

ART AND PUBLIC HEALTH:
REPORT ON DEVELOPMENT
OF A UNIQUE
COMMUNITY-BASED
APPROACH TO REDUCE
HIV/AIDS STIGMA IN VILLAGES
OF WEST BENGAL

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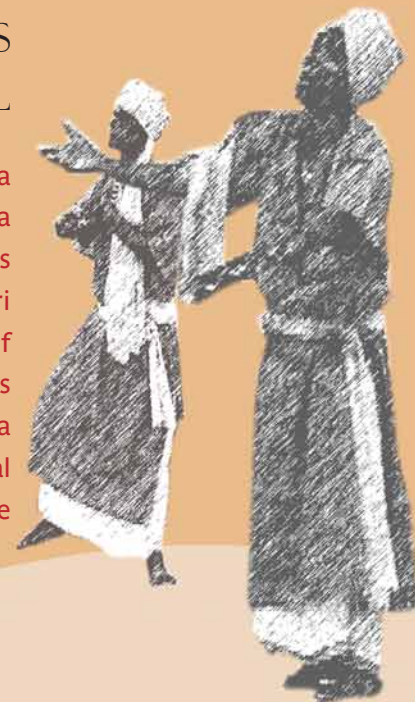
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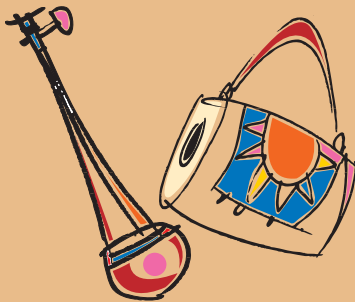
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1. Introduction

HIV poses many challenges to biological, behavioural and social interventions developed to curb its spread. Of critical importance is societal stigma associated with the disease, as it impinges negatively upon both prevention as well as care initiatives. From existing work, it is clear that there are two essential 'causes' of HIV stigma: the continued fear of casual transmission, which stems in large part from a lack of depth in knowledge; and the moral dimension that justifies stigma through judgment, shame, and blame¹. These two domains indicate how programs should change if reduction of stigma is desired.



In addition to identifying intervention elements that could reduce HIV related stigma, it is important to capture the debates and discussions underpinning an intervention approach so that others can draw upon them. From a public health

perspective, scaling up an effective program requires knowing the strengths and weaknesses of any approach. We document here such a development pursued by 'People Living With HIV/AIDS and their Friends' (PLWHAF) in West Bengal - a state located in the eastern part of India. The project that took shape through this process is 'Art and Testimonial: A Unique Community Based Approach to Reduce HIV/AIDS Stigma in Villages of West Bengal'. World Bank South Asia Regional Development Marketplace (WBSARDM) awarded a competitive grant to the community based non-government organization named 'Society for Positive Atmosphere and

1. Nyblade, L, R Pande, S Mathur, K MacQuarrie, R Kidd, H Banteyeraga, A Kidanu, G Kilonzo, J Mbwambo, and V Bond. 2003. Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia. Washington: ICRW.

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ଆମି ଏବେ HIV +ve ଆମିତ ମାନ୍ୟ

Related Support to HIV/AIDS' (SPARSHA) for planning, execution and evaluation of the project². Additional funding was obtained by SPARSHA and its partner organization 'MAKE ART/STOP AIDS' - a New Delhi based initiative of the Art | Global Health Centre at the University of California, Los Angeles (UCLA), from the Ford Foundation and Princess Diana Foundation. MAKE ART/STOP AIDS played a key role in securing this additional support. The outputs we intended to generate with the help of this top-up financial assistance were:

- a) to capture the thinking behind the development of the above mentioned innovative HIV stigma reduction intervention that combines public health and art in West Bengal; and
- b) to document the activities that lead to fine tuning of the artistic component of intervention entailing identification of new art forms (as compared to pilots where scroll painters were engaged); providing one-on-one inputs to the artists; arranging workshop for artists and subsequent refresher training and on-going support.

The current report presents the above-mentioned outputs in a 'two in one' format with printed narrative text as well as a DVD of documentary films. It also describes the observed immediate effects on the people infected with or affected by HIV during implementation of the intervention. We hope it will serve as an important advocacy tool for HIV stigma-reduction programming in India and elsewhere.

