

**EXAMINING THE ROLE OF CBOS IN PEER SUPPORT, ACCESS TO
CARE AND TREATMENT ADHERENCE FOR PEOPLE LIVING WITH
HIV/AIDS IN MYSORE, INDIA**

by

Lisa Lazarus

B.A., McGill University, 2004
Special B.S.W., McGill University, 2005

PROJECT SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF PUBLIC HEALTH

In the
Faculty of Health Sciences

© Lisa Lazarus 2010

SIMON FRASER UNIVERSITY

Summer 2010

All rights reserved. However, in accordance with the *Copyright Act of Canada*, this work may be reproduced, without authorization, under the conditions for *Fair Dealing*. Therefore, limited reproduction of this work for the purposes of private study, research, criticism, review and news reporting is likely to be in accordance with the law, particular if cited appropriately.

Approval Page

STUDENT 'S NAME: Lisa Lazarus
DEGREE: Master of Public Health
TITLE: **EXAMINING THE ROLE OF CBOS IN PEER SUPPORT, ACCESS
TO CARE AND TREATMENT ADHERENCE FOR PEOPLE LIVING
WITH HIV/AIDS IN MYSORE, INDIA**

Examining Committee:

Chair of Defense:

Dr. Pablo Nepomnaschy
Assistant Professor
Faculty of Health Sciences

Senior Supervisor:

Dr. John O'Neil
Professor
Faculty of Health Sciences

Supervisor:

Dr. Robert Lorway
Assistant Professor
Community Health Sciences
University of Manitoba

External:

Dr. Nicole Berry
Assistant Professor
Faculty of Health Sciences

Date Defended/Approved: August 16, 2010



SIMON FRASER UNIVERSITY
LIBRARY

Declaration of Partial Copyright Licence

The author, whose copyright is declared on the title page of this work, has granted to Simon Fraser University the right to lend this thesis, project or extended essay to users of the Simon Fraser University Library, and to make partial or single copies only for such users or in response to a request from the library of any other university, or other educational institution, on its own behalf or for one of its users.

The author has further granted permission to Simon Fraser University to keep or make a digital copy for use in its circulating collection (currently available to the public at the "Institutional Repository" link of the SFU Library website <www.lib.sfu.ca> at: <<http://ir.lib.sfu.ca/handle/1892/112>>) and, without changing the content, to translate the thesis/project or extended essays, if technically possible, to any medium or format for the purpose of preservation of the digital work.

The author has further agreed that permission for multiple copying of this work for scholarly purposes may be granted by either the author or the Dean of Graduate Studies.

It is understood that copying or publication of this work for financial gain shall not be allowed without the author's written permission.

Permission for public performance, or limited permission for private scholarly use, of any multimedia materials forming part of this work, may have been granted by the author. This information may be found on the separately catalogued multimedia material and in the signed Partial Copyright Licence.

While licensing SFU to permit the above uses, the author retains copyright in the thesis, project or extended essays, including the right to change the work for subsequent purposes, including editing and publishing the work in whole or in part, and licensing other parties, as the author may desire.

The original Partial Copyright Licence attesting to these terms, and signed by this author, may be found in the original bound copy of this work, retained in the Simon Fraser University Archive.

Simon Fraser University Library
Burnaby, BC, Canada

STATEMENT OF ETHICS APPROVAL

The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

(a) Human research ethics approval from the Simon Fraser University Office of Research Ethics,

or

(b) Advance approval of the animal care protocol from the University Animal Care Committee of Simon Fraser University;

or has conducted the research

(c) as a co-investigator, collaborator or research assistant in a research project approved in advance,

or

(d) as a member of a course approved in advance for minimal risk human research, by the Office of Research Ethics.

A copy of the approval letter has been filed at the Theses Office of the University Library at the time of submission of this thesis or project.

The original application for approval and letter of approval are filed with the relevant offices. Inquiries may be directed to those authorities.

Simon Fraser University Library
Simon Fraser University
Burnaby, BC, Canada

Abstract

To meet the HIV prevention needs of sex workers in India, well-coordinated community-based organizations (CBOs) have integrated peer education and community mobilization into structural interventions. As the role of CBOs continues to expand into new service areas, it is important to understand how people who frequent these organizations receive these new interventions. This paper draws on an agency assessment conducted by Ashodaya Samithi in 2009, a CBO led by female, male and transgendered sex workers. In the past year, HIV+ sex workers of Ashodaya have registered their own organization, Ashraya. Based on qualitative findings, this paper describes how community-based empowerment programs can play important roles in improving access to care and antiretroviral (ART) treatment adherence. The rapid growth of Ashraya and its success at fostering social solidarity and large-scale structural interventions hold valuable lessons for community-based organizations and public health practitioners working in the field of HIV/AIDS.

