



AIDS Community India



Solution Exchange Action Group for Local Community Response to HIV

Report on visit to programmes of
Samraksha in Raichur, and Salvation Army
Community Health Action Network,
Aizawl

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Divya Sarma and Sanghamitra Iyengar, Samraksha

List of Acronyms

AIDS	Acquired Immuno Deficiency Syndrome
CBO	Community Based Organization
CPT	Care and Prevention Team
CHAN	Community Health Action Network
CHAI	Community Led HIV Initiatives
HIV	Human Immunodeficiency Virus
IDU	Intravenous Drug Use
JAC	Joint Action Committee
NGO	Non-Governmental Organizations
PLHIV	People Living with HIV
PPTCT	Prevention of Parent to Child Transmission
RSH	Reproductive and Sexual Health
TI	Targeted Interventions
SW	Sex Workers
MSM	Men who have sex with Men
UNAIDS	Joint United Nation's Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNITAR	United Nations Institute for Training and Research

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Executive Summary

The Solution Exchange AIDS Community had organized a visioning workshop in October 2006, to identify some of the burning issues in the field of HIV. A few selected issues were further explored through Action Groups. The experiences of the Action Group, learnings and recommendations can be shared and carried forward by the larger community.

Ms. Sanghamitra Iyengar, the Director of Samraksha, made a presentation on the potential of working with geographical communities, as an effective strategy for prevention of HIV, reduction of stigma and discrimination, and promotion of care and support for People Living with HIV (PLHIV) in the community, through increased health seeking behavior. Samraksha has been using this approach in its work with 900 villages in North Karnataka. The activities involve building perspectives among communities regarding HIV, and develops community preparedness and competence to halt and reverse an advancing epidemic.

In the brainstorming session that followed, what emerged was the lack of relevant documentation, regarding the operationalization of such an approach, and how this approach could relate with existing interventions, including Targeted Interventions, and Care and Support services. An action group was constituted to visit some programmes using a geographical community approach and document them.

After discussions on the Solution Exchange AIDS Community, an action group selected two programmes, that of Samraksha in North Karnataka and Salvation Army Community Health Action Network in Aizawl, as sites for the visit.

Brief Description of the two programmes

Samraksha

Samraksha has been involved with HIV work for the past fourteen years. Its area of operation is six districts in Karnataka – Bangalore Urban, Raichur, Koppal, Gadag, Haveri and Uttar Kannada. First as a sector of Samuha, a development organization, and then, as an independent Trust, Samraksha has evolved in response to the HIV epidemic, its impact and its changing needs. Its mission of preventing the spread of HIV in the community and reducing its impact on those vulnerable to, living with or affected by it has guided its range of programmes on the continuum of prevention to care.

Samraksha's current interventions focus on prevention, care and support, and building community competence to deal with the epidemic. On the prevention front, Samraksha has a

series of focused prevention programmes with populations at higher risk, like men and women in sex work, and sexual minorities. A reproductive and sexual health (RSH) programme, providing services and health education, addresses the issue of higher vulnerability due to poor RSH status. The care and support programme, is a seamless continuum of care, addressing the multiple needs of PLHIV and their families, across the span of the infection. Community competence building programmes include a process of building perspectives on HIV among village communities, to help them evolve their indigenous response to the epidemic, and a programme to develop voluntarism to increase the spirit of voluntary human response to problems in the community

Nam Baduku, the programme that was reviewed, consists of a process of building community perspectives on HIV, based on the belief that communities equipped with adequate information and perspectives on HIV can evolve the best-suited response to it. Nam Baduku follows a three tiered approach: working with structures in the community including the Government department, and PRI, for orienting and sensitizing them to the issue of HIV; working with existing civil society organizations like NGOs, CBOs, and movements to mainstream HIV into developmental processes at the grassroots level; and working directly with the village communities.

Community Health Action Network

The Community Health Action Network (CHAN), Aizawl, was established in 1991 by the Salvation Army Territorial Headquarters, following a visit by the International Health Team of SA, which saw the need for initiating HIV preventive interventions in the region. It works in the field of Substance Abuse, HIV prevention, AIDS Care and support, and with women in sex work. The activities have focussed on IEC, care and counseling and pastoral care for drug addicts, alcohol dependent persons, women in sex work, distressed women and PLHIV. The basic objective is that of preventing the spread of HIV infection among the groups with high-risk behavior.

CHAN runs a focused intervention programme for groups at high risk, especially women in sex work and IDUs. The Family Counselling Centre provides counseling services in multiple areas and, includes HIV pre-test and post-test counseling. A Vocation Training Centre provides training for clients to help them become self-employed and self-sufficient. The Home and Neighborhood Care programme provides counseling, education, care and training to the members of the families affected by HIV and their neighbors, in order to improve the functioning of existing community support groups.

CHAN has recently been re-organizing itself, to take on a more facilitative role, whereby it can guide other NGOs to nurture more community based approaches. A conscious choice has been made to move away from direct interventions; CHAN now operates through the Territorial Facilitation Team, which plays a facilitative role in helping the local communities identify and deal with the problem. The Territorial Facilitation Team has been further decentralized to District Facilitation Teams, which handle the facilitation processes in their respective areas. The approach is to build a relationship, discuss the community concerns, encourage them to identify their strengths, find appropriate solutions for their problems, helping them implement their solutions, evaluate their action and outcomes, and come up with new action.

Core principles and ways of working

Based on the two programmes, the following core principles and ways of working with community were identified:

- An understanding of community resources, strengths and structures is essential for the organization. Organizations can help communities identify their own strengths and in the process empower them. Existing structures in the community can also help organizations engage with the community. However, power relations need to be understood so that organizations can challenge them in an appropriate way and not antagonize the community.
- Community responses as a result of the programme need to be of a collective nature, in order to increase visibility, sustain, and also benefit from the competence, contacts and experience of all members.
- Programmes need to acknowledge the human needs of PLHIV, respect their need for privacy, and also their need to stay connected to other PLHIV as well as the larger community.
- Programmes need to promote more open discussion on HIV, sex and sexuality, in order to demystify HIV and overcome the fear and misconceptions about HIV. By involving people in the response, they can demonstrate that HIV is not a killer disease with immediate life threatening implications, but an infection, with which people can live for a long time, if they take proper precautions.
- Programmes need to cut away the divide that separates PLHIV from others, by getting people to talk about factors underlying risk and get them to feel that "it could have been me"
- Geographical community approaches are in synergy with other services and

interventions, with the programme continuously linking and feeding into each other. Programmes using this approach strengthen both care and support, and focused prevention, and are also greatly strengthened by the groups they nurture

Demonstrating Community Ownership

The programmes have been able to promote and demonstrate community ownership of action in the following ways:

- Allowing communities to be involved in all stages of the action
- Allowing communities to make mistakes
- Following community agenda for action
- Promoting community action without any material incentives

Impact of the programme

Stigma and discrimination is reduced due to greater clarity on the nature of the epidemic, and greater reflection on the different driving factors of the epidemic. Community centered mechanisms to address stigma is evolved through PLHIV networks and AIDS Action Committees. On the care and support front, the programme has promoted awareness of services, and referrals. Family and community attitudes and capacity for care is also promoted. On the prevention front, the programmes promote self-risk perception, an understanding of what constitutes risk, and an informed adoption of safe behavior. This is continuously reinforced by the larger norm-change that is happening within the community.

Major challenges in implementing the programme

The approach is more a philosophy than a prescribed set of activities. Implementing this approach is a challenge for the organization. One of the major challenges is the creative design of measurement criteria, to measure the impact and demonstrate the impact to the policy makers and donor organizations. A committed leadership is essential and the investment in perspective building of staff, so that they believe in the potential of the communities is critical. Another challenge is ensuring the continuing of a minimum amount of funding to support core components of the programme, including personnel costs and programme overheads.

Conclusion

The Geographical Community Competence Building Approach is both a belief and a strategy. It has evolved from a rights based perspective of giving communities the right to information on HIV, and the right to evolve their own response to it. From a development perspective, it makes communities own the problem and the response, ensuring sustainability. From a sociological perspective, the approach acknowledges the social embeddedness of HIV, and promotes both individual behavior change and community norm-change towards safer, as well as non-discriminatory behavior.

Working with larger communities creates the environment to discuss issues of sexuality, risk, vulnerability, stigma and discrimination, which makes the problem real to the community and a part of their life. By effectively utilizing existing community strengths and structures, communities are empowered to recognize their own ability to deal with the problem in a sustainable way.

The NACP-III programme recognizes the importance of mainstreaming HIV, and introduces the concept of link workers at different levels, who will mainstream HIV into developmental work. The geographical community approach takes it one step further by mainstreaming the issue into grassroots development, and into the lives of the people in the community, who are the most fundamental agents of change for any intervention.

The approach is thus a viable strategy, which can be implemented with existing interventions, in order to promote a more sustainable response, which can meet the needs of a varied, advancing and gradually generalizing epidemic.

