestions that were received.

At the end of the interviewing process, we presented our findings to the community to ensure that the results were accurate and acceptable to them. We presented our results on the main floor of the drop in center to which all community members were welcomed and had equal access. A member from the technical team, Syed, translated the presentations into the local language, Kanada. This exercise was very helpful and we gained valuable feedback on our projects. We were impressed to see the community actively engaged and interested in the work that were doing.

2.3 Limitations

One of the biggest limitations of the research project was the language barrier. Very few sex workers spoke English, which made interactions quite difficult. We made an honest attempt at learning the local language, but conversations were limited in scope.
The majority of interviews took place with a translator, which broke up the flow of the dialogue. It was also difficult to engage in participant observation. A member of the project staff would give us a debriefing after community meetings, but the richness of detail and meta-text was gone.

Mysore is a learning site for training partners all over India. The staff is often very busy helping to train and build the capacity of sex workers in neighboring districts and cities. This led to many disruptions in our research. Interviews would often have to be cancelled because there was no one available to translate.

3. Capture/Recapture

3.1 Enumeration and Mapping

One of the first priorities when the project was implemented was to determine the number of sex workers in Mysore and to map out the main areas of solicitation. This was a difficult task because sex workers at this time went to great lengths to conceal their identity in fears of being discriminated against and persecuted. There was little communication even between sex workers themselves. The technical team wanted the community to take ownership of the project in this early phase and felt that they should be the ones to determine the number of sex workers in the city. They felt the community would be more likely to accept the number if they came up with it on their own. It was also felt to be a good opportunity to strengthen solidarity and build their capacity. Through networking, the sex workers pieced together rough estimates, but they did not come up with a definitive figure.
3.2 Bridging the Scientific Gaps

Sushena Reza-Paul, the project coordinator, taught the sex workers a scientific method that is commonly used to estimate an unknown population size in epidemiology. She agreed to bridge the scientific gaps, but insisted that the sex workers carry out the exercise on their own. The method that was used was referred to as capture/recapture in which you identify and tag a number of the population on two occasions and compare the number that had been marked originally to the number of new participants. Through mathematical modeling you can then estimate the size of the population (Gordon & Gordon, 1992).

3.3 Building Community Solidarity

The sex workers trained some of the other community members to help carry out the task. They decided to use lottery tickets as a way of marking people from the first capture. Those conducting the exercise were instructed to stay within their boundaries and give each sex worker only one ticket. When they approached an individual, they would explain the project and determine if that person was already in possession of a ticket; if they were not, they would be issued one. The distribution of tickets continued for 24 hours. On the second day of the research project, the trained community members handed out lottery tickets again, but if someone already possessed a ticket they would issue the recaptured sex worker an invitation card to the drawing of prizes.

The draw took place on February 8, 2004. Approximately 150 sex workers attended this event and brought their children and families. The staff used this
opportunity to speak to them about the project's objectives. Raghu is a male sex worker who currently holds a shadow position within the collective. There are only 8 sex workers in shadow positions. They are being trained to fulfill the role of the non-community technical team in order to make the project sustainable. He remarked that this event was the first time he remembers feeling like he was part of a community, as though “they” were “we” (2008).

From this method they determined there were approximately 1,420 female sex workers within Mysore who were predominantly street based. It was understood that in order for the community to take ownership and be willing to participate, they must understand the importance and usefulness of the knowledge being gained. This was achieved in the enumeration exercise where community involvement and acceptance were established as key assets and values from the outset of the project.

4. IBBS (INTEGRATED BIOLOGICAL AND BEHAVIORAL SURVEY)

4.1 Surveillance Survey

Since the project’s inception in 2004, the impact of the prevention efforts and trends of the epidemic in Mysore have been monitored through a surveillance survey. The integrated biological and behavioral survey (IBBS) was conducted by and for the community to determine the prevalence of HIV infection and syphilis among them, to assess sex workers’ knowledge and beliefs about STIs and HIV, and
to obtain baseline data that would permit comparisons of risk behaviors and HIV infections over time. It was conducted first in June of 2004, again in June of 2006, and will be carried out for a third time in 2009.

The survey's basic design follows World Health Organization guidelines with the appropriate revisions in order to sensitize the survey to the local environment. The IBBS was administered in Mysore and completed within 10 days. They surpassed all of their projected target numbers. Its success was largely due to the fact that the staff trained the community to conduct the survey themselves. This site became a model to the neighboring districts on how to mobilize, involve, and empower the communities they serve.