1.1 Why art?

While many public health interventions are built on text-heavy pamphlets and pedantic instruction, the project described here is based on the premise that thoughtful, engaging, challenging art has other goals. Art is not the same as more didactic forms of health communication. It cannot



be reduced to corporate-style advertising; it is not intended to 'sell'. It may educate and inform as an ancillary effect, but art's primary purpose is of a different order: to clear space for the imagination, for reverie, for broad and unencumbered thinking-and hence to open up possibilities for personal transformation.

Such transformation, it must be argued, is essential at this moment in the AIDS epidemic. With the number of infections in India now estimated by national and international health authorities as well above two million, and with a struggling health infrastructure unable to deliver the latest treatments to all but a small fraction of those who need them, new resources for AIDS intervention are needed, drawing on every possible sector.

This project should not, therefore, be seen as replacing existing modes of communication even as we seek to promote it as a distinct alternative. We do not advocate that it supplant advertising campaigns, public health brochures, public service announcements, or other standard means of health communication. Rather, this collaborative project seeks to offer an alternative to these forms of communication by mobilizing artists to make and distribute art that engages directly with the epidemic, that explores its meanings, and that seeks to do what art does best: provoke thought and inspire personal transformation.

2. The partner organization specifically responsible for evaluation is the National Institute of Cholera and Enteric Diseases (NICED), a permanent institute of Indian Council of Medical Research (ICMR) located in Kolkata, West Bengal, India.

2. Organizations in partnership

HIV stigma-reduction intervention, the conceptual development of which is described here, was written up in response to the 'Request For Proposal' (RFP) from WBSARDM, circulated in November, 2007. Dr Tarun Roy, a SPARSHA supporter and a public health professional, informed SPARSHA about this request through an e-mail with an attachment of the WBSARDM posting in Bengali. Grassroots workers of SPARSHA were extremely happy to see such a posting in their mother tongue, allowing them to participate in discussion of the proposal development. MAKE ART/STOP AIDS inquired about a potential partnership on the proposal, as both the organisations had worked together on two short-term pilot projects in late 2006 and mid-2007 addressing stigma in the villages of West Bengal. The last day for submission of the proposal was 31st January 2008. SPARSHA responded to the RFP based on the preliminary discussion initiated at the grassroots level, beginning a collaborative journey with each of the three partners - SPARSHA, MAKE ART/STOP AIDS and NICED (ICMR) - bringing along their respective strengths and perspectives.



2.1 SPARSHA – a community-based organization with a difference

SPARSHA was formed in West Bengal by a group of people living with HIV, their relatives and friends, health care workers, and individuals from different walks of life in 1998. While most support groups for HIV-positive people have exclusive membership of people living with HIV, SPARSHA since its inception consciously included those who did not know their own HIV status or were not infected with the virus. This approach helped SPARSHA grow from a 15-member organization to one with a little less than 1000 people living with HIV, by creating a welcoming environment that eschewed isolation. Addressing the injustice of social isolation due to HIV was a focus of SPARSHA from the beginning.



The organization became actively involved in HIV care and support activities in the villages of West Bengal in 2000. The outreach workers of SPARSHA quickly realised that without mitigating the impact of stigma and discrimination in these rural settings, reaching out to the many more in need of HIV care would not be possible. Innovative community sensitization programs were thus designed in which people living with HIV and those who were not would form a team and jointly address questions from the community. Most of these questions arose from common but irrational fears about methods of HIV transmission. The group also served as a role model, proving to the community that HIV-positive and HIV-negative people can eat, live, work and socialize together without fear of infection.

Actors, singers and painters joined together with SPARSHA, contributing in their own way on various occasions. For example, in 2003 Nandipat, a nationally renowned theatrical organisation, conducted a show in Rabindra Sadan, Kolkata ('Mrityu-Na-Hatya', the adaptation of Dario Fo's famous play 'Accidental Death of An Anarchist') as a fund raising initiative for SPARSHA. In the same year when SPARSHA observed Anti-Drug Day on 26th June in Raygaji - a locality close to the SPARSHA office, which hosts a considerable presence of heroin smokers - eminent singers collaborated in the event³. The following year the Anti-Drug Day was observed in the heart of the city of Kolkata. SPARSHA invited members of the 'Mukti Foundation' - an organisation of recovered substance users - to share their pains and pleasures with the audience. The audio-cassette titled 'Aashar Gaan' (Songs of Hope), a musical presentation of the courageous life of an HIV-positive SPARSHA staff, was inaugurated during