Keywords: community-based organizations; sex work; HIV; access; support; treatment; India; structural interventions

Acknowledgements

With special thanks to everyone at Ashraya, Ashodaya and DISHA for all of their support on the project., especially Seema Jairam, Syed Hafeez Ur Rahman and Akram Pasha. I would like to thank my supervisors, Dr. Robert Lorway and Dr. John, O'Neil, as well as Dr. Sushena Reza-Paul. This project would never have come to be without their tireless support. Their indispensable advice and thoughtful instruction guided every aspect of this work. I would especially like to thank Dr. Lorway for his constant encouragement over the course of the past two years. Finally, I would like to thank my family and friends for always believing in me and pushing me to go further. Funding was received from a CIHR Frederick Banting and Charles Best Canada Graduate Scholarships - Master's Awards.

Table of Contents

Approval Page	ii
Abstract	iii
Acknowledgements	iv
List of Tables	vi
Introduction	1
Methods	4
Site Setting and Study Design	4
Data Collection	4
Interview Participants	6
Data Analysis	7
Ethical Consideration.....	7
Results	8
The Role of Peer Support	8
Accessing Care: Decreasing Barriers through Peer Accompaniment.....	10
ART Treatment Adherence	13
Discussion	15
Study Limitations	17
References	18

List of Tables

Table 1: Participant Characteristics	6
--	---

Introduction

Epidemiologists have characterized the HIV epidemic in India as concentrated within “core groups”, most notably among female sex workers (FSWs) (NACO, 2010). Whereas, the HIV prevalence in 2008 is estimated to be 0.29 percent among the general population, it is estimated to be as high as 4.9 percent among FSWs (NACO, 2010). Rising prevalence has been linked to the population size of FSWs and high frequencies of unprotected commercial sexual practices (Claeson and Alexander, 2008). Although it can be difficult to estimate the impact of commercial sex work on the rise of the HIV epidemic in India, mathematical modeling has suggested that up to 75% of all new HIV infections in India are believed to result from sex work and that prevention programs targeting sex work alone could drive the epidemic to extinction (Arora et al., 2004; Nagelkerke et al., 2002). To meet the HIV prevention needs of FSW sub-populations in India, well-coordinated community-based empowerment programs have integrated peer education and community mobilization into structural interventions (Evans and Lambert, 2007).

The Sonagachi Project, a community-based organization (CBO) run by and for sex workers in Kolkata, successfully increased condom use in 1999 and has maintained a lower HIV prevalence compared to FSW populations in other urban centres in India (Arora et al., 2004; Ghose et al., 2008). Reza-Paul et al. (2008) have found that community health mobilization conducted by the sex worker collective Ashodaya Samithi in Mysore, Karnataka, is strongly associated with an increase in condom usage and a significant decrease in STI prevalence. The process of collectivization in Karnataka has also increased the effect of peer education in reducing HIV-related risk behaviours among sex workers (Halli et al., 2006). The success of these projects has led these same CBOs to become directly involved in delivering other vital health services (Ghose et al., 2008; Reza-Paul et al., 2008). Within the last year, Ashodaya has

registered a new organization, Ashraya, to provide care and support to HIV+ sex workers, including antiretroviral treatment (ART) adherence counselling. However, little is known, in the context of India, of how such community-based programs affect access to care and ART adherence.

As the role of these CBOs continues to expand into new service areas, it is important to understand how people who frequent community-based organizations receive these interventions. The double stigma faced by sex workers who are also living with HIV leads to an increased need for comprehensive HIV prevention, care and treatment services (Spire et al., 2008). This paper focuses on three types of support provided by CBOS: peer support; access to care; and ART treatment adherence. Peer support plays an important role in empowering sex workers living with HIV/AIDS.