Chapter 1: Introduction

Solution Exchange AIDS Community

Solution Exchange is a knowledge sharing initiative of the different UN agencies in India, which builds 'Communities of Practice', by connecting practitioners from across the country, who share a commitment to reduce poverty and promote sustainable development, through electronic e-mail discussions and face to face interactions. The different 'Communities of Practice' are organized thematically to reflect India's Tenth Five Year Plan targets as well as the Millennium Development Goals. Each community is anchored in one or more UN agency operating in India.

The Solution Exchange AIDS Community is concerned with the achievement of Millennium Development Goal 6, 'to halt and reverse the HIV epidemic', as well as the objectives of India's National AIDS Control Programme, with respect to prevention of new infections, assuring quality of treatment for those living with HIV, and mitigating the impact of HIV on people, communities and the country as a whole. The community is anchored in UNAIDS and the main focus of the community is on the following issues :

- HIV prevention
- Condom programming
- Testing, care and treatment
- Communication and advocacy
- Stigma and discrimination
- Universal access
- Mainstreaming
- Orphans and vulnerable children

The different Solution Exchange Communities organize periodic Visioning Workshops to identify the burning issues within their domain. Critical or interesting issues which emerge from the workshops are further explored through action groups, constituted by different members of the community.

One of the ideas explored during the workshop conducted in October 2006 was the Geographical Community Approach to HIV interventions, where interventions were based in geographic communities and led by the members of the community. At the Visioning Workshop, Ms. Sanghamitra Iyengar, Director, Samraksha, made a presentation on the geographical community

approach to working with HIV. This approach seeks to build perspectives among geographical communities regarding HIV, in order to increase self risk perception and promote safe behavior, reduce stigma and discrimination and strengthen supports in the community for people living with HIV. The approach envisages an important role for the local communities in halting and reversing the epidemic. Samraksha has been working with communities in over 900 villages in Raichur and Koppal districts in North Karnataka. Recently 75 of these communities assessed themselves on 10 different domains of AIDS Competence, using a Self Assessment Framework, a tool developed by the Constellation of AIDS Competence, a group of individuals and organizations who are also working with geographical communities to promote 'AIDS Competence'. The Self Assessment Framework allows communities to rate themselves on different domains of AIDS Competence. Samraksha used this assessment framework with 75 of the 900 communities they work with. The exercise showed that many communities assess themselves to have achieved basic levels of AIDS competence, with some of them feeling they have progressed to further levels.

The Geographical Community Approach

Geographical Community Approach seeks to involve local communities in preventing the spread of the epidemic, as well as providing care and support for people living with or affected by HIV. By bringing the issue of HIV into the consciousness of the community, the approach also seeks to reduce stigma and discrimination. In this context, communities can be defined as a group of individuals who reside in a specific geographical location, have a sense of belonging and ownership of the area, are bound by common interests, and frequently have a common cultural or historical heritage.

Geographical Community Approach is based on the belief that once communities have adequate information and perspectives on HIV, they are in the best position to evolve indigenous, appropriate strategies for controlling the epidemic, and caring for those individuals and families who are infected or affected by it.

The approach is based on a rights based framework, and draws from perspectives of community organization and development. Communities are at the centre of the programme and bear the onus of change while external organizations play a supportive, facilitative role. In this way, people and communities are empowered to carry on with the activities beyond the life of the project. Community led approaches can effectively utilize indigenous community resources- the material, social and spiritual capital to influence behavior, and 'normalize' and better manage the epidemic. It focuses on the community's strengths, capacities and potential for change.

The Geographical Approach complements the Targeted Interventions (TI), which have so far characterized the national response to HIV, and addresses certain lacunae in the TI model. Targeted Interventions have focused on the designated 'high risk groups' and is based on the epidemiological standpoint of prioritizing the allocation of scarce resources for maximum impact and benefit (Amin 2003). However targeted interventions are not enough to address the epidemic in its current state in India. The epidemic has already generalized in some states, and there is also an increasing feminization of the epidemic, with 38.4% of those affected being women, many of them monogamous, who have been infected by their regular partners. The governments of India's focus on PPTCT programs is itself a testimony to the fact that TIs have been neither adequate nor effective to address the state of the epidemic in the country.

The classification of "high risk" groups, which is central to TI, has some conceptual flaws. TIs are unable to include some very important groups within the sexual networks, with whom interventions are necessary, including the wives of the clients of sex workers or the regular, non-paying partners of sex workers. Recent studies have also cast doubt over some of the assumptions on which groups are classified into risk categories. Mobility for instance was seen as an important determinant of sexual partner behavior. Truckers and migrant laborers were logically seen as a high risk group. However, the findings of the recently undertaken NFHS III survey indicate that men who never leave their homes for long periods of time are just as likely to have multiple partners as men who are mobile. Hence men who are not geographically mobile cannot be ignored as a low risk group (Government of India, 2007). In the light of recent literature, which shows that practices like long time concurrent partners, prevalent in parts of Africa, which has contributed significantly to the spread of HIV, there is a need for more broad based interventions, which takes into consideration the previously neglected groups.

TIs have also not tried to address some of the structural issues in society which contribute to the epidemic. Sexuality, though one of the most intimate aspect of life, is also something which is governed to a large extent by social norms, practices and existing power relations. Unequal power within a sexual relationship is a product of power asymmetry in the larger society. TI has focused on individuals, but sexual intercourse happens between people, who are social beings. The experience with IEC shows that information is necessary but rarely sufficient for behavior change. A woman might be aware of safe sex practices, but the social situation renders her powerless in making her partner(s) adopt such practices. There is, thus, a need to involve communities in discussions and critical reflection of the power hierarchies existing amidst them, and look towards ways of creating a more equitable society.

There are also some inherent problems with the philosophy of the Targeted Interventions. By

characterizing certain groups as 'core transmitters', it perpetuates the stigma around an already marginalized and vulnerable group like sex workers or intravenous drug users. Moreover, characterizing HIV as an infection of the High risk groups, decreases self risk perception. HIV is seen as an epidemic for the 'others', the 'promiscuous' and 'morally degenerate' people and an individual's own risk of becoming infected is ignored (Amin, 2003, Epstein, 2007) . Community based interventions on the other hand does not seek to identify any specific high risk groups, but addresses the risks for the entire community.

Community based approaches mainstream HIV into larger development work. More importantly, they promote discussion and reflection on HIV in communities, both in public forums as well as within families and peer groups. This makes HIV more real to the lives of the people. People are able to understand the epidemic in terms of its driving forces, certain social or structural issues which can increase the chances of an individual or group being affected by HIV. These forces may be universal, or may be specific to their communities. Communities may themselves take action to control some of the driving forces over which they have control.

The concept of AIDS Competence has gained popularity in recent times. AIDS Competence means that people in families, communities, in municipalities, in organizations and in policy making - acknowledge the reality of HIV and AIDS, act from strength to build their capacity to respond, reduce vulnerability and risks, learn and share with others and live out their full human potential.

The AIDS competence approach has emerged from certain experiences of tackling the epidemic, which revealed the strength and resources of the community members. The Salvation Army Chikankata Health Service, in Southern Zambia started with the idea of home based care, where mobile health units visited people living with HIV in their homes and communities and provided treatment and education. Interactions with the family and communities clarified the nature of HIV and the needs of the infected people. The mobile teams were gradually dismantled, due to their unwieldy nature, and community based Care and Prevention Teams (CPT) were formed. The needs of people living with HIV were prioritized, and the resources and strengths of the community were identified, and matched with the needs. CPTs provide a good model of care ensuring that the sick get care within the community, and the family members of the sick person can also carry on with their productive activity, without devoting all their time to care (Silomba, 2002).

The Salvation Army experiences in working with the communities in some of the worst affected regions in Africa, led to the development of community counseling approach. Community

counseling is a process of listening and reflecting with the community about the problem of HIV and the losses the community has suffered due to HIV. Through this process of facilitated truth sharing, communities are encouraged to go beyond helplessness, and try to address their problems in a more active manner. Community counseling is essentially transferring the principles of individual counseling, like belief in capacity to change, emphasis on listening and acceptance, and ideas of confidentiality and shared confidentiality, to working with communities (Salvation Army, 1996).

In Malawi and Senegal, the UNDP used an approach of Community Capacity Enhancement, through Community Conversations, a process of engagement with the communities, which help people analyze the ways in which their values, norms and practices affect people's lives and create spaces for listening and thinking things over, for clarifying doubts, learning and changing together (PNG SDP and Save the Children, 2007).

Another effective community based approach, which dramatically reduced prevalence levels was seen in Phayao province in Northern Thailand. Prevalence rates among military conscripts fell from 20 % in 1992 to 7 % in 1994, and among pregnant women, from 11 % in 1992 to 5 % in 1995. This rapid decline was a result of a multi-sectoral response, including the government, civil society organizations, and religious leaders. Change was initiated and maintained at multiple levels. Individuals started modifying their sexual behavior, the numbers of commercial sex establishments declined rapidly, men delayed their first sexual experience to have it with a regular partner, rather than a sex worker, as was previously the norm. Condom use was encouraged, initially among sex workers, and then among even regular partners and couples. Government and civil society organizations began addressing some structural issues, like lack of livelihood options in some areas, and lack of education among women, which drove many women into cities to practice sex work. Families started taking more responsibility for keeping girls in school. The high prevalence levels made communities realize that AIDS was not a disease of the 'other'. Sex Work is a job, not an identity, and sex workers might be housewives, with husbands or lovers. Thus no one was 'safe'. The change was sustained by a Phayao AIDS Action committee, set up in 1994, with links to government bodies, community structures and non-governmental organizations (UNAIDS 2000).