this event. Dr. KL Narayanan, esteemed psychiatrist and friend of SPARSHA, spearheaded both these events. The movement gained momentum on World AIDS Day 2004, when well-known theatre personality Bibhas Chakraborty came to observe the day, and famous poet Amitabha Dasgupta read a self-authored poem dedicated to members of SPARSHA living with HIV. Distinguished painter Sanu Lahiri invited all the people present on this occasion to mark their impressions on a large canvas - thus creating a joint painting. This was followed by inauguration of a painting workshop for women living with HIV, who captured their own emotions on art paper. The workshop received technical assistance from 'Lokayata', a city based non-government organization. Finally, in the same year, Mr. Saumitra Poddar-a founding member of SPARSHA-helped develop a street play (skit) dealing with discrimination and isolation of people living with HIV. The theme was interwoven with messages on HIV prevention and care. Nandipat, the theatre group with which Saumitra was associated, once again extended its support, mounting the skit titled 'Aami Bhoj Korbo na' (I won't live in fear). Multiple shows were conducted on different street corners of the city of Kolkata and also villages in West Bengal.

SPARSHA paired up with Nandipat during these performances, interacting with the audience to clarify myths and misconceptions about HIV/AIDS. Keeping in line with its evolution as an organization based on collaboration between people living with HIV, their friends, public health professionals and artists, SPARSHA collaborated in 2005 with a musical troupe to create lyrics on 'how HIV is spread and how it is not spread'.

The journey described above was marked by challenges as well as successes. SPARSHA outreach workers learned of a child in the district of Paschim Medinipur who was isolated in his school due to HIV in the family. In response, the organization arranged a 'sit and draw competition'. This was a pioneering event in the district, bringing HIV-positive and HIV-negative children together for the first time in a public social event. Eminent painter Sandip Suman Bhattacharya, whose paintings and compositions artfully capture SPARSHA's vision and mission, worked with the children during this competition.

³ Rupankar, Kharaj Mukhopadhyay, Anusua Chowdhury were the artists in this event and Satinath Mukhopadhyay was the anchor. Being joined by Subhamita, Sumit Samddar and famous Bangla Band troupe 'Bhoomi', Rupankar participated in similar program organized by SPARSHA the next year.



2.2 MAKE ART/STOP AIDS-mobilising artists to stop HIV/AIDS⁴

MAKE ART/STOP AIDS, the signature global initiative of the Art | Global Health Center at UCLA, is an international network of scholars, artists and activists committed to ending the global AIDS epidemic. The array of artistic projects in the early 2000s in response to AIDS in India was stunning in its creativity and markedly different from projects produced elsewhere in the world. For example, H.N. Girish, a science teacher in a village near Mysore had artfully designed a roadside shrine dedicated to 'AIDS-Amma'-an attempt to combine religion, science and art for the cause of AIDS. The project was inspired by the double-suicide of a married couple who were ostracized after they revealed their HIV status. Or 'Jasoos Vijay', the Doordarshan detective television show that reached as many as 100 million people and ranked among the top ten most-watched

programs in India, featured a private investigator who was HIV-positive. AIDS awareness scrolls in the rural areas of West Bengal were painted and sung by bards whose texts twenty years ago would have dealt exclusively with traditional religious narratives. The Tamil theatre group Nalamdana had established over the years an impressive network of connections through street theatre, musical cassettes and television dramas followed by an interactive session with a medical expert and critical dialogue with local communities. Anurupa Roy, a puppeteer working out of New Delhi, had devised a play aimed at reducing stigma against persons living with HIV, with sponsorship from UNICEF and the Delhi Public Schools.

Consistently the artists producing these works felt that they were working alone, without sufficient support, and without knowledge of other artists working with a similar commitment. Thus these artists were clamoring for the opportunity to meet with others similarly concerned about the spread of HIV, to share ideas, to benefit from constructive critique in a supportive environment, and to rejuvenate themselves for the work ahead.

It was in direct response to these needs that a workshop in Kolkata was organized during July 1-4, 2004, under the MAKE ART/STOP AIDS banner. An unprecedented rallying point for a proactive, collaborative response to AIDS in India, the workshop involved more than fifty participants, including performing and visual artists from different states in India. Although the workshop was designed primarily as a site for performance, the forum was utilized for discussion and feedback from a comprehensive representation of activists, doctors, ideologues, journalists and concerned citizens. Looking back, we now recognize that in addition to what the entire workshop achieved, it certainly marked the beginning of partnership between SPARSHA and MAKE ART/STOP AIDS.

⁴ MAKE ART/ STOP AIDS July 2004, Kolkata and New Delhi, India (Workshop Report).