A study examining the role of collectives in HIV/AIDS prevention among female sex workers in Karnataka argues that shared personal experiences facilitate mutual support, trust and collective empowerment (Halli et al., 2006). Without the ability to access vital care services, ensuring ART adherence is not possible. A non-judgmental harm-reduction approach to the prevention of the sexual transmission of HIV is needed, including greater opportunities to know one's serostatus and measures to fight stigma and discrimination that may increase HIV-related risk behaviours (Spire et al., 2008). Implementing structural interventions that increase access to care services is a necessary step to ensure that people living with HIV/AIDS receive proper treatment.

Finally, this paper will look at ART adherence. Findings in other cultural contexts have demonstrated that peer support can play an important role in increasing adherence to ART (Koenig et al. 2004; Nachega et al., 2006; Torpey et al. 2008). The impact of community-based

support on access to care and ART adherence in the context of India has been under explored.

This paper will examine the relationship between community-based peer supports, experiences accessing care and ART adherence of people living with HIV/AIDS (PLWHA) who access services offered by Ashraya.

Methods

Site Setting and Study Design

The following paper is based on the results of an agency assessment conducted by Ashodaya Samithi from April 23 to July 8, 2009. An agency assessment, rather than an external evaluation, was done due to the highly sensitive nature of the questions addressed in the assessment. The involvement of Ashodaya staff ensured participation in the study. The inclusion of Ashodaya staff and members in the assessment process also draws on concepts of empowerment evaluation that call for a collaborative approach, providing ownership of the evaluation to the organization and increasing the utilization of evaluation results to improve service delivery (Garaway, 2004; Secret et al., 1999). Ashodaya Samithi is a CBO led by female, male and transgendered sex workers. The CBO's main office is located in Mysore City, in the southern Indian state of Karnataka. In April 2008, HIV+ sex workers of Ashodaya registered their own organization. Ashraya is the only organization in India for HIV+ sex workers and presently has over 500 registered members. Services include the placement of HIV+ volunteers in government-run HIV testing and treatment centres, accompanied referrals, follow-up for ART adherence support, home visits, and support group meetings. Membership of Ashraya is open to both sex workers and non-sex workers living with HIV/AIDS. Program funding for Ashraya comes from Ashodaya, which is supported financially by the Emmanuel Hospital Association (EHA), the University of Manitoba and Avahan, the Bill and Melinda Gates Foundation's India AIDS Initiative.

Data Collection

Ethnographic field notes were taken throughout the assessment and the technique of

participant observation (Bradley, 1993) was used to gain insight into the functioning of the organization. The author was present daily at the Ashodaya office and was invited to participate in meetings and events that took place. Close relationships were established with a number of key members, many of whom were HIV+, and allowed for the first author to learn from their experiences. Informal meetings with community members and staff provided important context to the assessment. Site visits were conducted to the satellite Ashodaya offices and to the government-run HIV testing and treatment centres, known as Integrated Counselling and Testing Centres (ICTC) and Antiretroviral Treatment (ART) Centres, in both Mysore and Mandya District.

One focus group was held with the hospital-based volunteers. Seven volunteers from both Mysore and Mandya Districts participated in the focus group, which lasted approximately one hour. Questions were asked in English and translated into Kannada. Detailed notes were recorded during the focus group and immediately after the discussion. Focus group questions covered topics including the responsibilities of the volunteers, how the role of the volunteers differs from that of the other health care providers and how things have changed since the integration of the volunteers into the hospital treatment teams. The findings of the focus group were used to generate questions for in-depth interviews.

Ashraya members participated in in-depth interviews and were recruited through a purposive sample. Questions were asked in English and translated into Kannada. Two members of the Ashodaya technical team were used for translation. Due to the highly sensitive nature of the questions discussed, it was deemed appropriate to use translators who were well-known and trusted by the participants. Thirteen semi-structured interviews were conducted; these included 11 face-to-face interviews and 2 phone interviews. Interviews lasted from 30 minutes

to 1.5 hours. Seven of the 11 interviews were audiotape recorded and transcribed verbatim. The remaining four interviews were transcribed based on detailed notes taken during the interview and immediately after the interview ended.