The Phayao experience reiterated the centrality of people's response to the epidemic. People decide to adapt their sexual, social and economic behavior to minimize chances of infection. Institutions play a facilitative role in the process.

These multiple experiences converged in 2003 with a UNAIDS/UNITAR sponsored AIDS

Competence programme launched in partnership with various governments and CSOs in about 30 countries. The evaluation in 2005, showed that this programme plays an effective facilitative role, and is a good support mechanism for existing programmes, multiplying their impact, without any drastic change in strategy (UNAIDS and UNITAR 2005) . Service delivery can continue for the people, as individuals who are at high risk, and who need them, while the geographical community approach continues to address them as people, within specific social systems. The costs are also low compared to the reach. At the end of the programme, a group of 12 people involved in the programme, reaffirmed their commitment to knowledge management in this field and launched the Constellation of AIDS Competence to further enhance the approach through knowledge sharing, and enhancement of the different tools used to assess and promote AIDS competence.

Other successful community led interventions include ACORD in Northern Tanzania, who used a community-led rights based approach in mainstreaming HIV. Communities initiated the action and ACORD's role was confined to increasing the participation of marginalized people in the community, establishing effective partnerships, and encouraging the development of emerging and existing networks (HASAP 2003). The Uganda AIDS Commission initiated the strategy of Community Led HIV Initiatives (CHAI), where a team of trained district level workers help the communities carry on AIDS related activities, along with a committee consisting of members of the community. The strategy allowed various CBOs to avail funds from UACP to carry out activities related to treatment, care and prevention (Kiirya, 2004).

Building AIDS competence cannot be done through a pre-decided set of activities. It needs a more flexible approach, with certain core beliefs and strategies, which can be operationalized into different activities, based on the context. What is important is meaningful engagement with communities, which involves developing mutual trust and respect and nurturing this. There are some guiding principles for this engagement. Firstly, the process needs to appreciate and value the existing resources in the community and the past experiences. Secondly, the process needs to be owned by the community. This means that communities are allowed to work at their pace, and sometimes on activities which they choose to be important, and not according to the priorities of the organization. Communities frequently start responding to the epidemic, based on the issues they may feel are most relevant to their lives. For instance many communities feel that the welfare of orphaned and vulnerable children is important, and start responding to this need. They subsequently identify and respond to other needs. Thirdly, the key to involvement with communities is to engage them in critical thinking and dialogue, rather than just information dissemination or behavior change communication (PNGSDP and Save the Children, 2007).

Clearly this approach cannot work in isolation. Although it has the capacity to reach out to all sections of the population, from those at highest risk to those at low/zero risk, it cannot address the specific needs and circumstances of the different groups. At the same time, it expands the reach of the programme, and brings in more people into the prevention spectrum.

The Response to the Geographical Community Approach

The presentation on the Geographical Community Approach evoked mixed responses. The idea was seen as exciting, and involving a paradigm shift in the way of conceptualizing AIDS interventions, moving away from an externally imposed idea to an internally driven sustainable idea. However while the philosophy behind the idea was appreciated, skepticism was expressed regarding the on the ground implementation of the idea and on how replicable it was.

There were also doubts expressed regarding the relevance of this approach to different contexts, like high prevalence/low prevalence areas. The approach has also so far largely worked in rural settings, and its applicability in urban situations was questioned. There were also some questions on whether by working with communities as a whole: the approach might not reach out to marginalized people within the community. Greater clarity was also needed on how this approach could co-exist and feed into the different existing interventions, including TI and care and support services.

What emerged from the brainstorming session was the current lack of relevant documentation on the geographic community approach. It was felt that this gap must be addressed and some of the promising interventions in geographic communities need to be documented and reviewed to understand their relevance and applicability to different situations. Hence it was decided to constitute an Action Group on Local Community Response to HIV.

The Action Group on Local Community Response to HIV

As a first step in constituting the Action Group, Ms. Sanghamitra Iyengar, on behalf of Samraksha posted a query on the Solution Exchange AIDS Community, describing the experiences of Samraksha with community led interventions, and seeking other similar experiences. There weren't many experiences in the country, and based on the responses, two projects were selected for further review. These were the project of Samraksha in Northern Karnataka and that of Community Health Action Network in Aizawl, Mizoram.

An Action Group comprising the following people was constituted, to review the two programmes

1. R Meera, WINS
2. Bobby Zachariah, Salvation Army Health Services Advisory Council
3. Mohd. Rafique, Solution Exchange
4. Rituu B Nanda, Solution Exchange
5. Sanghamitra Iyengar, Samraksha
6. Divya Sarma, Samraksha

Special Invitees :

1. Elizabeth Reid
2. Asa Andersson Singh

A team consisting of some of the Action Group members visited the two project areas and interacted with the different stakeholders over a period of three days in each site. This document is a report of the visits to the project sites. The different processes are described, and the impact of the programme is captured, using the words of the community members, as well as some reflections of the Action Group members.

Chapter 2: Practicing Geographical Community Approaches : Samraksha and CHAN programmes

Description of the two programmes

Samraksha

Samraksha has been involved with HIV work for the past fourteen years. First as a sector of Samuha, a development organization, and then, as an independent Trust, Samraksha has evolved in response to the HIV epidemic, its impact and its changing needs. Its mission of preventing the spread of HIV in the community and reducing its impact on those vulnerable to, living with or affected by it has guided its range of programmes on the continuum of prevention to care.

When it began to respond to the epidemic in 1993, it adopted the primary preventive national strategy of protection of people at the highest risk through **Namjeeva**, a classical Targeted Interventions Programme. As it became apparent that the groups at high risk went beyond women in sex work, truckers, MSM and transgender communities to men in prison, women in garment factories, and youth living away from home in hostels, Samraksha extended its interventions to these groups.

After a few years, it became very apparent that despite theoretical assumptions about variable risk levels of different groups of people, HIV had gone beyond the primary "Target Groups"; certain locations appeared to be providing more opportunities for sexual networking. Some of these were large social aggregation points, permanent ones like towns, trading centres, industrial units or temporary ones like weekly markets and large community festivals and fairs. There were patterns of sexual service seeking in rural populations which were culturally determined and influenced by availability of sex at certain times. Men at risk were wide ranging and yet could be reached through interventions in certain locations and at certain times. This meant new strategies and structures that took targeted interventions beyond the classical brothel based or urban centric interventions; it also meant moving to rural, dispersed populations at risk and working in districts to saturation.

Similarly, the sex work scenario in Karnataka, with its part time and seasonal sex workers, led to work with women who practice sex work as an additional occupation and do not accept the identity of a sex worker. Interventions that could reach them in the identity of "women", proved successful. So, **Namarogya** or the reproductive sexual health programme with its community

outreach and clinical services was born. This again expanded to include women whose risk came from their husbands or long-term partners. These were women who were largely monogamous or had regular partners. Within these groups, young adolescents, particularly girls had an increasing risk. **Yuvashakti**, a programme to promote the sexual and reproductive rights of adolescents, by working directly with them in different communities, and working with older women, who as gatekeepers in the community can positively advocate for the exercise of these rights by adolescents.

On the impact reduction side, Samraksha began with a counseling service at points of diagnosis which were STI Clinics and Microbiology units of 3 government hospitals in 1993. The stigma and fear surrounding HIV in the early years had led to a widespread refusal to treat in public and private sector health care facilities. Samraksha saw its role as two-pronged: providing interim medical services and working with health care providers to reduce stigma and increase access for people living with HIV. So the Continuum of Care that emerged grew to include care and treatment on an outpatient basis, community care centers for acute and end of life care, home care, adherence support teams to help the state run antiretroviral therapy programme and family carer support programmes. Medical and nursing services, too were embedded in this web of psychosocial interventions.

By 2001, it became very apparent that risk behavior was not confined to any specific group. It was equally clear that sexual behavior patterns that put people at risk were socially determined and could not be changed by health education or counseling alone. Socio-cultural contexts had to internalize risk and communities had to evolve their own responses. It was also clear that the scale and speed of the epidemic required large scale community responses to influence people to adopt safe behaviors. It was ironic that while responses to the HIV epidemic had done so much for the streamlining of blood safety and making visible the issues of sexual minorities, it had totally disregarded the potential of communities. Most interventions were neither community evolved nor community led. Sustainability and cost effectiveness of these interventions were important issues to address.

