



Supporting Community Action on AIDS in India





# LEARNING FROM OUR ROLE IN THE HIV RESPONSE IN INDIA







### About India HIV/AIDS Alliance

As part of the International HIV/AIDS Alliance (or Alliance), the India HIV/AIDS Alliance (or Alliance India) began operations in 1999 to expand and intensify the Alliance's vision and mission, and mitigate the impact of Acquired Immuno-Deficiency Syndrome (AIDS). Since its inception, Alliance India has been a leader in fostering and supporting the development of community-driven approaches to HIV prevention, care and support, and impact mitigation. Its work also includes reducing stigma and discrimination, particularly among the most vulnerable and marginalised communities key to the epidemic - sex workers, Men who have Sex with Men (MSM), Injecting Drug Users (IDUs) and adults and children living with and affected by HIV. It has done so through building a network of four strong national intermediary organisations, Lead Partners {also known as Linking Organisations (LOs) in the Alliance} across Andhra Pradesh, Tamil Nadu, Maharashtra and Delhi states, a project office in Andhra Pradesh, and a state partner in Manipur. These partners, in turn, work in partnership with their networks of over 100 community-based nongovernmental organisations (NGOs) and community-based organisations (CBOs). Alliance India supports these organisations by providing financial and responsive technical support including technical assistance, skills building, policy, programmatic and organisational development inputs.

Alliance India is also a member of the Regional Technical Support Hub (TSH) for the Asia region to support Alliance programmes in South Asia. A core purpose of the TSH is to build national and regional capacity to respond effectively to HIV/AIDS. The Hub provides services and uses approaches which strengthen country and local partners' capacity to manage technical assistance effectively. Through this capacity transfer, the Hub is able to provide technical assistance which is sustainable and in a range of specialist areas. The TSH includes a well established and quality assured database of consultants who work with the Alliance in the Asia region.

Within the complex picture of HIV and aiming to support communities to reduce the spread of HIV and to meet the challenges of AIDS, Alliance India takes a systematic yet innovative approach to delivering on its objectives through a continued focus on its programme activities: prevention, care, treatment and related support, and on capacity building of implementing NGOs and CBOs to deliver effective services. Our advocacy work aims to enhance the policy and financial environment. Network building strengthens the capacity of the Alliance across India. Quality communication increases attention to ensure all interventions are effective to meet community needs. The Knowledge Management functions of Alliance India strive to share learning and help replication, conduct operations research and best practice documentation to feed into the programmes, and support policy and advocacy initiatives.

( )

#### **Our Vision**

"A world in which people do not die of AIDS"

For us, this means a world where communities have brought HIV under control by preventing its transmission, and enjoy better health through access to comprehensive HIV prevention, care, support and treatment services.

#### **Our Mission**

"To support communities to reduce the spread of HIV and to meet the challenges of AIDS."

We are working to prevent HIV infection; improve access to HIV treatment, care and support; and lessen the impact of HIV and AIDS worldwide, particularly among the most vulnerable and marginalised.



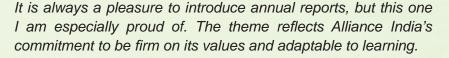
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### **Director's Note**



Learning is a popular word in the HIV response but it is also a daunting one. To be open to learning means being open to criticism, it means having to acknowledge mistakes as well as successes, it means changing plans and strategies and never being satisfied just because targets are met.

Therefore, being open to learning makes us vulnerable, especially in a sector that naturally likes to celebrate good news. Good news appeals because we want to believe that what we are doing is needed, and equally importantly, we want other people to believe it, especially our donors, on whom future projects and funding depend.

We can be afraid that if we admit that our results are not significant or that there are things that we don't understand, then we shall appear weaker than peers who make no such confessions, and our support base will dwindle.

So we cling to the good news, even if it is fragile, and we concentrate on success stories, focusing often on numbers rather than evidence of change.