Interview Participants

Table 1. Participant Characteristics

Participants (Pseudonyms)	Sex	Engage in Sex Work	Member of Ashodaya (in years)	Currently on ART
1. Badri	Male	Yes	3	No
2. Chadna	Female	Yes	1.5	Yes
3. Daksa	Female	Yes	4	No
4. Faiza	Female	Yes	5	No
5. Geeta	Female	Yes	5	No
6. Harsha	Female	Yes	5	Yes
7. Iham	Male	Yes	4	No
8. Jagan	Male	Yes	4	Yes
9. Kala	Female	No	2	Yes
10. Latika	Female	Yes	3	No
11. Mahika	Female	No	0.75	Yes
12. Nadir	Male	No	2	Yes
13. Pari	Female	Yes	5	No

Pseudonyms were assigned to all participants. Specific ages of the participants have been removed for reasons related to confidentiality. The age range of the participants for the in-depth interviews was 17 to 45 years. The mean age of the participants was 31.3 years. Of the

participants, 4 were male and 9 were female. Six participants were on ART at the time of interview. The remaining 7 participants, although HIV+, were not on ART. Ten participants were employed as sex workers, 3 participants did not engage in sex work as their profession. 69% of those interviewed have been a member of Ashodaya Samithi for at least 3 years

Data Analysis

All methods of data collection were considered to inform the assessment. Ethnographic field notes, in addition to providing rich detail on the lives of HIV+ sex workers, served as the vital backdrop for the interpretation of the interviews. Transcripts from the focus group and in-depth interviews were used for content analysis to identify main themes. Selected quotations were highlighted to illustrate the main themes. The results of the assessment were presented to Ashodaya Samithi in order to assist with their program planning activities.

Ethical Consideration

The agency assessment was conducted by Ashodaya Samithi. Written informed consent was obtained for the face-to-face interviews. Verbal informed consent was obtained for the phone interviews and focus group. Permission to use the results of the assessment as secondary data was granted by Ashodaya and approved by the Simon Fraser University Ethics Review Board.

Results

The Role of Peer Support

One of the key ways that Ashraya provides support to its members is through support group meetings. Being diagnosed with HIV led to feelings of inner shame and guilt among all participants. Initial suicidality was commonly expressed, with some participants admitting to past suicide attempts. Unconditional support from members of Ashraya and staff played a key role in helping all participants come to terms with their HIV diagnosis. Support groups were created in order to bring positive members of the community together. By coming together in these group meetings, participants came to realize that they were not the only people living with HIV in their community.

“But later I realized, I saw many of them, those ones who are positives and those who are living with that and they have not died, so somewhere it has come in my mind that being a positive is not a death. Being a positive is just an infection. Many people are living with that virus. So that has given really a strength for me” – Geeta, female sex worker

When asked about their first experience at a support group meeting, participants expressed a range of emotions, including concerns about having to publicly disclose their HIV status. People are not forced to disclose their HIV status at support group meetings. Instead, they appear motivated to do so after hearing other peers share their stories. Participants explained feeling the need to disclose their positive status in order for Ashraya to grow strength as an organization.

“Somewhere it is there definitely that I have the fear that I could not be able to disclose myself...[but] if we want to take Ashraya and we want Ashraya to grow, we have to come out

with our identity and until we will not disclose our own identity, the others will also not feel comfortable disclosing their own identity.” –Faiza, female sex worker

Support group meetings are central to fostering a sense of community among members. They also serve as a source of practical health-related information, such as: where to access HIV-related services; the importance of good nutrition; proper condom use; housing; and services for children. By focusing discussions around concrete types of support, members begin to feel comfortable opening up about experiences with stigma and discrimination.

“Then many people started disclosing and discussing all the issues. If they want good medicine, where do they have to go? If they want ART, where do they have to go? For opportunistic treatment, where do they have to go?...then slowly slowly they spontaneously started discussing their own family problems in the meetings, like for example...if they are facing stigma and discrimination in their home...So we had created the courage, and unity and strength in that meeting to come out of their problems.” – Jagan, male sex worker

Participants described the positive effects of having a safe place to share their problems and concerns, regardless of whether a concrete solution is proposed.

“Maybe I am thinking that my problem is bigger than others, but until I will not share with others, until I will not know what others are facing, what others are having as problems or not, then we cannot say that ours is a big problem or theirs is a big problem... Maybe we will get a solution or maybe we will not get a solution, but at least by sharing with others, we will get our burden a little bit less.” – Faiza, female sex worker

An important component of the support group meetings is that they are peer-led.