Samraksha's journey of responding to the epidemic and its impact led to a deeper understanding of both HIV and the inadequacy of any single approach. It also brought back the emphasis on the very basic tenet of development, forgotten by the biomedical model: Community centric approaches. In 2002, after a series of reflections with staff, and communities, **Nambaduku**, a programme for community perspective building on HIV, for communities to evolve their own responses to tackle the epidemic, was launched.

Strengthening the community response is **Spandane**, a programme that seeks to enhance voluntarism and to strengthen volunteers in the community, through perspective building on HIV, disability and mental health issues in the community.

The Nambaduku Programme

Nambaduku is based on the belief that once communities develop a perspective on HIV AIDS, they will then be able to evolve their own indigenous strategies for prevention, care, treatment and support for those who are affected by HIV. This approach will not only reinforce risk reduction, but also reduce stigma and discrimination and build community preparedness for an advancing epidemic.

Samraksha recognizes that the fabric of society has a warp and weft of influences. Social change will need responses that are not just horizontal. So, Nambaduku follows a 3 tiered process of perspective building, which simultaneously addresses:

1. Structures: orients and sensitizes government departments, and Panchayat Raj Institutions, industries or formal workplaces in the area to the issues around HIV. The idea being that these have a sphere of influence to help or hinder and need to be involved.
2. Movements and NGOs and CBOs working in the area : mass movements like trade unions, political parties, dalit and women's movements have a different level of access and influence in communities. If HIV is absorbed by them into their day to day discourse, it is powerful mainstreaming at the grassroots level. Similarly NGOs and CBOs who are working for social change at multiple levels are good sources of support to communities, if they have the perspective
3. Community members of a village or a town ward to help build perspectives on all aspects of HIV. The strategy is to saturate the community with information regarding HIV, help them understand and identify their own risks, reflect on the problems faced by **people living with HIV** and create a non-stigmatizing accepting environment, where they can access care and treatment within the community.

One of the unique elements of the programme is the ***village process for perspective building***, where a team from Samraksha visits and stays in the village for about three days. During these days, the team interacts with the members of the village, through a series of individual interactions, group discussions, and meetings with opinion leaders, existing groups, etc. on the issue of HIV. At the end of the three days, at a village meeting, the community

discusses its own issues relating to HIV, sets certain goals and makes an action plan. Samraksha, during its periodic follow-ups (once in three months) observes the progress of the community towards its goals, and helps them with any aspect that they are asked to.

Box : 1 The Village Process for Perspective Building

Preparation:

- Family level: Impact analysis jointly with the whole family through reflection tools to effect change
- Village level: Opinion leaders meeting, Social mapping, bringing HIV risk, vulnerability, acceptance and segregation issues into public discourse through a variety of interactive methods. (games, exercises, magic, street plays , individual and group discussions, school sessions and reflective sessions).

Action Phase

- Community formulation of action plans
- Capacity building of volunteer teams to keep the issues alive
- Formation of AIDS Action Committees, to deal with stigma and discrimination within the community / in the health care setting

Community Monitoring & Review

- Quarterly follow-up visits and community's self review of progress.

Communities are involved in monitoring and evaluation of the programme through a participatory process, where a team of local leaders, health care providers, community members, and Samraksha staff from Nambaduku and other programmes evaluate the programme and its impact. The community response is an indicator of the programme impact. Communities have now progressed to the next step and evaluate their own response and competence using the self assessment framework for AIDS competence.

The programme is fueled by a team of community catalysts, 6 people per taluk ; gender balanced to ensure at least 2 if not three are women. These are members of the same community The team has undergone an intensive six month training on HIV, participatory methodologies, listening and reflective skills, to help them to facilitate this process.

The programme has facilitated the formation of AIDS Action Committees at the Taluka level, which are citizens forums, involved in various activities of prevention, awareness generation, stigma reduction and advocacy. The programme has also supported the formation of networks of

people living with HIV at the taluka level, federating at the district level. It has provided the support of a senior facilitator with a history of working in different movements to all the networks, to smooth out their teething problems, to write their byelaws and evolve their organizational culture.

Community Health Action Network

The Community Health Action Network (CHAN), Aizawl, was established in 1991 by the Salvation Army Territorial Headquarters, following a visit by the International Headquarters HIV/AIDS Technical Assistance Team (as it was known then) of SA, which saw the need for initiating HIV/AIDS preventive interventions in the region. Prior to that, in 1990, the Salvation Army Bawngkawn Corps (Church) established the Samaritan House, a shelter for women in sex work, which also provided counseling and health care services.

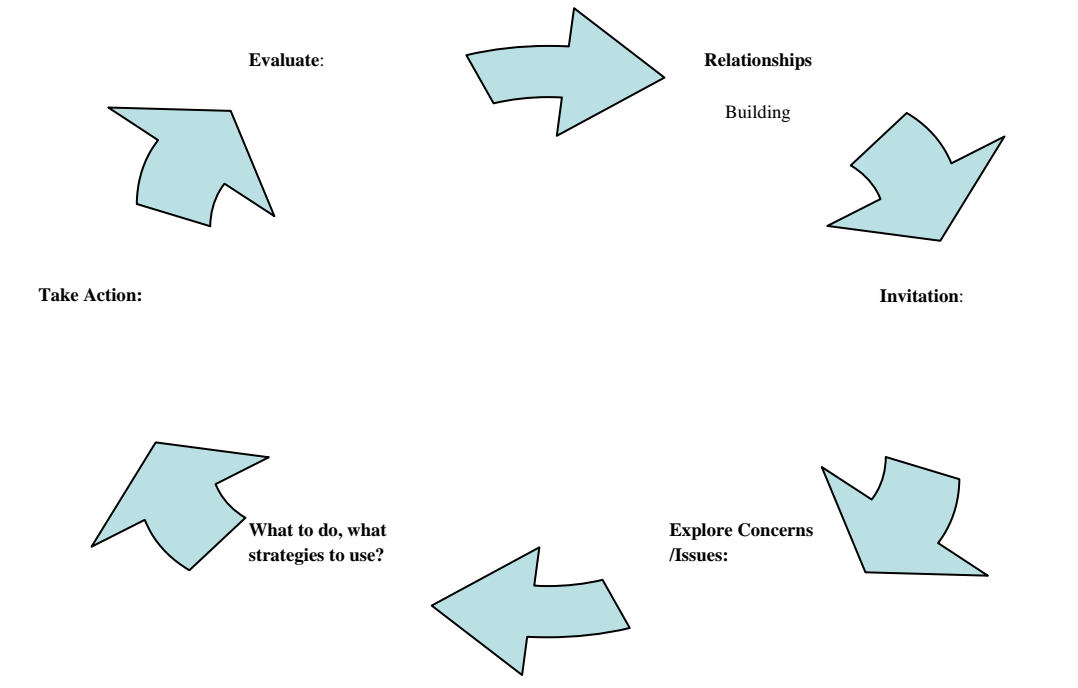
CHAN has been working since 1991, in the field of Substance Abuse, HIV/AIDS and commercial sex workers. The foundational belief has been that caring for drug dependents, alcohol dependent persons, sex workers, distressed women and people living with HIV, will provoke expanding circles of change in their lives.

The program provided shelter services to women in sex work through the Samaritan House, condom promotion, needle syringe exchange, early detection and treatment of STIs and abscess management among IDUs, other groups at high risk and counseling services including pre and post-test counseling. A Vocation Training Centre to provide training for clients to help them become self-employed and self-sufficient.

The relationship built with the clients through these programmes became entry points which were strategically followed up by CHAN staff (health care workers, counselors etc.) through regular home and neighborhood visits for home based care, community counseling, and training purposes. Other entry points such as invitations from the local churches, NGO's, CBO's etc. too have been used.

CHAN uses the methods of participatory group exercises, developed by the Salvation Army, in the facilitative process. The different tools and techniques used are community counseling, development planning framework, self assessment framework, facilitating the formation of support groups in the community for PLHAs and facilitating the linkage of community, family and neighborhood. The SALT process of Stimulation, Appreciation, Learning and Transfer guides much of these methodologies.