3. Addressing public health issue through art

The cases of stigma recorded in villages⁵ of West Bengal always involved a group of people marginalising an individual or a family due to HIV. While HIV intervention programs run by Government as well as development partners in the State address issues around stigma in health care settings and at workplace, the efforts directed towards the community have mostly remained limited to posters or hoardings carrying messages like 'treat HIV positive people with dignity' or highlighting the origin of stigma from ignorance. While interventions in health care settings are important and stemmed from the understanding that access to care (and particularly to antiretroviral therapy) would reduce stigma, we realised through our own formative research that something more needs to be done - something that would improve 'quality of life' in the households, in the society and in schools and not just at the hospitals or workplace.

The key question was 'what should be the form of intervention that would emotionally and intellectually engage community including clusters of people stigmatising others', so that a positive change could be fostered. 'Art' paired with 'opportunities for interpersonal communication with people living with HIV' and

'a platform where community members could ask questions and seek clarifications' came as the answer. The examples that helped us draw these conclusions were: involvement of folk singers in campaign for polio immunization, audio cassettes distributed to truckers to spread HIV/AIDS message, and involvement of scroll painters in issues like family planning. Our own work with the theatrical group Nandipat, eminent painters and singers, and scroll painters from the village 'Naya' in the district of Paschim Medinipur, singing songs and exhibiting scrolls on HIV, underlined this assertion.

We were convinced that art presented in a socio-culturally appropriate form has the potential for mass appeal. Art has the ability to make people think and folk art can present information in a way that people can absorb better than a written static message. Illiteracy, a reality for many rural inhabitants, also does not stand on the way of comprehension of messages if presented in this manner. Therefore art appeared to be a pragmatic public health choice for the issue we were dealing with, 'HIV-stigma'.

Lessons learnt from pilot projects

Pilot projects completed by us had clearly revealed the existing split between knowledge and attitudes in the villages of West Bengal. Although knowledge about HIV transmission was high among villagers, negative attitudes against people living with HIV with support for extreme and most coercive measures was no less. The projects played an important role in this setting by being able to show that these attitudes are amenable to change. Innovative stigma reduction approach where people living with HIV worked hand in hand with those who were not infected with the virus and scroll painters from a village of West Bengal was the cornerstone of this change.

5 Arachchi Chami. University of Washington, Seattle. Department/ Health Services, School of Public Health MPH (Dissertation work was carried out with support from University of Alabama, Society for Applied Studies, Kolkata & SPARSHA) year accepted 2009; research was completed in 2005.

4. Genesis and evolution of the current intervention plan

4.1 Community engagement

Working in villages of West Bengal, we have learned that different community members perceive HIV/AIDS problems differently. While some villagers do not see the need for more information on HIV and some are unwilling to engage in discussion involving sex and sexuality at all, others still think HIV awareness programs in villages are very important. Regardless of the composition of these populations, stigma and discrimination continue - in families, in schools, in the neighbourhood, at health centres and at work places. We therefore decided that community engagement should be a major intervention component. Direct responses recorded during pilot projects on stigma reduction are quoted below (see text box). These responses guided us in the development of the current project.

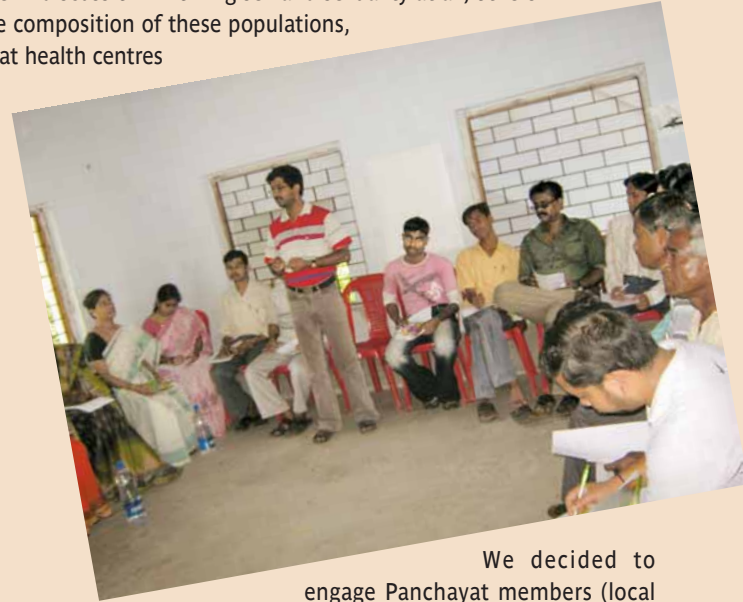
"We know everything about HIV from TV & Radio. We have unmarried young girls in our houses. This type of discussion will create problem in their marriage. If you do the program we will break the stage and destroy all arrangements. You may even be physically injured. You rather go to other places where we will go to listen to your program." (Housewife, 35, in a village)