“One of the main reasons of coming together in the support group is, we realize that...when

some counsellor is counselling them or they are talking to them, they will not take them that seriously... we realized that being a positive, if I will talk with them, if I will show them, I will give my own examples, I will give my own experiences and I will talk to them, then they are listening more.” – Harsha, female sex worker

There was general agreement that PLWHA, whether involved in sex work or not, feel more comfortable speaking to other positive people.

Accessing Care: Decreasing Barriers through Peer Accompaniment

Ashodaya played an integral role in getting people to get tested for HIV in Mysore. The Integrated Biological and Behavioural Assessment, first done by Ashodaya in 2004, reported an HIV prevalence rate of 24% among sex workers in Mysore. The assessment brought attention to the risks associated with the practice of sex work. By coming together as an organization, sex workers in Mysore became aware of high prevalence rates of HIV among sex workers and began to get tested.

“And because we are working in a day-to-day activity, once the process was started here by many of the guides, once they have come to know about the prevalence here in Mysore, then one by one they started ...asking the doctor for referral to ICTC...By seeing them, somehow we feel that we are not one or two.” –Geeta, female sex worker

Experiences of stigma and discrimination and fear of being identified as a sex worker were major barriers in willingness to access care.

“When I went to the hospitals and all, I faced difficulties in accessing the services, like you have to wait in that hospital. Even I, I am only worried and hesitant to ask them about where I should go and get the services and all. If I reveal my status they might have stigmatized me,

discriminated me. And they won't treat me very well.” – Pari, female sex worker

In the event that people had undergone HIV testing, participants often reported not receiving test results for weeks and having to return to hospital numerous times. In instances where it was known by the health care provider that the participant was a sex worker, participants reported being told that they would undoubtedly test positive for HIV, even before undergoing testing.

“At that time, we are facing the stigma there because whenever we go and we disclose that we are sex workers and that we are positive and that we are on ART, people, even the staff and the doctors and others, feel like sex workers because of their profession, because of their habit, and because of their work, they will get HIV. This is common among them.” – Faiza, female sex worker

Despite experiencing widespread discrimination, the biggest barrier to care identified by the community was wait-times. People would present for appointments and never be seen by a health care provider. Through discussions at support group meetings, it was decided that it would benefit the community to have peer volunteers integrated into government hospitals. Ashraya trained and placed 12 volunteers, all of whom are HIV+ sex workers, in testing and treatment centres in 8 government hospital in the Mysore and Mandya Districts. Volunteers see all new patients who come to the hospital for testing and treatment, including non-sex workers, and are involved in all aspects of care, such as accompaniment for all referrals, counselling, and follow-up. Volunteers also serve to build rapport with the health care team in order to sensitize them to the needs of the community and decrease instances of discrimination.

“And if you are a doctor...you need to identify a patient, not his profession. You will see the patient as a patient. Those things they will tell them in a polite way and make them understand.” –Faiza, female sex worker

Since the placement of the volunteers, participants describe feeling much more comfortable accessing care and no longer experience discrimination when accessing services.

“Actually I have never been to a hospital. But Ashodaya made me go to the hospital to get my blood check-up done... I am not stigmatized at any hospital because Ashraya has accompanied me... for all the tests, ART. They are following me, so I will not have any difficulty in accessing the care.” – Kala, female, non- sex worker

Volunteers keep track of follow-ups and remind people of their appointments. If people are missing their appointments, it is the volunteers who work to understand the reasons why. Volunteers will also keep track of people’s current addresses and will visit their homes. If people are facing discrimination from their family or community, volunteers will visit to provide education and support.

“Before that, my family members...have given me separate food and they are telling my children not to go to me, that it will be spread, like that. And [the volunteer] came and spoke [to my family] and told them that...if we come sit with her and eat with her, sleep with her, wear her clothes, be with her, it won't come to us. Only then did they accept it and now they are treating me good. They are taking care of me. It was a good experience for me that they came and explained all those things.” – Kala, female, non- sex worker

These visits are frequently well received by participants and their families, and can lead to family reunification and a better understanding of participants’ health and emotional needs.

ART Treatment Adherence

Another key function of the hospital-based volunteers is to ensure adherence to treatment regimes. Through their partnership with ART centers, Ashraya is informed if people are missing follow-up appointments. They are able to do home visits, provide education and counselling on the importance of proper adherence and ensure that people are physically able to make their appointments.