Community counseling diagram



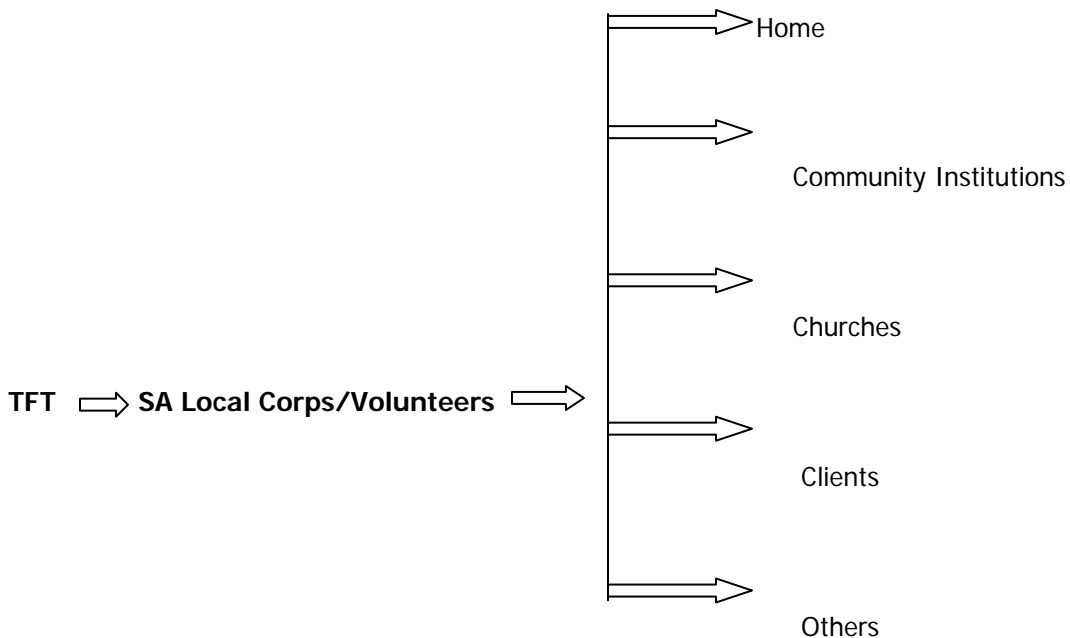
During the process of interaction, systematic discussions were stimulated in the homes of people. The communities openly ventilated their anger and frustration about the 'sinfulness' of the clients. Grief was acknowledged. Further discussions helped the communities to identify and initiate actions to address their concerns. The need for inclusive care for clients was affirmed. Stigma reduced drastically.

There are multiple examples of how communities have taken over the ownership of the program. Eg. The number of dressings in the clinic dropped and the total number of dressings increased drastically as a result of the community outreach. The clients, their families and neighborhoods were increasingly managing their day to day dressing in the homes and approach CHAN only in case where they need the acute medical help. Another example is the community of Dinthar, where the Joint Action Committee (JAC) regularly runs the program with community resources.

By the year 2000, about 20 communities around Aizawl were having active neighborhood based volunteer teams. Volunteers also visit homes from other localities, to develop community to community linkages, learn and support each other. CHAN program regularly conducted combined meeting of community volunteers from different localities to facilitate experience and vision sharing.

It was evident that communities in the outlying areas (of Mizoram and other north eastern states where TSA was operating), were needing support to respond to drugs and HIV, but with few organizations equipped to do it. In the year 2005, during the evaluation of the program with the support of the International and National Health program facilitation team, CHAN management council made the strategic decision to change its direction and become a 'Territorial Facilitation team', further decentralized to 'District Facilitation Teams' which handles facilitation of community processes in their respective areas.

CHAN is currently involved in conducting electoral visits to different areas and facilitating community and organizational response based on the principles of Human Capacity Development. CHAN is now working with the vision of building motivated local teams in the communities. Involving people in the homes and neighborhood including different community institutions and leaders in the activities, community to community transfer of learning, synthesizing the lessons learnt, and networking and advocacy with other government and non-government agencies, are some of the ways of making the processes deeper and more sustainable.



TFT Facilitation Process Framework

Comparing the two approaches

When we compare these two programmes, what emerges is not just the common underlying beliefs in the potential of the community and their role as the central player in the response, but also the completely different ways in which this approach has evolved in the two organizations.

They operate in diverse contexts, and the programmes unfolds through a different set of activities.

Samraksha, a secular, non-governmental organization, emerged, as a wing of a larger organization working in development, to focus specifically on issues of HIV prevention, treatment, care and support. The geographical community approach has been used with the communities, in Raichur and Koppal districts, two drought prone areas with which have extremely poor development indicators. Literacy levels are also low. HIV prevalence is high in the area, with antenatal prevalence exceeding 1 %, indicating a generalized epidemic. Heterosexual transmission is the primary route of infection.

SA CHAN is a faith based organization, with close affiliation to the Salvation Army Church. In the context of Mizoram, where Christianity is the majority religion, this affiliation is significant. Geographically, the hills of North Eastern India are a challenge to work in because of poor transport and communication facilities. On the social front, the state has one of the highest literacy rates in India, second only to Kerala. It is also a highly structured society, with many different groups of the population established as formal associations, for instance, the Mizo Youth Association, Mizo Association for the Elderly, etc. Almost the entire population are members of at least one of these groups, and involved in their activities. HIV prevalence is low in the state, but it shares a porous border with two high prevalence states, Manipur and Nagaland, where needle sharing due intravenous drug use is the major route of transmission.

CHAN's work with communities has evolved from earlier experiences with marginalized groups, like providing shelter for women in sex work, or pastoral care for people addicted to substances. The approach itself is significantly related to other experiences of the Salvation Army International Teams as well the AIDS Competence Process, promoted by the Constellation for AIDS Competence. Different tools and techniques from the AIDS Competence processes are used within the programmes. As a faith based organization, CHAN has also been significantly influenced by the church and its teachings. It has also been able to utilize its own relationship to a church, and the centrality of the church to life in Mizoram, to facilitate its engagement in the community. This is manifest in different ways in their activities, both at a practical and a philosophical level. While at a practical level, it is this link with the church, and its different groups, like local corps, salvation army youth groups etc. which facilitates CHAN's engagement with the communities, at a philosophical level, concepts like love, compassion and caring, are largely articulated using the language of Christian discourses.

Samraksha on the other hand, has developed this approach independently, based on their experiences in working in the field and constantly responding to the changing scenario regarding the epidemic. An awareness about the developmental scenario in the area, as well as an understanding of the culture of the area, led to a greater understanding of HIV in the context of specific cultural and developmental factors. The tools and techniques used by the team are the community and local team's adaptations of popular PRA approaches, which have also incorporated popular cultural traditions. Samraksha's links with the Constellation for AIDS competence has been recent and so is its use of the self assessment framework for AIDS competence in different villages.

The approach also unfolds differently in the two settings. Samraksha operates through a rapid perspective building process, after which there is a direct community link only once in three and subsequently six months. There are fixed action points such as the Candlelight Memorial Day in May and the World AIDS Day in December. Otherwise, interaction between Samraksha and the village is not a continuous process; linkages are established through Taluka Level AIDS Action Committees and PLHIV networks. The rapid process promotes community ownership early, and also allows Samraksha to increase geographical coverage.

SA CHAN however maintains a more sustained, direct long term link with the community, and are involved with the community for a longer time, either in implementation or as mentors. Communities have a religious and spiritual link to the Salvation Army and therefore to CHAN, which is not limited to the specific interventions. Links continue on a more regular continued basis through SA local groups, youth groups and other groups in the community.

The two organizations have been able to design different activities and processes depending on their strengths, their understanding, presence and relationships with the communities. The different contexts in which the organizations have used this approach suggests that geographical community approaches have wide applicability.

Chapter 3: Core principles and Ways of Working

Working with geographical communities is based on a belief in the potential of the communities to understand and respond to the specific nature of the HIV epidemic, in their communities, as it affects their lives. Since communities vary so much in their contexts, needs and resources, it is not possible to evolve a universal programme design. However, there are some core principles, based on which specific programmes and activities can be designed.

Understanding and managing existing structures and resources in the community including the different power structures

Understanding of the community, its resources, structures and hierarchies is essential to productively engage with communities in different actions. Organizations can then help communities understand their potential and respond from a position of strength, channelise community resources and structures to strengthen the response, and involve all sections of the community in the response.

Communities also have a lot of resources, material, non-material and structural which can help carry out an effective response to the epidemic. When organizations operate from a strengths based approach, it can help communities, which perceive themselves as resource poor, appreciate the extent of their own resources. It moves them from a position of receiving aid to a position of identifying ways of helping themselves.

Existing formal and informal structures in the community can facilitate organization's interaction with communities, during the programme. CHAN has successfully used not only the church, as an important institution in the social fabric of Mizoram society, but also the highly structured nature of the society to facilitate entry and interaction with the community. Linking with the church is a challenge for CHAN, since it cannot let its own affiliation with a certain church affect interactions with churches of other denominations. The issue of HIV and condoms itself is a potentially divisive one among churches. CHAN has to effectively manage these relationships.

Samraksha works in more heterogeneous contexts, and it is difficult to find a single existing formal structure, to reach out to all members, but different formal and informal structures can help sustain the action. These could vary from development related groups youth groups, women's savings groups, health systems, literacy programmes to mass movement groups like Dalit Seva Sangh, as well as governance structures like gram panchayats.

Power hierarchies operate in all communities, and organizations need to understand this in order to reach out to all the groups in the community. Power structures also need to be challenged in appropriate ways, in order to not antagonize the community and deter community engagement.

Entering the community in a non-threatening way is crucial; because HIV is associated with socially unsanctioned and therefore taboo behavior like multiple partner sex or Intravenous drug use, organizations with a perceived agenda of identifying specific groups with such behavior, can be a perceived threat. It is generally good to enter into the community with prior interaction with some members and leaders, which gives organizations some legitimacy in the community. CHAN enters a community through their own links with existing groups like SA local teams and youth groups. Rehabilitated IDUs, or women in sex work, or people living with HIV sometimes invite the CHAN team into the community. Involving local leaders is done through the interacting with Joint Action Committees, a community based group looking at social problems in the area. Samraksha might also enter the community through some interactions with existing women's or youth groups, but the formal entry is established through a letter seeking a prior permission. In the first meeting with the community, Samraksha tries to involve all members, specially the village leaders, as well other opinion leaders like religious leaders, leaders of women's groups.