Yet responding to HIV is a complex business rooted in the intangible worlds of culture and gender and of private and intimate relationships. The HIV response aspires to nothing less than social transformation in attitudes towards sex and sexuality. We cannot expect project inputs to result in predictable and consistently positive outputs in areas where there are so many different and hidden influences at play.

But we can learn how to engage in these issues intelligently and openly, and that is what this annual report is about.

It considers what the data, and what communities are telling us about what is working and not working, it highlights and explores gaps in the way we are responding to HIV and suggests new ways of approaching problems. It doesn't pretend to be a report of answers, but it does aspire to be a report of creative engagement with complex issues.

Preparing it has helped us face gaps in our own knowledge and services, and we intend to be stronger as a result. I hope other readers will also find something to learn from its pages.

**Alexander Matheou** 



Name of the Child: B. Chakravarti Sex: Male Age (March 2009): 13 years Place: Gullepalli, Maddipadu, Prakasam, Andhra Pradesh

#### Sub Recipient – Plan India Sub-Sub Recipient - SARDS

Chakravarti is a child affected by HIV. His maternal grandparents are his only companions in life and lone caregivers, who are parents of four children (two daughters and two sons). Chakravarti's father, B. Narsimha Rao, was a supplier and chief cook in a local hotel. Rao remained ill for one year; however, he came to know his HIV status in his last stages. He was alcoholic, and while he was on ART, he got affected by tuberculosis, and died subsequently.

### Year 2009

We met Chakravarti and his mother, Subbarattam (35 years old) in early 2009. Subbarattam was deaf and mute, was HIV positive and suffered from tuberculosis. At the same time, in her own way, she told us how much she missed her husband (he had died one month before we met them).

We also met Subbarattam's father, K. Venkateswarulu, a 65 year old man, a daily-wage labourer, who was staying with his daughter and grandson to take care of them. He said—"They used to live on their own. Now we have to help them to sustain. They had a good income as Rao worked in a hotel for twenty years". With tears in his eyes, he told us—"my daughter and her husband were very affectionate with each other. He used to bring a lot of things for his son (Chakravarti). She is very depressed and has lost a lot of weight. Whenever she is reminded of her husband, she cries a lot".

We observed a deep bond between Chakravarti and his mother. He interacted with his mother in sign language. It was clear, that for Chakravarti his mother was his whole world...

## Year 2010

Chakravarti lost his world. His mother passed away. We came to know this when we met him again in early 2010. This time, he was at his grandparents' home. His grandfather had gone out for some work; instead we met his grandmother, Kotamma.

Chakravarti is now an orphan. Unlike in 2009, it was hard for us to locate even a smile on his face. His grandmother cried and told us how worried they were about his future when they are gone, while Chakravarti complained why he was being given a special treatment at home. He also expressed his desire to be in a hostel as he was unable to see his grandmother cry for him everyday.

In the end, while Chakravarti posed with his cricket bat to be clicked by Donna, our volunteer photographer, we thought about his future, not only after his grandparents, but also after CHAHA...



### The Case for Care and Support for Children affected by HIV

"Before joining CHAHA, I faced difficulties in getting materials for my school but after joining CHAHA, I think my problem has become less. The most significant change is that I can come out and talk to other people. I was scared when I went out and played with others, but that fear is no more"<sup>1</sup>

... Tracy, one among the 35,947 children reached by CHAHA project by December 2009

n March 2011, Alliance India's child-centred care and support programme for families, CHAHA, will have reached its target of providing services to 64,000 children living with and affected by HIV. From April 2011, if nothing changes between now and then in terms of funding, the programme will stop, and the children and families will receive no more support.

With a prospect like that on the horizon, it is not surprising that Alliance India has been asking itself tough questions in 2009. What has been achieved? Can it be described as sustainable impact? Is it wrong to stop the programme and if so, why is it wrong? And if the programme were to continue to provide support, then what should that support look like once we consider our learning from four years of implementation?