“We have to talk with them and resolve that reason. What is the real reason that they are not coming and not accessing the services? It is not like we can just say you have to come. First we have to see if they are comfortable coming, if something is happening.” – Faiza, female sex worker

During this study, participants were asked if they have ever had any difficulties in taking their medications. Those participants not currently on treatment were asked about perceived barriers to adherence. The most common barriers identified were physical side effects including: headaches; nausea; vomiting; vision problems; skin problems; loss of appetite; and difficulty concentrating. Once physically adjusted to ART treatment, the majority of participants did not immediately identify any other barriers to adherence. Only after probing into whether or not there were any difficulties other than physical side effects associated with taking ART, did participants address other barriers to adherence.

Other non-physical barriers to ART adherence identified by participants included: “mental tensions”, such as concerns about taking medications in front of family; disruptions in treatment due to alcohol and drug use; difficulty taking medications at regular times due to irregular working hours; difficulty in accessing medications due to old age; not being able to miss

work for medical appointments; long travel distances to treatment centres; and discomfort accessing care in their designated treatment centre. As stated by one participant, “starting is easy, continuing and side effects are hard”.

“One thing is definitely the volunteers will identify whoever is not coming for the follow-up...And many times the issue, the thing is, they are not coming for ART because they do not have the money to come, they do not have money to pay for the travel...and even sometimes, I get the reason that people stop taking ART because they do not want to take ART because they do not want to live.” – Faiza, female sex worker

Whereas ART centres monitor follow-up appointments and treatment compliance, Ashraya has focused on understanding barriers to adherence and providing adherence support counselling to patients and families to ensure that they succeed on ART.

Discussion

"I want to talk about my dream, that I have a vision. Like me, many of them are positives, those wherever they are in the world. They should get all sorts of facilities and care, whatever they require and they should not be discriminated from the society and they should get all support and they should live a happy life. That is my vision." – Geeta, female sex worker

Since registering a separate organization for sex workers living with HIV in May 2008, Ashraya has managed to both empower its members and implement community-led structural interventions that increased accessibility of care services, resulting in the necessary support to ensure proper ART adherence. Experiences with stigma and institutional boundaries to care shared by participants prior to the formation of Ashraya mirror those expressed in a qualitative study conducted with the members of the Sonagachi Project (Ghooose et al., 2008). Stigma and fear of stigma are known to constrain access to both information and services (Spire et al., 2008). The success of collectives, such as Ashodaya, has much to do with the creation of social solidarity (Halli et al., 2006). The organizational philosophy of Ashodaya follows the model set forth by the Sonagachi Project, which calls for a 'reliance' on sex workers' understandings and capability, a 'respect' of sex workers and their profession and the 'recognition' of sex work as a profession (Jana et al., 2004). By decreasing the isolation of HIV+ sex workers through peer support groups and breaking down institutional boundaries in hospital settings by sensitizing health care providers to the needs and rights of HIV+ sex workers, Ashraya has managed to also address the importance of ART adherence.

The supports offered by Ashraya follow the "triple therapy" approach to address stigma and discrimination in concentrated epidemics: fight for greater acceptance of people living with

HIV/AIDS; improve relevant laws and policies; work with people rather than for people (Spire et al., 2008). Empowerment of individuals and ability to access care services are crucial components to assuring adherence to ART. Although government ART centres may monitor appointment attendance and count pills to assess adherence, these policies do nothing to address issues of stigma and discrimination that may prevent someone from ever accessing care. Through the integration of Ashraya volunteers into treatment teams, people now feel safe accessing care services in government hospital settings. Social support has been shown to be a crucial component in assuring proper treatment adherence (Nachega et al., 2006). Ashraya is both a source of social support and also plays an important role in assisting its members in disclosing their HIV status to their family in order to allow family to assume the role of treatment supporter.

Ashraya has grown rapidly as an organization and its members have expressed a desire to see Ashraya continue to expand in its provision of services. A main goal of the organization is to develop its own funding sources in order to meet the needs of its members. Interview participants expressed a need for Ashraya to play a greater role in advocacy and to develop education and awareness programs for people living with HIV/AIDS. With an ever-growing membership base, Ashraya has seen an increase in requests for financial support, food, housing and assistance in assuring that the educational needs of its members' children are met. At the end of this assessment, Ashraya was preparing to open an HIV-testing site in their Mysore office.