Organizations also need to creatively reach out to the marginalized groups and ensure their participation in the response. For instance, it might be a challenge to reach out to women, since women might be reluctant to voice their opinion in community forums, or might not even have the time to get involved in their forum, given their burden of work. Samraksha reaches out to women, primarily through one to one interactions, which take place at the women's convenience. Since the team stays in the community for a few days, the team members interact with the women at night as they are cooking, or in the morning when they are walking to fetch water or perform their ablutions. Women might also need separate spaces and activities for themselves, to promote more uninhibited discussions on issues, including issues of sexuality and HIV. Samraksha realized that when social mapping exercises were done with the entire community, women seldom participated, but when it was done separately for women, not only was there more participation, but women were also able to map some resources and structures, which was specially relevant to their lives, which helped organizations understand communities better.

Collective learning and action

Programmes are based on the principle of collective responsibility and action. Certain existing groups in the community, or newly formed groups can emerge from the community engagement, and give impetus to the community response. Collective responsibility ensures that a larger

number of people are involved in the action, there is greater visibility of the issue in the community, and the activities can benefit from the knowledge and skills of a wider range of people.

Samraksha has nurtured various AIDS Action Committees in the different talukas, as an informal voluntary group of prominent opinion leaders in the community, spreading awareness about HIV and intervening in cases of stigma and discrimination. What is interesting about the AIDS Action Committee is that it is actually a collection of diverse individuals, each motivated by different reasons, and with varying levels of interest, who bring in their individual competencies and contacts. For instance, the leaders of various women's federations and co-operatives, can network with other women's groups. The Taluka Literacy Co-ordinator uses his network of literacy animators to take forward the awareness work in the communities. The social activist leads other members to take up issues of discrimination with the concerned community members. As one of the members put it, "We are all from diverse backgrounds, if one person tries to do something, it might not be effective, but if many people think it is important and do it, they can have a better impact."

Another important group within communities which has given impetus to the collective action is the network of people living with HIV. These groups are uniquely placed to influence community led action since they are from the community and understand the community, and their powerful testimonies brings home the multiple ways in which lives are affected by HIV. Community action can thus be made more empathetic and responsive to their needs.

CHAN's work involves Salvation Army Youth Groups and Joint Action Committees in the community. Ownership of response is not limited to these groups. Community ownership is not restricted to these groups, the larger communities also demonstrate ownership. For instance, in the community of Dinthar, while the Joint Action Committee has set up a half way home for drug addicts and people with HIV, the salary of the counselor is paid by contributions from the entire community. (*The Dinthar half way home is explained in greater detail in Chapter 3*).

Respecting the human needs of people living with HIV

While working on the issue of HIV in communities, the human needs of the individual people living with HIV need to be acknowledged and addressed. The need for privacy is paramount. Community based approaches have expanded concepts of confidentiality, beyond the one-one confidentiality, to include 'shared confidentiality' and different but overlapping circles of confidentiality, within the different social systems, in which the individual operates.

Organizations need to be fully aware of the different spaces for sharing confidentiality, and not breach them in any way. CHAN ensures this is by not targeting any single affected household for home visits, but by visiting multiple houses in the community. This gives the affected individual or family the choice to remain anonymous if they so desire.

Atmajyoti : The PLHIV Network in Sindhanur

People living with HIV first started meeting at Samraksha's outpatient clinic. They started with discussions on health issues and treatment. According to the president of the network, "When we first sat together, we were too scared to even look at each other. It was the first time we were acknowledging our status to others. We talked about our health concerns, about ART and other problems." Slowly, it evolved as a group. Today, the network is involved in many activities for advocacy, treatment access and stigma reduction. They have been able to produce many concrete results.

The network is very proud of the way they created awareness about the services available at that taluka hospital. They had concerns that many people living with HIV do not have enough information as they keep their status a secret, and hesitate to ask even when they come to the hospital. So, they raised money through their personal contributions and put up a big board at the entrance of the taluka hospital to help PLHIVs identify the different services provided and the point of service delivery. Another action they cite as an achievement is their efforts to break the nexus between medical labs and doctors, who referred people for unnecessary and more expensive tests, and promoted the less expensive testing options. They also made the Taluka Hospital change its board from AIDS testing, to HIV testing, in order to emphasize the difference.

"Stigma is always there, if not for AIDS then for something else. I think we need to go beyond it and continue with our lives"

"During the World AIDS day programme, I was on stage with different local dignitaries. It was a great honor for me, and it changed the way my family and community saw me,"

"I declared my status as HIV positive on World AIDS day. I felt that if I take the lead, so many others can also follow"

"I used to be an agriculturist. But now my brothers look after my land. I visit people who have been identified as **people living with HIV**, and refer them to the district hospital and Asha Jyothi. I have even put up my mobile number in various public posters, so that people can get in touch with me, whenever they need some help. I must say that my family has been very supportive, they realize the importance of this work and let me do it. "

"We made them change the board from AIDS testing to HIV testing, there is a difference between the two."

People living with HIV also need to be connected to each other, even as they live within larger communities. This helps them share and learn from their collective experiences, and derive strength to cope with their lives. Samraksha has therefore facilitated networks of PLHIV which are connected with their families and communities. Coming together, sharing stories, and drawing courage from each other, they can also engage in activities in the community, where their positive outlook dispels fear, and provides inspiration and courage for other positive people to come out and seek treatment.

Promoting open discussion, and clarifications regarding HIV

The initial knee-jerk response to HIV by the media, the government and indeed many of the non-governmental organizations, have ended up making HIV seem like a dreaded disease, with immediate life threatening implications. This has also contributed to some of stigma and social exclusion faced by some of the people living with HIV, and their families. Involving communities in the response allows people to understand for themselves, the true nature of HIV infection, and its impact on a person's life. They can understand better that a productive life with HIV is possible, and also understand how they can contribute to enhancing the lives of the affected members. For instance, many of the members of the AIDS Action Committees were not aware of the HIV as an infection as different from AIDS. Their understanding was that death would result immediately after the infection. It was their involvement with the committee which made them understand this difference.

Not such a dreaded disease after all

"I used to think people died quite fast if they had HIV. Now I realize that they can live for quite a long time", a member of the AIDS Action Committee

"Initially I was very scared even at the mention of HIV. Now I know that it is just an infection, maybe not even as serious as TB", a woman member of the AIDS Action Committee

"Why should they feel scared or shy. Diabetes is also an incurable disease. Does anyone feel scared or shy to tell that they are diabetic" a community member in Nanjaledani responding to another member's comment that people might not disclose their HIV status because they are scared or shy.

Geographical community approaches can also effectively discuss issues of sexuality in different open and closed forums. This discussion can lead to a greater acknowledgement of one's own sexuality, as well as how personal expression of sexuality can place them at different levels of risk. Thus communication on prevention and safe sex is not restricted to only information, but to an understanding of what safe sex means in their circumstances.

Samraksha uses various IEC material, as well as games, puzzles, magic tricks etc. to initiate discussion on sexuality issues. The experiences suggest that once the topic is broached in the right way, communities are quite open to discuss the subject, and even women can involve in uninhibited discussions, specially in forums, where they are comfortable.

Acknowledging one's own sexuality

"Even brahma could not resist women. Who are we?" This was said by one of the villagers in Dumti, while summing up that everybody was at risk, during an exercise to increase self risk perception.

"We don't talk about sex with our parents, but among ourselves, we talk about it. Local healers tell us a lot of information about sex. They start lecturing some 5 people and slowly about 20 people join them and listen." A youth from Nanejaldani

" Condom should be like lipbalm. Women need to use it for their own protection. They should start using them regularly" Women at K Basapur

"NGOs should provide women with condoms and not ask her if she is married, widowed, single or whatever. Then, more women to ask for condoms", women in K Basapur.

Working in synergy with other services and programmes

Programmes based on the geographical community approaches can work in synergy with other services and programmes, either run by the organization or otherwise. Geographical community approaches enhance the effectiveness of other critical programmes like focused preventive interventions and care and support programmes. Activities carried out by groups, which have emerged from the programme, like PLHIV networks and AIDS Action committees, continue their functioning as independent entities, whose activities also enhance the programme. Connecting with other communities is also critical, to ensure continuous growth and learning among communities, who cope with newer and newer challenges of HIV.

On the care and support front, the geographical community approach promotes greater service seeking behavior by addressing stigma and discrimination which hinders treatment access. It promotes greater awareness about the existence of services, which can lead to community based referral for services. Appropriate care and support services sustain community responses by reinforcing health seeking and referral behavior. When people living with HIV are referred to or seek services to manage conditions like acute opportunistic infections and improve their health status as a result of this, it reiterates the importance of timely management for a longer and better life.