"We are not getting any help from government, suffering from the bad condition of the road, no tube well here, etc. In this condition how come you arrive to do program on HIV? We will not allow you to do any program here. Either you go to other places, or we will destroy all the arrangements." (Housewife, 28, in a village)

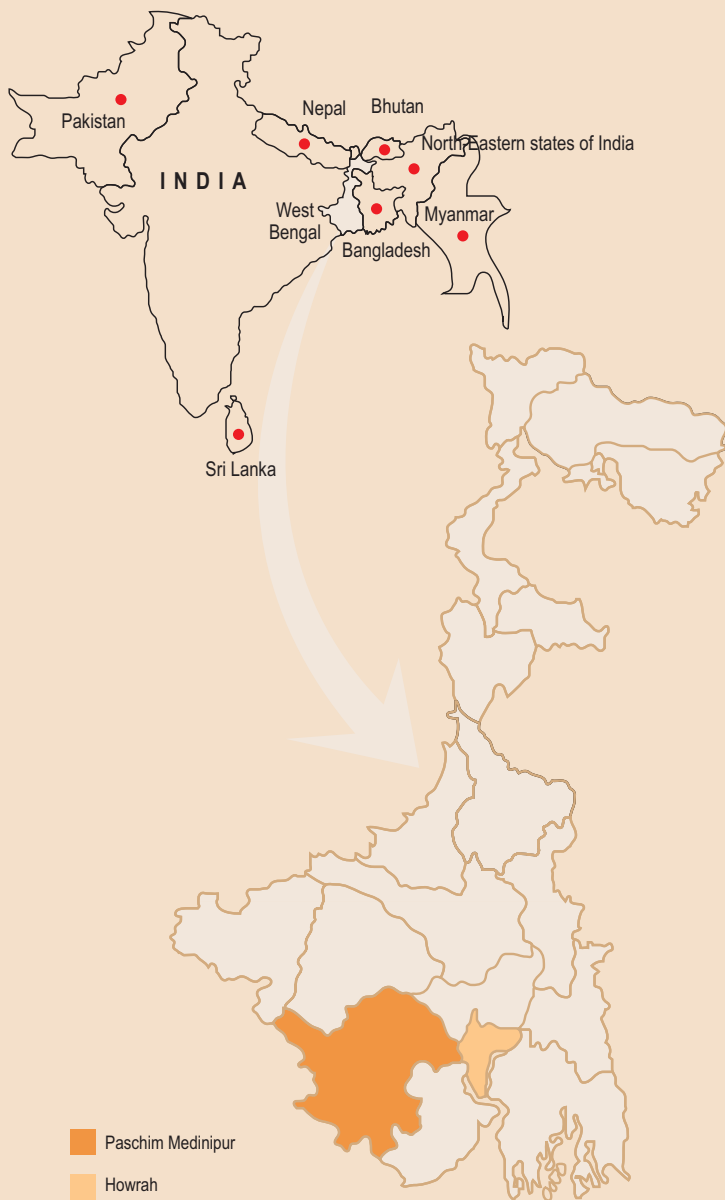
"You are getting money, that is why you come for doing all these silly programs on HIV." (Integrated Child Development Scheme Supervisor of a Health Centre, 40)

"We know everything. What is the need of doing all these farces with HIV? You better go to them who do not know about these matters." (Physician, 45, working in a village Health Centre)

"I don't think that you (ICDS workers and physicians) know everything. We may not have all the information about HIV. Let them (the intervention team members) do their program smoothly." (Block Medical Officer of Health, 38, in a group discussion)



We decided to engage Panchayat members (local village administration), school teachers, youth club members, physicians and other opinion makers in the community at every stage of project implementation. Furthermore, we planned to help them form 'Stigma Reduction Committees' (SRC) in each of the intervention villages. Intended to ensure sustainability beyond the end of the project, these committees would comprise people living with HIV, members of affected families and other community members. We devised this concept in the interest of sustainability; leaving something in the community to reduce stigma after the project's end.