Suggestions have come from the community that Ashraya should be able to provide ART directly to its members. As a new organization, it is important that Ashraya continue to assess its long-term goals in order to evolve as an organization and best meet the needs of its members. The rapid growth of Ashraya and its success at fostering social solidarity and large-scale

structural interventions hold valuable lessons for community-based organizations and public health practitioners working in the field of HIV/AIDS.

Study Limitations

There are several limitations to the agency assessment. Due to the highly sensitive nature of the questions addressed in the assessment, Ashodaya staff members were used as translators as it would not have otherwise been possible to gain access to community members. Although the use of Ashodaya staff members for translation ensured participation in the assessment, it may have biased participants' responses towards providing more positive feedback of the organization. However, it can be argued that program participants may be more invested in obtaining objective results if the goal is to improve services and service delivery (Secret et al., 1999). The small sample size and use of a purposive sample may also influence the findings.

As this was an initial exploratory study, it is recommended that a larger scale evaluation be done by the organization. Non-members of Ashraya should also be included in the study in order to inform program-planning relating to membership recruitment.

References

- Arora, P., Cyriac, A., and Jha, P. (2004). India's HIV-1 epidemic. *CMAJ*, 171(11): 1337-1338.
- Bradley, J. (1993). Methodological issues and practice in qualitative research. *The Library Quarterly*, 63(4): 431-449.
- Claeson, M. and Alexander, A. (2008). Tackling HIV in India: Evidence-based priority setting and programming. *Health Affairs*, 27(4): 1091-1102.
- Evans, C., and Lambert, H. (2007). Implementing community interventions for HIV prevention: Insights from project ethnography. *Social Sciences & Medicine*, 66: 467-478.
- Garaway, G. (2004). Participatory evaluation. In K. deMarrais and S.D. Lapan (Eds.), *Foundations for Research: Methods of Inquiry in Education and Social Sciences* (249-265). New Jersey: Lawrence Erlbaum Associates, Inc.
- Ghose, T., Swendeman, D., George, S., and Chowdhury, D. (2008). Mobilizing collective identity to reduce HIV risk among sex workers in Sonagachi, India: The boundaries, consciousness, negotiation framework. *Social Science & Medicine*, 67: 311-320.
- Halli, S.S., Ramesh, B.M., O'Neil, J., Moses, S., and Blanchard, J. F. (2006). The role of collectives in STI and HIV/AIDS prevention among female sex workers in Karnataka, India. *AIDS Care*, 18(7): 739-749.
- Jana, S., Basu, I., Rotheram-Borus, M., and Newman, P. (2004). The Sonagachi project: A sustainable community intervention program. *AIDS Education and Prevention*, 16(5): 405-414.
- Koenig, S. P., Leandre, F., and Farmer, P. (2004). Scaling-up HIV treatment programmes in resource-limited settings: The rural Haiti experience. *AIDS*, 18(3): s21-s25.
- Nachege, J. B. et al. (2006). Treatment supporter to improve adherence to antiretroviral therapy in HIV-infected South African adults. *Journal of Acquired Immune Deficiency Syndrome*, 43(1): S127-S133.

- Nagelkerke, N.J.D., Jha, P., De Vlas, S.J., et al. (2002). Modeling the HIV epidemics in India and Botswana: The impact of interventions to prevent transmission. *Bulletin of the World Health Organization*, 80: 89-96.
- NACO. (2010). *Annual Report 2009-10*. Department of AIDS Control, Ministry of Health & Family Welfare. <http://www.nacoonline.org>.
- Spire, B., de Zoysa, I., and Himmich, H. (2008). HIV prevention: What have we learned from community experiences in concentrated epidemics? *Journal of the International AIDS Society*, 11(5). doi: 10.1186/1758-2652-11-5.
- Torpey, K. E., Kabaso, M. E., Mutale, L. N., Kamanga, M. K., Mwango, A. J., et al. (2008). Adherence Support Workers: A way to address human resource constraints in antiretroviral treatment programs in the Public Health setting in Zambia. *PLoS ONE*, 3(5): e2204. doi: 10.1371/journal.pone.0002204.
- Reza-Paul, S. et al. (2008). Declines in risk behaviour and sexually transmitted infection prevalence following a community-led HIV prevention intervention among female sex workers in Mysore, India. *AIDS*. 22(5): S91-S100.
- Secret, M., Jordan, A., and Ford, J. (1999). Empowerment evaluation as a social work strategy. *Health & Social Work*, 24(2): 120-127.