Availability of services is also critical to address the issue of frustration in communities if they can identify the people who need services, but cannot identify appropriate services. Organizations may need to take a proactive role in service delivery, in the absence of services. Samraksha and CHAN are both involved in service delivery. Samraksha runs an in-patient center, Asha Jyothi and conducts periodic outreach clinics for people living with HIV. CHAN has a health unit providing services for wound dressing, abscess management and ulcer management. But organizations

cannot function as a parallel service delivery point in the community, and may need to withdraw once the government systems or the community itself begins to respond. CHAN has done this, by almost completely phasing out the health unit, when it felt that the community could provide the service itself.

The approach also effectively feeds into focused intervention programmes for people with high-risk behavior. It is more suited to approach issues of social structures and power inequality, which govern sexual relationships, and create a more enabling environment for the marginalized group. Thus a general community intervention to promote condom usage might help women negotiate better for condom usage, in all forms of sexual contact, with regular or non-regular partners. Individual behavior changes for the groups at high risk, is strengthened and reinforced by changes in community norms, with regard to sexual contact.

The geographical community approach is also a more non-threatening way to reach out to the hidden populations at risk, like home based sex workers, who might shun association with TI, for fear of disclosure. But these groups can come within the reach of TI, and access some of the services, through this relatively non-stigmatizing intervention.

Collective entities which emerge from the geographical community approaches, like the networks of people living with HIV, or action committees also enhance the impact of the geographical community approaches. While these groups might have emerged due to the organization's initial interventions, they continue reinforcing preventive as well as non-discriminatory behavior.

Communities can also learn from each other's experiences and responses, network among each other, in order to manage their responses better. Organizations can play an important role in establishing these community to community linkages. CHAN used the strategy of facilitating 'big group-small group' meetings, among the different communities they worked with. This allowed communities to pool together their resources, connect clients to nearer, more accessible service delivery points, and also transfer experiences. A successful demonstration of the transfer of experience is the experience of Dinthar community in Aizawl, which set up a drop in center for distressed people. When people from other communities like Armaiveng saw the center, they asked the Dinthar community to help them set up a similar center.

Chapter 4: Demonstrating Community Ownership

Community ownership of response is crucial to the geographical community approach, since it makes community engagement more meaningful and sustainable. Community ownership means that communities are at the center of every stage of action : planning, implementing and evaluating a response. It means that actions emerge from community priorities and their agenda. It also means that communities have the opportunity to make and learn from their mistakes. In all this their actions remain internally driven, with no material incentives.

The two programmes have been able to demonstrate community ownership in multiple ways.

Allowing communities to take responsibility during the intervention

Samraksha's programmes are carried out through a team of community catalysts, who stay in the village to interact with every member of the village during the primary community process. The community ownership begins here as the community agrees to host them by providing food and shelter. The community also offers volunteers, who can accompany the process as well as take it forward, in future. The interactive street play, a powerful programme on awareness generation and stigma reduction, is performed by the volunteers, with some inputs from Samraksha team. The culmination of the perspective building process is the Antima Sabhe or the closing community meeting, where the community makes a plan of action and sets certain goals for itself. The community is accountable to itself on its commitment to these plans. Frequently, Samraksha is invited back into the community, to continue interactions. These are established through follow-up visits, which are carried out every three months to keep the responses alive in the context of ever changing pressures and priorities of communities.

Samraksha's experience shows that communities do perform at least some of the activities agreed upon. As part of an exercise, 56 communities reviewed what action they had taken after the perspective building process. Every one of the 56 villages had initiated some action. Overall, there were 541 activities: 334 related to awareness generation; 98 to providing care and support to people living with HIV in the village, while 30, to increasing risk perception among youth, 8 to advocacy and 91 miscellaneous preventive interventions.

In CHAN's programmes, community ownership is seen by the involvement of local volunteers, and Joint Action Committees in the response. After CHAN reorganized itself as a facilitation team, these groups carry out much of the action. CHAN's disengagement from direct action itself promoted more local involvement in the action. As one of the youth volunteers in Chaltlang Corps

put it "We got to know that CHAN was no longer doing any direct work. We saw this as an opportunity for us to get involved and play an important in preventing this epidemic."

An example of Community Ownership and Action

CHAN has been working with Dinthar community since 1997. In 1998, the community decided to set up a counselling board, as part of the Joint Action Committee. This board consists of church leaders, and other opinion leaders in the village. The Counselling Board reaches out to the people addicted to alcohol or other substances, people living with HIV and sex workers in the community and their families, and tries to make them change their behavior. A special counselor is appointed for the purpose and paid a salary, from community contributions. In 2005, the Dinthar community, based mostly on community contributions, with some minimum help from the Mizoram Government set up a half-way home to provide counseling and rehabilitation services. The home is run by the counselor, who is paid by the community.

Following the Community Agenda for Action

Communities face many problems in their day to day life. HIV risk is not always the the most pressing issue, and in many cases, due to the hidden nature of the epidemic, may not even be a perceived need. It is therefore important to let the community take up the issue along with any other issues they may choose to champion.

Letting Communities Decide their Priorities : Community members voicing their priorities

"I think we need to work on recreation activities for the youth. Since they have no recreation facilities, they start experimenting with sex, which makes them at risk for HIV", counsellor at the Dinthar Half way home in Aizawl.

We are taking you to a home, there is no one with HIV in the family. But the family is in bad circumstances, because the mother is widowed, and cannot work, due to an accident. Although the case is in no way linked to HIV, we want to work with this family." A volunteer with the Chaltlang Corps Youth Group, Aizawl.

"We do not have any regular HIV related activities; but we have organized some things. We also want to work for health, disability and soil conservation" A youth group volunteer in K Basapur Village Raichur.

Allowing communities to decide their priorities and set their agenda is also the best way to address some of the driving forces of the epidemic. Communities are best placed to identify the driving forces of the epidemic, and also identify how they can control some of these driving forces. The counselor in Dinthar community (quoted in the box above), identified lack of recreation facilities as a driving force, which forced increased sexual experimentation, and proposes to tackle it by increasing recreation facilities.

Working with groups whose interests are diverse also ensures that HIV remains an issue which the community has chosen to respond to. The groups only respond based on their interest and the extent to which they think it is relevant to them, and the responses are voluntary and internally driven. The diversity of interests ensures that there is no weariness or burnout among the communities and groups. Members retain interest in variety of activities, HIV issues is not the binding force of the group. If some members in the group or community are interested to work on the issues, they come up with their own ways of attracting the other community members.

Innovations to get the Communities Involved : Experiences of two communities

In Gopalnagar, the youth group wanted to do a programme on HIV in the main street. The leaders however said that they could do a HIV AIDS Programme in some corner and not bother them. So they asked for permission to put up a street play, and immediately everyone agreed. The enterprising group then put up a street play on stigma and discrimination and even incorporated this particular incident in the script.

In Nanjaldani Village in Raichur, a Sangha (Group) of about 60 women wanted to get involved in HIV activities. When they called women to attend their programmes, few women turned up. So the sangha decided to take out a rally, shouting slogans in the different streets and carry banners. The rally forced women to come out of the house and listen to what was being said. The rally was totally financed by the sangha members who pooled in money for tea and the banners, and culminated in a function in the school, presided over by the revenue officer and school principal.

Encouraging Action without any material incentives

Encouraging community action without any material incentives is essential, to ensure that responses are intrinsically motivated, and will continue, without being interrupted by issues like funding gaps. Communities will look to their own resources to handle the issue. This can itself be an empowering process for the communities, who can appreciate the full extent of their own potential. In fact, at times, the presence of funding might lead to a communities losing a sense of

ownership of the programme. Financial incentives, while they may show quicker results, can prove to be disincentives in the longer run.

Samraksha's programmes do not produce any material incentive for the community responses. They only provide encouragement and guidance if requested. Similarly CHAN's support to community action is more in the role of a mentor. When the Dinthar community set up a drop in centre, the costs of the action was borne by the community. Community members continue to contribute to the counselors salary. Interestingly, the replication of Dinthar's experience in another community, Armadveng, did not sustain, primarily since the community did not take financial responsibility for the center, and gradually lost interest in it.

Letting Communities Make their Mistakes

When communities are placed at the center of activities, as initiators and leaders, not every action needs to be successful. Communities need not always know the correct facts about the epidemic and its nature. Some members might have some wrong notions, due to inadequate information, or misconceptions of the nature of the problem. However, when communities end up expressing such a view, organizations become frantic to correct them. An excessive anxiety on the part of the organization that the community express the right opinion can stifle debate and discussion, as people might not mention their notions, for fear of being wrong, or being ridiculed. There is no open discussion or clarification. However, if communities are allowed a free space to express their notions, even wrong notions expressed by one member, can be corrected by others within the community itself. Even when organizations are required to clarify their misconceptions, if it is done in a more non-threatening way, it seems to work.

Allowing Mistakes

" I feel HIV breeds in women. I have seen it in cities also. The disease is caused by women," This was the opinion expressed by one of the community members during an exercise to increase self risk perception in the village of Dumti. The remark was greeted calmly. It sets some people thinking on the issue, but no one challenges the view.