4.2 Choosing an art form to work with

From the earlier pilots with scroll painters, we understood that positive attitudinal change in communities fades away considerably without (1) repeated exposure to correct information, (2) socio-culturally appropriate communication methods and (3) opportunities for reinforced inter-personal communication. We view these elements akin to booster dosing technique adapted for vaccination, which confers adequate immunity against a potential future infection. Immediately after community-based events by scroll painters and health workers of SPARSHA, negative attitudes were drastically reduced. In these interventions, scroll painters exhibited their scrolls and sang songs on HIV-related issues while community health workers from SPARSHA, some of whom were openly living with HIV, responded to questions from audience members, sharing personal testimony where appropriate. Evaluation found this pilot intervention to be a huge success. At the same time, however, we realized that there were compelling reasons to expand the intervention to include art forms other than scroll painting. The pool of Patua or scrollpainters was small and therefore, we knew, inherently limited possibilities for future scale up. Moreover, if we could incorporate new art forms with local appeal, opportunities for repeated exposure would increase. We knew from early results that the stigma-reduction effect reduced over time (table 1). Repeated exposure to the intervention was therefore essential. Short-term nature of the pilots also did not allow time for adequate community engagement.

Through our interaction with villagers, we subsequently came to know about local groups of 'Baul singers' who are frequently invited to perform at cultural events. Baul music is a way of life in these villages. This holds true for both the districts we worked in; Paschim Medinipur as well as Howrah. We identified another traditional form of singing in the district of Howrah named Tarja. It is an art form that is emotionally and intellectually engaging due to its method of presentation; it is essentially a debate on an issue of social relevance through song. Baul and Tarja therefore appeared to be art forms well suited to spread HIV/AIDS messages in our study settings. We hoped that, once trained, the artists would perform the HIV-themed songs at all events rather than at those only organized through the project. Realising that the performers' perception of HIV would heavily influence such possibilities, we interacted closely with them and felt that the commitments were strong; some of these artists had actually encountered HIV in their personal lives or close neighbourhood. Subsequently SPARSHA's community health workers, most of whom are from the districts in which they work, witnessed the hope of sustainability turning into reality; Bauls were singing pieces on HIV learnt through the Project in general village events.

Table 1 Measured Changes in attitudes in the villages of Howrah districts at different time points

Statements	Assessment before 1st pilot intervention	Assessment after 1st pilot intervention	Assessment before starting 2nd pilot intervention	Gap between 1st intervention and the 2nd assessment
	$n_1 = 94$ adults	$n_2 = 88$ adults	$n_3 = 199$ adults	4 month
	(Proportion disagreed with statements)	(Proportion disagreed with statements)	(Proportion disagreed with statements)	
People with HIV should be ashamed	28%	94%	43%	
People with HIV should be legally isolated	32%	93%	48%	
Although people with HIV can work with others they should not be allowed to handle food/rice	27%	86%	45%	
People with HIV deserve to be punished	51%	91%	65%	

⁶ Baul is the dance of the wandering minstrels of rural Bengal. These minstrels, their songs and their dance, are all called Baul. They play the ektara, a one-string drone instrument, and dance ecstatically in praise of nature and its keeper. (Khokar AM 2003. Folk Dance: Tribal, Ritual & Martial forms- Publisher Rupa & Co).



4.3 Session planning and training

As mentioned above, the intervention combined 'delivering HIV/AIDS message in a socio-culturally appropriate art form' and 'providing opportunities for interpersonal one-on-one communication'. The plan also incorporated 'sharing of personal testimony'. As one of our HIV-positive colleagues articulated, "If you hear a song about somebody's life with HIV you still think about it as something distant ...it does not become real for you ... but when someone like me speaks, it makes a difference, as I am the next-village girl".

Following consultation with villagers, it was decided that we would implement the curriculum in three instead of four community-based events (four sessions were conducted during pilots), one each week of three successive weeks. The curriculum would cover: a) HIV transmission and non-transmission,



b) Love with care, and c) HIV care and management. As part of the second session, 'Love with care', SPARSHA's HIV-positive community health workers would share personal testimonies with the audience. Village opinion leaders would be invited to inaugurate all these events and also to participate in discussion. Before and after each event community health workers would interact with audience members for question-and-answer sessions on HIV and related issues. Intervention activity also involved holding small group discussions with women, youth club members and others who might not be able to attend the community-based events.

Other elements in the intervention package were: a) outreach to people living with HIV and their families by the participating health workers in order to mitigate the impact of stigma on their lives, b) forming village level Stigma Reduction Committees, and c) organizing events in schools. All these intervention elements gained roots from the experiences of SPARSHA working in the villages of West Bengal described in the earlier section of this report.