4.2 Capacity Building

The training of the staff to implement the survey involved helping them to understand the theory behind the IBBS and the importance of knowing the prevalence of HIV in their community. Knowing the number of those infected would allow the guides to be more confident in communicating the risk to their peers. They were also taught practical aspects of the survey such as gaining consent, conducting the behavioral survey and how to collect the biological samples. Two days were spent training the sex workers on how to conduct the survey. Mock interviews made the participants more comfortable. They were encouraged to familiarize themselves with the questionnaire so it could be conducted in more of a conversational manner.
The guides recognized the importance of the survey and began to take control of the project. They were able to mobilize the community and reiterate the need for people to participate. Many community members volunteered to help out with the survey in either participant recruitment or in making sure ethics were adhered to. It was discovered that 24 percent of the community was infected with HIV, a number significantly higher than the general population. The final results were shown to the community first, it was up to them to decide how and to whom the information would be disseminated. Not only did this survey allow the community to obtain baseline data in which to monitor their progress and be better able to communicate risk of HIV to their peers and the general public, it also led to team building and mobilization of the community.

Of particular concern to the community members was the impact that the results of the IBBS would have on the community. If HIV rates were reported to be high, this was perceived to have potentially devastating effects on the morale of the community members, as well as on their financial welfare if clients decided the risk was too high in the Mysore environment. Extensive discussions took place between the IBBS team and community members and it was agreed that results would first be reviewed at the community level before being released to funders or the public. Workshops were organized to explain IBBS results and sex workers became fully involved in interpreting the results for both internal and external distribution. Other safeguards were also put in place to ensure a degree of confidentiality around the specificity of the locale for public distribution of the results. Ashodaya was also
involved in efforts to mobilize public opinion in support of their efforts to prevent HIV transmission.

5. RATIO BASED VS. SOCIAL NETWORK BASED OUTREACH

5.1 Ratio-Based Outreach

Guides or peer educators were chosen at the outset of the project based on geographical location, strengths and availability. The women who were the most popular and influential were recruited, as they had the most contacts and could, theoretically, mobilize the most community members. They obtained knowledge from the training site about HIV and other STIs such as prevention methods, identification of symptoms, and where to access health services. They would bring this information to the field and relay it to the larger community. Essentially, the peer educators acted as the bridge between the community and the project.

We started developing friendships among community members and focused on bringing them together. We started giving info about STIs and risks. We started disseminating this info and giving our own testimonials, like this happened to me and it could happen to you. (PC Rathna, 2008)

The reasoning behind peer-based outreach is that sex workers have shared similar experiences and will be more likely to trust someone in the same line of work than an outsider who is delivering the same message. When a guide approaches a community member for the first time, they do not mention the project immediately. They take the time to get to know the individual and share their own
experiences as a sex worker. Over time, they share the information and importance of the project as well as the health services and other opportunities that are available to them.

Since the project’s inception in 2004, outreach has evolved from a ratio-based to a social-network based approach. In the original ratio-based outreach, contacts were divided equally among the guides. They were each assigned 30 to 40 contacts within their geographical zone and expected to mobilize them. This method proved to be very limiting and rigid. It did not take into account people’s relationship with their contacts and networks or their influence over them. Some people were presenting over and over but new contacts were not being reached. It soon became evident that they needed to come up with new strategies for outreach.

5.2 Social Network-Based Outreach

After the first 8 or 9 months of the project, following the first IBBA, there was a transition to social network-based outreach. The staff explained the significance of this new approach to the guides. It was and is important for the community to understand the reasoning and importance of the strategy and to take ownership of it, in order for it to be successful. The staff realized that the nature of the relationship was more important than the mere presence in the same geographical area because the information they were dealing with was so personal and invasive. The staff sat with each peer educator and made a list of contacts who they were closest to and who they felt they had the most influence with. From this information, they constructed the new networks.
The mapping of the networks took 3 to 4 days to complete and in the end, 20 networks were established. It emerged that guides could influence certain contacts directly and others only indirectly through another contact, termed a node. If it were discovered that this nodal agent had a lot of strong contacts and were willing, they would be recruited as guides themselves. Initially, there were only three guides, but this slowly increased over the last few years to seven then twelve. Currently, there are 36 guides operating the project in Mysore.