Then, the facilitator gradually leads the community through what they think about this subject and discuss why they feel HIV is caused by women. Others in the group provide a different view bringing up the agency of men in transmission. The facilitator provides additional data on the different ways in which women could be more vulnerable than men to HIV. What gets emphasized is not women as the 'source' of infection, but of women, as being more vulnerable to the infection, and the community is encouraged to think of ways of making them less vulnerable.

Chapter 5: The Impact of the Programme on the Community

The approach promotes discussions on HIV in multiple spaces in the community, at the family level, at the school level, between peers, among women's groups. Conventional community mobilization approaches have been limited to public spaces, distancing communities from the reality of HIV. Geographical community approaches have made HIV more real, and encouraged reflection on the part of the communities. Once this reflection starts, stigma and discrimination reduces, there is increased care seeking, and community norms promote and reinforce safe behavior.

Responses to the approaches are multipronged in nature, and simultaneously addresses stigma reduction, care and support and prevention. These responses feed into each other and reinforce positive changes in the community.

Stigma Reduction

The approach has been able to address stigma by involving community members in the response to HIV. There is a better understanding of the nature of HIV and the dynamics of HIV transmission. Various community centered mechanisms have also been initiated to address episodes of discrimination. The AIDS Action Committee is a good illustration of this. For many members of the AIDS Action committees, it is their involvement with the committee, which helped them understand and reflect on their own prejudicial behavior. Stigma reduction has not remained the prerogative of AIDS Action Committees. Even other groups in the community have been involved in intervening with families in cases of stigma and discrimination.

"We heard about some person living with HIV being thrown out from the nearby Hosalli village. We spoke to the villagers, and made them accept back", women in K Basapur

"I had a friend with HIV, when I was taking him to Kerala for treatment I made him sit in a separate seat in the bus. Now I know that HIV is not contagious like that. I am more accepting"

"My domestic help's father is HIV positive, I did not even want to touch the money which she had handled. Now I have helped her take her father to Kushtagi"

Stigma reduction is addressed by the open discussions on the nature of HIV and the different ways in which larger driving forces, can increase an individual's risk of HIV infection. This can promote a non-judgmental discussion with persons living with HIV, and their different

circumstances and choices in life, which increased their risk. By increasing self risk perception, the 'othering' of the people at high risk ceases, and they can respond more empathetically to the needs of the people living with HIV.

Care and treatment

Reduced stigma and discrimination encourages increased care seeking behavior. The approach also promotes increased referral and linkages to the health services systems. It also promotes community based care by helping communities understand the nature and course of HIV infection, so that they can respond to the needs of their family or community members, who are affected. The following quotes illustrate some instances of care and support.

"My daughter in law has HIV, she sometimes feels very weak and cannot do much work. I do all the house work then" Woman from Nanjaledani

"One person had HIV in this village, we sent him to Kushtagi after we heard about it, but it was too late. People should start taking medicines early, so that they can live longer. If we come across anyone else, we will tell them to go to Kushtagi early"

"We help the PLHA in this area with their daily activities like bringing water etc.", Women at K Basapur

"We don't know much about HIV, our parents don't tell us anything. HIV does not spread while touching. We can help people with HIV, we can get milk for them, water and other things", a group of school children aged about 8 in Nanjaldainii.

Prevention

By targeting the entire community, the approach equips the entire community to act as agents of prevention among themselves. The message is not something, which becomes invisible once the organization moves away, rather it is kept alive by the numerous informal discussions which continue long after the organization leaves. Preventive interventions are themselves not a set of behavioral prescriptions, but a series of discussions and reflections on what constitutes risk, how their own behavior might add to risk, and how they can reduce the risk. The effectiveness of the preventive intervention can be seen in the following quotes, which demonstrate a deeper understanding of risky behavior and how they can be addressed.

"We have sex education classes for the young people in the school campus on Sundays. It helps them understand about sex and clear their doubts. They need to have a clear understanding of the issue, they are at risk" Youth from A K Gopalnagar Ward

"Bandaite Bandaite HIV AIDS roga Bandaite. Namma yuvakara naduve, namma yuvathiyara naduve..... (HIV AIDS has come amongst us, among our young men and women) A song rendered with gusto by the volunteers in Gopalnagar. Interestingly some children in Nanjaldini started singing this song immediately after seeing the Samraksha jeep.

"If you have control over the seed, why will you get it. So you need to behave in a responsible way" Villager at Dumti

"Just because you are educated does not mean you will not get it. It is not about education. A doctor might know about HIV, but still visit women. So it is about your behavior" Villager at Dumti

"Youth are getting into risky behavior, because they don't have any other recreation. We need to look at recreational activities within the community" Counsellor at Dinthar, Aizawl

It is also interesting to note that with information, people can connect risk behavior to other issues. The counselor in Dinthar, for instance, is looking at the link between lack of recreation and high risk behavior. The people in North Karnataka, not only show a remarkable openness to talk about sexuality, but also acknowledge the reality of high risk sexual behaviour among them and accept the fact that they can all be at risk, specially the youth. The onus is put on personal responsibility. Information has not created a false sense of complacency, but entered the community consciousness.

Major challenges in implementing the programme

Implementing this approach needs a certain orientation on the part of the implementing agency, which has to be more creative and flexible in working with the communities, appraising their programme and measuring the impact.

Measurement of Change

Community led approaches have a different life cycle. They are more process oriented and may appear less tangible in their impact as they do not produce rapid action. However, the results are more dramatic and long lasting if the pace of the community is not forced. These approaches are

not just looking at individual behavior change, but at community behavior change and norm change, which can happen only gradually.

Communities drive the action, and therefore while broad indicators of change can be predicted, the actions cannot be spelt out. Organizations cannot make concrete plans, given the fact that community responses evolve as the programme proceeds. Organizations need to have faith in the communities' commitment and ability to respond.

Qualitative tools like Most Significant Change tool and the self assessment tools, can help in assessing both the process, and the qualitative impact, as perceived by the community. Indirect quantitative indicators can also be used to measure some aspects of change. For instance increased referrals for services or increased service seeking behavior, can serve as an indicator for greater knowledge about HIV, awareness about services, and lesser stigma and discrimination.

The need for committed leadership and staff

Given the highly dynamic, unpredictable environment where the community approach works, it is imperative that organizations have a committed leadership, who believe in and champion the cause. In CHAN for instance, the community approach provided the best dividends when the leadership completely believed in the approach. When priorities shifted at the top, and the emphasis was on a more directive programme, the community contributions and involvements suffered a setback. With the leadership in favour of a community led approach again, the community ownership is evolving with renewed vigour.

Resources to sustain the programme

It is important to have continuity, even among the staff, who nurture the community, and in due course of time get to see the communities responding to the issue. High turnover or movement of staff between different programmes may mean that the organization will lose the social capital, which former staff had helped build with the community.

It is therefore important to have staff dedicated to this programme. While the programme is owned by the community and it meets much of the programme costs, some staffing in the form of community catalysts and community counsellors are needed for a period of time. This ensures continuity in initiating the process with different communities and help the process of perspective building and initiating action.

Chapter 6: Conclusion

The Geographical Community Competence Building Approach is both a belief and a strategy. From the rights-based perspective, communities have the right to information which helps them build a perspective on the various aspects of HIV. They also have a right to evolve their own responses to the issue in ways which they find best for them. They have the right to self determination and can deal with this crisis as they have dealt with others in their life time. From the developmental perspective, communities need to own both the problem and the response for effective results and sustainable impact. From the sociological perspective, HIV is the problem of individuals that is embedded in a social context . Behaviours of risk taking for self and others, and stigmatizing and discriminating behavior can change at the individual level but community norms, pressures and sanctions also need to change to reinforce and sustain the change in individual behavior.

Geographical community approaches make HIV real and relevant to the lives of the members by creating an environment to talk about sex and sexuality, risk and vulnerability, stigma and discrimination. It empowers communities to own their responses, by using existing community based resources and structures, and helps communities understand the full potential of their actions. Since communities do not see HIV issues in different compartment of prevention, care and support and treatment, this approach can help address these issues more holistically.

The scale of the epidemic, its widespread and dispersed nature, its reluctance to confine itself to any occupational or ethnic group, its psychosocial and developmental causal and impact factors all point to one critical strategy: mainstreaming. While the National AIDS programme looks at mainstreaming across the structures of government and industry , at the ground level, these approaches facilitate mainstreaming into family and community life. NACP III promotes mainstreaming through a link worker model, which envisages the creation of a cadre of link workers, who will work with the district administration units and address key issues through participatory life skills based processes. The community competence building takes this further and lets communities take this whole responsibility.

The approach does not address HIV in isolation, but also the social structures and systems that influence the spread of HIV. It overcomes the vertical approach which has so far characterized the response to HIV. The approach is thus a viable strategy, which can strengthen existing interventions, in order to promote a more sustainable response, which can meet the needs of a varied, advancing and gradually generalizing epidemic.

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