MAKE ART/STOP AIDS contributed to the discussion around HIV-stigma reduction intervention development with its unique perspective on how



art could amplify the effect of an intervention. This grew out of the organization's experiences of working with artists internationally, and clearly emphasised the need for multiple orientation workshops to ensure the desired effect. Thus we planned for smaller orientation meetings at the artists' homes, as well as larger training sessions at SPARSHA field offices and NICED (ICMR) meeting rooms. Rupankar, the singer who worked with SPARSHA on various occasions (vide footnote 3), and Anurupa Roy, the puppeteer working from Delhi, took part in some of these orientation sessions. A well-known singer from erstwhile Medinipur district (now Purbo Medinipur), Mr. Amit Pahari, was also engaged as a resource person, helping to write lyrics and melody together with the Baul singers.



5. The Intervention

Uniqueness of the current intervention lies in its design of combining mass approach (thorough socio-culturally appropriate artistic performance at clusters in villages where stigma is intense), group approach (small meetings at village level) and interpersonal approach (personal testimony by people living with HIV and question answer sessions) - three pillars of communication. Two other critical elements in the design were linking community members who are willing to access HIV testing or care services, and mitigating the impact of HIV-stigma on individuals and families through outreach. Condoms were also made available on request.

Central to these lyrics were the lives and personal stories of SPARSHA's community health workers, and social issues around HIV/AIDS. The authors of the current report also provided inputs regarding accuracy of information as well as how to improve upon a performance. Highlights of some issues addressed in these training sessions include: 'More time on right information', 'clearly underlining what is a myth in the songs', 'avoiding judgmental words' and 'having a balanced mix of music and songs'. One of us (Sobha) actually doubled up as a song writer for some of the numbers sung by Bauls, in addition to her responsibility as project coordinator. Improving communication skills of the community health workers and improving their knowledge base was another component in the entire capacity building plan. In this regard we used a booklet answering common questions raised by secondary and higher secondary school students as well as held orientation training on 'essential techniques of verbal communication'⁷.



⁷ Panda S, Roy B, Bhattacharya S. 'Our Questions: subject AIDS' published by West Bengal Voluntary Health Association in December 1996.





The 18-month Project supported by WBSARDM started in July 2008. Within a year we completed the first round of community-based events combining one-on-one and one-to-group interaction, with personal testimony and folk songs on HIV/AIDS by Bauls (in the districts of Paschim Medinipur and Howrah) and Tarja singers (in Howrah). Moreover a number of group meetings were organized with community stakeholders where questions on HIV/AIDS were answered and concerns were addressed. Community engagement has remained central throughout implementation of this intervention project and 'Stigma Reduction Committees' (SRCs) have been formed in the respective villages that house the intervention clusters. The school-based component of the intervention is currently on going.

Before choosing the sites for intervention we collected information on recent incidents (during 2006-2007) of HIV-stigma with the help of SPARSHA care team workers. Subsequent field visits revealed that stigma in the reported villages did not involve the entire village, which were big

in size and rather occurred in clusters. These clusters were formed by the members of households surrounding a family with HIV, local youth clubs, political party office or 'Integrated Child Development Scheme' (ICDS) office staff. In light of the group-origin of stigma, it therefore deemed appropriate to cover all the members of an intervention cluster. Furthermore intervention for other parts of these villages was also designed through interactive planning meetings with opinion leaders and small group interactions. Community members such as teachers and panchayat members participated in random allocation of clusters, to allow for testing out the efficacy of the intervention trial. Thus, we had a community agreement on choosing which clusters would serve as intervention arm and which ones as control. This activity was undertaken at NICED in presence of the Director of the Institute and the Project Director of the West Bengal State AIDS Prevention and Control Society (WBSAP & CS) thereby ensuring participation of various levels of stakeholders.

Through this process four clusters were selected for intervention and four were to serve as controls. The project received approvals from 'Institutional Ethics Committee' and 'Scientific Advisory Committee' of NICED for execution of its experimental design.



⁸ While proportion of outcome (change in stigmatizing attitude) in experimental group was assumed to be 50% that in control group was assumed to be 10%; variability in clusters was considered to be .04 and the size of the each cluster was recorded to vary from 40 to 50. The two sided test used to calculate sample size was based on 80% power and 5% alpha error.



6. Immediate effects and conclusion

Stigma Reduction Committees are now in place in the intervention villages. Currently they are in the process of preparing roadmaps to follow; should discrimination against people living with HIV take place in the future. These committees are joint projects of people living with HIV along with other community members. The committee members are also in communication with the Baul and Tarja singers, as they are planning to organize community based events in line with the events organized by the Project in the late 2008.