The staff cross-referenced all the networks. In places where there was overlap, they would sit down with both guides and determine who had the best rapport with that particular person and therefore the most influence. With this method, the number of contacts that a guide was responsible for was not uniform. Some would have only 25 contacts while others may have more than 50. Those guides who had fewer than 10 in their network stepped down as peer educators. One woman who was extremely integrated and involved in the community had 110 contacts. She was a broker, had excellent problem-solving ability, good contact with politicians and government officials and participated in many community activities. This was an extreme case, but it solidified the idea that new networks were being constructed based on the skills and influence of the guides.

With the original ratio-based methodology, the guides were only able to reach 250 members. This number increased drastically with the transition to a social network-based outreach. By trial and error, it was established that outreach efforts needed to be more dynamic in order to incorporate the community's ever-
growing needs. There has now become a strong sense of solidarity amongst the collective and everyone knows one another. The networks have slowly evolved and merged over time. This type of outreach requires a constant monitoring and evaluation system in order to assess the progress of mobilization and modify techniques accordingly to continually reach more and more people.

6. **PEER APPRAISAL**

6.1 *Community-Based Monitoring and Evaluation*

Shortly after the project commenced, the community decided that they should have some sort of monitoring system or tool in order to assess their progress with outreach. Weekly monitoring began in which each guide (peer educator) filled out a form that included their name and the month, as well as the names of their assigned contacts. This was a way for them to document their activities in the field and for the staff to assess the quality of their work.

Originally, the guides had defined 5 or 6 different activities to appear on the sheet which included condom distribution, complete and incomplete information delivered in the field, identification of STIs, health check-ups, and follow-up of PAT (pre-asymptomatic treatment). For each activity, they came up with a corresponding symbol that they could mark down on their sheet in order to keep track of their work in the field.
Symbols were used in order to be sensitive to those community members who were illiterate and could therefore not recognize their contact's names nor record the daily events. Symbols were not only determined for activities, but they were also used to make associations with each contact. As an example, if someone wore glasses, the guide would put a picture of spectacles next to their name. If someone brought in flowers, the guide would use a picture of a flower to represent that contact and if someone were always on their mobile phone they would use this symbol to represent them on their sheet. This also proved helpful in distinguishing between contacts if more than one of them had the same name. The community also implemented literacy courses, which everyone was welcome to attend.

A supervisor who was a non-community member would sit with each guide at the beginning of the week and help them outline a detailed plan of action for the next seven days. An example of such a plan might be that they would bring four specific contacts in for a health check-up on Monday and three others for follow-up treatment on Wednesday, etc. It often happened that something would come up in the field that would prevent the guide from carrying out their delegated tasks; they might go to the field and find that their contacts would not be there or they would get interrupted in their discussion of STI symptoms with a particular community member.

6.2 Revised Monitoring Sheet to Meet Community Needs

If a guide fell behind in their plan of action, they would often get confused and be unable to complete their planning sheet. The system lasted only a few
months as the guides and staff quickly realized that this method was inherently flawed and proven to be unsuccessful. The nature of sex work seemed to require a monitoring system that was much more flexible. They realized that they needed a monitoring system that was more dynamic and fluid in order to cater to the spontaneity of the field.

After the first IBBA (Integrated Biological and Behavioral Assessment) in July of 2004, the monitoring system was reassessed and the monitoring sheet was revised accordingly. The IBBA showed that rates of STIs were very high among the community and so they added a few more activities to their sheet in order to address this issue. Group discussions are an example of one of the additional activities. The guides would hold meetings with three or more contacts in the field in which they would relay information on how to identify the symptoms of various STIs and what to do if they presented with those symptoms.

The guides and staff also realized that building rapport within the community and increasing self-esteem and support of the project was just as important as promoting HIV awareness and utilization of the health services. It was essential for the collective to have a strong sense of solidarity and belonging. For this reason, activities such as attending rallies, community meetings, talking to the media, registering new members and identifying underage sex workers (anti-trafficking) were also defined as key activities for the guides to undertake. Symbols were decided upon to represent these activities on the monitoring sheet. In
addition, group norms were established such as not drinking in the field or causing
disturbances, attendance at guide meetings, and punctuality.

6.3 Self-Assessment of the Guides’ Work

The revised monitoring sheet included the names of each guide’s contacts
down the side and each day of the month across the top. In each slot, the guides
would record their daily activities using the symbols they created with respect to
each contact. This sheet served as a way for them to assess their own work and plan
their activities.

At the end of the day, I fill up my monitoring sheet so that I know exactly who I’ve
made contact with, what kind of help they need and what my next steps will be.
(Rathnama, 2008)

If the slots following one of their contacts’ names were blank for a few days,
the guide would know they had to spend more time with that person. With this
system, they were able to identify gaps in their activities and change their behavior
accordingly. This was also a way for the staff to find out how many sex workers
were being reached and what information they were receiving. They were able to
reveal overall gaps in the outreach and come up with solutions to problems that
arose.

It is very useful for us to assess our own activity, we can just go to the monitoring sheet
and see what we have done, who we left out, and see why we had not met her last
week. Like that we can do follow-ups also. If I did not bring her, and I need to bring
her within 3 days, then I will do the follow-up that I see as reminder on this sheet.
(Vijiyamma, 2008)
The monitoring sheet has continually evolved over the last four years based on need and activity of the community. It currently has 16 symbols representing the different activities done by the guides in the field. See Figure 1 for a list of these activities. Initially, some of the guides had a difficult time remembering which symbol corresponded to which activity. The staff would sit with them each week on an individual basis and go over it as many times as necessary to ensure that they were comfortable with the system.

<table>
<thead>
<tr>
<th>Activity</th>
<th>Symbol</th>
<th>Activity</th>
<th>Symbol</th>
</tr>
</thead>
<tbody>
<tr>
<td>STI identified</td>
<td>Δ</td>
<td>Group discussion</td>
<td>: :</td>
</tr>
<tr>
<td>Health check-up</td>
<td>C</td>
<td>New contact</td>
<td>→</td>
</tr>
<tr>
<td>One-on-one education complete</td>
<td>•</td>
<td>Taken to clinic and treated</td>
<td>+</td>
</tr>
<tr>
<td>One-on-one education incomplete</td>
<td>O</td>
<td>Partner treatment</td>
<td>♥</td>
</tr>
<tr>
<td>Condom distributed</td>
<td></td>
<td>Referral</td>
<td>F</td>
</tr>
<tr>
<td>STI follow-up</td>
<td>□</td>
<td>Violence</td>
<td>☻</td>
</tr>
<tr>
<td>SHG membership</td>
<td>↑</td>
<td>Police Raid</td>
<td>R</td>
</tr>
<tr>
<td>Literacy classes</td>
<td>1</td>
<td>Registration of new Membership</td>
<td>↑ ↑ ↑ ↑</td>
</tr>
</tbody>
</table>

Figure 6.1: A list of the different activities on the peer appraisal self-monitoring sheet and the corresponding symbols. Symbols are used in order to be sensitive to those guides who are illiterate. The monitoring sheet originated with only 5 symbols (first five on the left) in 2005 and now has evolved to have 16.

The guides have commented that it was not too difficult to learn since they started with only 6 symbols/activities and have slowly added to them over the
years. They feel very comfortable and familiar with the current monitoring sheet. When asked if the sheet could be simplified, one of the guides replied:

> Actually, this monitoring sheet is simple. Earlier it looked very difficult because the symbols were new to us. But once we started using it, it got a lot easier. If violence happens, we just mark down which name and date or if someone got a condom we just check it off. (Bhagya N., 2008)

The peer educators currently meet every morning at Ashodaya for a guide’s meeting. Attendance at these meetings has been established as a community norm and given great value. If someone is absent at any of these meetings and without a valid excuse, they have points deducted from their monitoring sheet. During these meetings, the guides share their activities from the previous day and discuss any problems or issues that arise such as instances of violence or trafficking in the field. They go over the event in detail and plan what further actions need to be taken.