It is heart-warming to know that the artists trained through the project are disseminating the message through their performance beyond project activities.

Immediate effects of the project on the lives of people living with HIV and their families are striking. Neighbours, who closely witnessed interaction of the project staff and artists with these individuals and families, have proactively started social mixing once again. Two brothers living with HIV, who were discriminated by the society are currently selling vegetables in the local market. A girl has again started commuting daily to her school on a bicycle that the project helped her to get repaired. Authorities in schools where the children from intervention villages study have started working on preparation of policy doucement that would support non-discriminatory practices in schools. A child who was refused vaccination due to his father dying of AIDS has been given immunization. His mother, who broke into tears during one of our community-based events, has regained her smile.

Expansion of these stigma reduction initiatives is worth the resources. If well-planned, they do not take a prohibitively long time to produce results.

7. Executive summary

Despite the fact that HIV stigma-reduction initiatives would increase the efficacy of prevention and care services, they have received abysmally low financial support. This is specifically true for developing country settings where HIV stigma and efficacy of intervention methods to reduce stigmatising attitudes have been poorly researched. The present document fills an important gap in this regard in for the Indian sub-continent.

Our work in West Bengal over the last three years clearly reveals that art-based innovative intervention approaches for HIV stigma reduction are capable of gaining acceptance even in social environments such as rural West Bengal, where denial and stigma are strong. It is also clear that people living with HIV, their friends and artists living in communities with high levels of stigma could play important roles in stigma reduction campaigns.

Drawing on the experiences described in this report, we urge that essential elements for any HIV stigma reduction intervention should comprise:

- a) Community engagement at every stage,
- b) Formation of Stigma Reduction Committees in which people living with HIV and other community members participate as equals to prepare roadmaps to tackle future discrimination,
- c) Joining together people living with HIV and their friends in intervention teams and living the principle of non-discrimination through practice,

- d) Engaging local artists in intervention efforts and enhancing their creativity through appropriate training and orientation, and
- e) Considering the needs and rights of children who suffer due to societal stigma, rather than focusing on adults only.

We have also recognised that even a complete 'intervention package' as proposed above will only be successful if the project staff REACH OUT themselves to those HIV-positive men, women and children who need a vaccine, or a supportive environment in school, or a humane treatment during social interactions and ensure providing them. Our proposed model thus bridges the gap between those who stigmatise and people who suffer from its negative impact through innovative approach which combines strengths of public health thinking and art.



Artists

Tarja Group, Howrah

Mohan Singh - Singer (uses Ghoongoor - bunch of small bells tied around ankles - while singing and moving on the stage) & also plays Kansor (a hand held flat metal disk that is struck rhythmically with a solid piece of wood) while the other team member sings

Panchu Gopal Guchait- Singer (uses Goongoor) & also plays Kansor while the other team member sings

Michri Roy - Plays Dhol (a type of drum made of wood and leather played with a pair of wooden sticks in West Bengal - see the sketch on the cover of the present report)

Baul Group, Howrah

Sukanta Dari, Singer and also plays ektara (mono metal string instrument) and harmonium

Sanat Dari, Singer and also plays Ananda Lahari (a nylon, or animal hair string instrument that is tied on one end with a resonating box made of wood and leather and held at other end with hand)

Sujata Ghosh, Singer and plays harmonium

Sudipta Bhattacharya, Plays Guitar

Sanjoy Golui, Plays Dugi and Tabla (a set of drums played in Indian subcontinent)



Artists

Gananatya Baul Sampradaay (Group), Paschim Medinipur

Bankim Majhi, Singer and plays harmonium

Chittaranjan Dolui, Singer and plays Ektara

Pranab Barik, Plays Dugi and Tabla

Brajagopal Majhi, Plays Naal (a spindle shaped drum made of wood with two ends covered with leather)

Dilip Dolui, Plays percussion ring

BM Baul Sampradaay (Group), Paschim Medinipur

Bimal Mani, Singer and plays harmonium

Bishwanath Kandar, Plays Ananda Lahari

Mathur Pal, Plays Dugi and Tabla

Dayal Chandra Das, Plays Kartal (hand held concave metal plates, which are struck rhythmically against each other to create music)

Shambhu Manna, Plays Ektara
Prabhat Chandra Kuila, Singer and plays harmonium

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MAKE **A**RT
STOP **A**IDS

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One small gesture of your help
will assist us to go a long way



ESTD 1998

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