At the end of 2005, the community discovered that some guides were working very hard and effectively while others were not quite meeting the mark. They decided they should design a way of appraising their performance and quality of work in the field. A guides’ assessment form was created which included different aspects of evaluation for each guide such as level of mobilization, communication skills, attitude, problem solving ability, knowledge about STI and HIV, punctuality, etc. Initially, supervisors who were non-community members were collecting this information. Over time, the guides decided this was something they should take on themselves.
Earlier, supervision had to be done by non-community staff, but now we took on this role ourselves. We do the monitoring and see what activities are completed or not. In the field, we do the supervision. We belong to same community and operate in same area. (Vijiyamma, 2008)

6.4 Outreach Management Committee

An outreach management committee (OMC) was formed which dealt with issues that arose in the field and the assessment of the guide's work. Currently, there are 12 people on the committee. Eighty percent are from the community, including guides and shadow positions and 20 percent are non-community members. They meet once in 15 days to discuss outreach-related activities and the performance of each guide. If problems arise that require immediate attention, such as instances of violence in the field, an emergency meeting is called.

At the end of each month, when the guide has completed their monitoring sheet, it is given to the OMC. The committee also does qualitative interviews in the field with the guide's contacts in order to assess their work and crosscheck the events on the sheet. These interviews are very informal and usually consist of a casual conversation with the community member regarding the guide's availability and work for that month. The committee decided on a minimum of 5 contact interviews for each guide per assessment, yet on average they typically speak with 8 to 10 of the guide's contacts.
6.5 *Top-down and Bottom-up Assessment*

Because the community is so well integrated, the community members understand the guide's responsibilities and even some of the symbols on the monitoring sheet. They often give unsolicited feedback about the guides to the OMC or staff of Ashodaya, if they feel a guide is not doing her work properly or causing problems in the field. Thus monitoring is being done from the bottom-up as well as the top down.

*We have many friends there so they will tell us if she is not doing her job. Even the community members do this observation and interference. They know feedback will get to us, we have a good rapport with them. In this way, monitoring is from the bottom level also.*

(Bhagya N., 2008)

From the information collected through field observations and the guide's assessment sheet, the guide is given a color as a grading for their work: green for good, yellow for fair and red for not satisfactory. Peer appraisal takes place once in three months. The information from this assessment form along with the monitoring sheets are compiled and recorded onto a final rating sheet, which is then used to evaluate each guide's performance.

6.6 *Consequences and Rewards of Peer Appraisal*

Based on the peer appraisal, guides are either promoted or demoted. If a problem arises, the OMC speaks to the guide on an individual basis, identifies the problem they are facing and tries to offer solutions. As an example, if there is a new guide who knows many people in the community but does not have good
communication skills or feel knowledgeable about HIV and STIs, they will work on this problem with them. They may pair them up with a senior guide in order to help them learn by observing the way that person relays information to their contacts and builds rapport.

One case that illustrates the issues that the OMC faces in their oversight role involved a new peer educator who started off doing an excellent job for the first 8 months. She had a strong rapport with the community and solid communication skills. She suddenly started creating problems. She would drink and cause disturbances in the field by picking fights with the other community members. In cases such as these, the OMC will issue the guide a warning and work with them on resolving the issue. If their behavior does not change they may reduce their honorarium or have them work for three months as a volunteer, depending on the severity of their infraction. In this particular case, the woman was issued a warning to 'clean up her act' in the next three weeks and when she failed to do so, was removed as a peer educator. The community makes the final decision of whether to demote or remove the guide if performance is not satisfactory or if she/he has created any problems in the field.

In the same manner, guides are also rewarded for outstanding performance. They are often given an increase in their honorarium or promoted to senior guide or community consultant. This is done to show recognition and appreciation for their hard work. It should be noted that the honorarium is only a small stipend and not comparable to what they make in the field as a sex worker. In order to be promoted
to the next level, the guide must perform consistently well for 2-3 consecutive assessments.

Community-based monitoring of outreach activity was implemented very early on in the project’s development. It has continually been built upon and revised as the community sees fit and continues to evolve even today. It is essential in monitoring and evaluating the work that is being done by the guides in the field and for ensuring that more and more members are being reached and encouraged to join the collective. It is an ongoing process, which continues to evolve as the project advances.

7. EMPOWERMENT

7.1 Empowerment

The term ‘empowerment’ has been used quite frequently in the academic literature and is currently a very popular buzzword for measuring a programs’ success. It has been defined as a process by which people, organizations and communities gain mastery over their own affairs (Rappaport, 1987). The World Bank defined empowerment as “the process of increasing capacity of individuals or groups to make choices and to transform those choices into desired actions and outcomes” (Wallerstein, 2006).

One of the major objectives of the HIV/AIDS prevention project in Mysore, and throughout India, is to empower commercial sex workers. It is thought that through empowerment their health circumstances will improve as they gain the confidence and
skills to assert themselves. This will not only ensure that they demand their clients wear condoms, but will also allow them to make better choices on which clients they accept and locations they choose for the sexual transactions.

7.2 Effective Empowerment Strategies

In 2006, the WHO outlined four effective empowerment strategies for health promotion in order to ensure that participation is empowering. The strategies were: to increase the communities’ skills, control over resources, and access to information; use small group efforts, which enhance critical consciousness on public health issues, build a greater sense of community and supportive environments; promote community action through collective involvement in decision-making and participation in all phases of public health planning, implementation and evaluation; and be sensitive to the health care needs defined by community members themselves. I will go through each of these strategies in sequence and provide examples of how Ashodaya has adopted them to achieve true empowerment of the sex workers in Mysore.

The first strategy is to increase the community members’ skills, control over resources and access to information (WHO, 2006). The sex worker collective in Mysore is called ‘Ashodaya Samithi,’ which means ‘ray of hope’. The collective has their own drop-in center that is located close to the city center and is open to all of their members. It is a space that is truly their own where they feel comfortable and can talk openly about their problems and experiences. The main floor of the building is where the daily meetings are held and where the secretary, treasurer, president and vice president have
their desks. The upstairs is an area where people can come to rest and relax. Mats and pillows are supplied to facilitate this. There is also a clinic and counseling room where the sex workers and their families receive health check-ups and STI treatments free of charge. Other resources offered in the building include a community kitchen and beauty parlor.

Many classes are offered through the collective including literary classes, HIV/STI awareness and public speaking. In addition to this, there is a peer-based educational approach in which senior guides inform their contacts in the field about the repercussions of HIV and other STIs, how to protect themselves, how to recognize symptoms and what to do if they present with them. This method greatly increases the entire communities’ access to information.

In 2009, Ashodaya hopes to transition to a community-based organization. In anticipation for this, eight sex workers currently hold shadow positions in which they spend quality time each day with the member of the technical team whom they will be replacing. The purpose of this is to build their capacity to perform the particular role so they can eventually take it over, such as going to the police station to diffuse a heated situation or developing strategies for expanding outreach.

The second effective empowerment strategy as outlined by the WHO is using small group efforts, which enhance critical consciousness on public health issues to build a greater sense of community and supportive environments [2006]. Ashodaya has several smaller groups within the collective who meet on either a daily or fortnightly basis. There are 36 peer educators who meet every day to discuss any problems that arise in the field as well as communication and outreach strategies.
They even do peer appraisal every three months to monitor their own work and ensure their efforts are being effective, as discussed earlier.

‘Ashraya’ is the name given for the HIV positive support group within Ashodaya. There are currently over 400 members. They meet once in fifteen days to share their experiences and any problems they have been facing. The members are very grateful for this additional support in their lives.

*Here there is an opportunity for the positive people to work for their own rights. The main purpose of this organization is to prevent HIV/AIDS. I like very much how they approach positive people and show us love and affection. I got the training of the HIV prevention and can talk in front of everyone.*

(Sheankar, Ashraya member, 2008)

The third empowerment strategy is promoting community action through collective involvement in decision-making and participation in all phases of public health planning, implementation and evaluation. The HIV prevention project in Mysore has achieved this in all aspects. Examples of this come from the community involvement in the enumeration exercise, the integrated biological and behavioral survey and community-based monitoring and evaluation.

The WHO's last effective empowerment strategy is to be sensitive to the health care needs defined by community members themselves (2006). Ashodaya has catered to the community’s health needs from the beginning of the project. One recent example of this was the opening of a second drop in clinic last year on KR circle. This is in the heart of a highly commercial area where the majority of sex workers go to solicit, otherwise known as the B-zone. The sex workers asked for this additional service and suggested that it be located close to where they work so they...
did not have to travel a far distance to get health check-ups and treatment, saving them both time and money.

Participation is very important for empowerment, but alone it is insufficient. Participation can often be passive rather than empowering. It is not just a matter of showing up. For true empowerment to be achieved, it is necessary to promote capacity building amongst the community and to involve the members in decision-making and advocacy (Cornwall, 2003). It is essential that the community take ownership over the work that is being done. Ashodaya is a leading example of this best practices approach.

8. DISCUSSION

The success of the HIV prevention project in Mysore is largely due to the fact that the community has been at the forefront of the endeavor since the very start. Involving the sex workers in decision-making, building their capacity to carry out what needs to be done and creating an enabling environment that is sensitive to their many needs have been core objectives and realized in all aspects of the project. The community has taken particular responsibility for the ongoing monitoring and evaluation, which allows them to track their own progress and identify any gaps in their activities.

The sex workers have taken ownership over all aspects of monitoring and evaluation including enumeration and mapping, conduction of the surveillance survey and collection of baseline data, managing clinical services, outreach planning, and peer appraisal. This has allowed them to understand the importance of the information being gained and to promote a high level of compliance with data
collection in a community who only five years ago were completely disassociated and unwilling to identify as a sex worker in fear of stigmatization and discrimination.

Before Ashodaya we were scattered here and there. Never had any sense of belonging. Now we are like children of one Mother. (Anonymous, 2008)

The Mysore intervention utilized and pioneered many best practice approaches to HIV prevention among sex workers. The project showed early signs of success and in 2007 was awarded an additional grant by the Bill and Melinda Gates Foundation to implement a learning site (Reza-Paul et al., 2007). The Mysore Learning Site allows the community members to share their knowledge and experience with other sex workers throughout India. Through participatory visits, the learning site provides hands-on training to educate partners in order to improve HIV/AIDS intervention development within Karnataka and the rest of the country.

Members of the sex worker collective in Mysore have taken charge in the fight against HIV/AIDS. They have truly been empowered in all senses of the word, which has led them to make healthier choices and increase their self-esteem. They are going a step further in terms of community ownership, as they prepare to transition to a sustainable community-based organization (CBO) by the end of 2009. This will allow the sex workers to run and operate the project independently creating lasting, long-term results. Eight sex workers are currently in shadow positions, learning the roles and skills of the technical team in anticipation of taking over this responsibility and making the transition possible. As one sex worker of Ashodaya put it, “this is only the beginning and our fight continues...”.
Figure 8.1: Members of Ashodaya and Adarsha show their affection to one another after participating in the ITPA rally downtown Mysore.
Figure 8.2: Members of Ashodaya at a house warming celebration for a former driver of the organization.

Figure 8.3: Members of Ashodaya, Adarsha and sex workers from Mumbai, training at the Mysore learning site, prepare for a community meeting with the MLA.

Figure 8.4: Members of Ashodaya and Adarsha at the drop in center in Mysore.
Figure 8.5: Sex workers from Mysore and neighboring districts participate in a rally to protest the Immoral Trafficking Prevention Act (ITPA), which would essentially criminalize sex workers and drive the industry underground, making HIV/AIDS prevention efforts very difficult.

Figure 8.6: Ashodaya’s vice president, Baghya Lakshmi, leads fellow sex workers throughout Mysore during the ITPA rally. They march through the highly commercial area, KR Circle, and in front of the Maharasha palace.
Figure 8.7: Members of Ashodaya and Adarsha assert their legal and human rights as sex worker professionals. Just five years before, this vulnerable group did not communicate with one another in fear of being identified as a sex worker and discriminated against.

Figure 8.8: Ashodaya President, Rathnama, speaks to the media on behalf of the collective about how the ITPA will negatively affect HIV/AIDS prevention efforts.
Figure 8.9: Members of the technical team who have supported the sex workers from the project’s inception in 2004. KT and Venu assist with mobilization and outreach efforts. Suma is a counselor for Ashodaya. All health services are offered free of charge to the sex workers and their families.

Figure 8.10: Ashodaya’s president, Rathnama, and secretary, Prakash, along with two peer educators prepare for a community meeting. The community meets twice a week to discuss any issues or problems within the collective or in the field. All major decisions are voted on and determined by the community.
Reference List:


**Interviews:**

- Raghu (Adarsha member/ shadow position)
- Vijiyamma (Ashodaya member/ Shadow position)
- Rathnama (Ashodaya member, President)
- Shreankar (Adarsha/Ashraya member)
- JSyed (Technical team member/ Outreach Supervisor)
- Sushena Reza-Paul (Program Director)
- Nagendra (Adarsha member/ Shadow position)
- PC Rathna (Ashodaya member)
- Baghya N (Ashodaya member)

**Translators:**

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- Fathima Mary