#### **Community Voices**

It is tempting when describing what has been achieved to focus on the number of children reached, and the numbers are impressive. This tells us too little to claim impact. Qualitative data however, have taught us three main lessons.

"....As I am a young widow, everyone in the village wanted to take advantage of me. I was very much afraid of talking to men. They were very rude towards me and insulted me verbally."

> ...G. Manga, 25 year old wid<mark>ow</mark> from Andhra Pradesh

The first lesson is that care and support often has to begin with emergency support. We had not fully appreciated in the original programme design that we would be faced with women and children-headed households who would require immediate stabilisation interventions before we could open a dialogue about longer term support and health seeking behaviour. Neither the government's social welfare system nor its HIV programmes are designed to respond to such a challenge. Children-headed households, or children living with grandparents, or widows coping alone, all are particularly vulnerable to the social, economic and health pressures of living with HIV. Within the CHAHA programme, our data shows that 35% of the households are headed by women and 8% by orphaned children. Widows experience particularly higher levels of stigma.

The second lesson is that we should have paid more attention to Sexual and Reproductive Health (SRH). Thanks to improved access to Anti-Retroviral Treatment (ART), we are now working with a generation of young people living with HIV and of a sexually active age. They will have partners and will get married. They have numerous special needs and fears around SRH that are not being adequately addressed in CHAHA or anywhere else.

"....we do not get information about sex, hence, I feel that sex education should be provided through the organisation."

> ...Jeevan Bhan<mark>uda</mark>s Jadhav, an 18 year old boy from <mark>Ma</mark>harashtra

The third lesson is that even when people are informed of services and have potential access to them, stigma and discrimination continue to act as the most significant barriers to testing, disclosure and accessing ART.<sup>2</sup> Therefore, priority has to be given to sensitisation of communities, their leaders and service providers. This requires a proactive campaign of "normalising" HIV that cannot be managed by health systems alone. Equally important is the attention that needs to be given to children and their caregivers in overcoming the self- stigma that prevents children from feeling entitled and able to participate in school life, work and friendships. Again, this is a need that must be addressed by seeking out children and spending time with them, and not by waiting for them to turn up at healthcare centres.

"....for the success of CHAHA, we must create a situation where general community accepts PLHIV as one amongst them and extend their wholehearted support in improving their lives."

... Chadrashekharan, an outreach worker from Tamil Nadu

#### **Making the Case**

While the qualitative data suggests that care and support for children does add value, it may appear less convincing to those primarily interested in



understanding whether such programmes should be funded as part of a national response to HIV.

To answer this challenge, Alliance India has collected data to consider the relationship between care and support and the uptake of services. These are the four main findings:

### 1) Improvement in testing, ART registration and adherence to treatment

It is estimated that about half of the children born with HIV die before they are two years old. Of the children

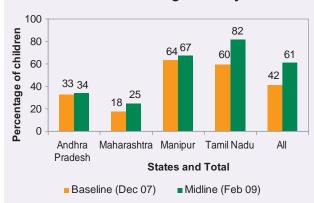
#### Table 1: CMIS Data of CHAHA on Children Referred for Testing (Dec 09)

	Number of children tested	Number of children tested Positive	Number of children on ART
Manipur	233	33	285
Tamil Nadu	662	72	184
Andhra Pradesh	3871	434	790
Maharashtra	1916	417	1436
Total	6682	956	2695

<sup>2</sup> Chaturvedi, Vaishakhi M., K. Vijay, Facilitating HIV Testing and Disclosure with Children and Adolescents, India HIV/AIDS Alliance, December 2009

#### Figure 1: ART Adherence Data from CHAHA Baseline and Midline

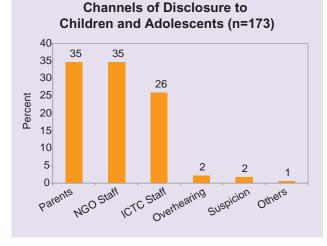




that survive the first two years, a third will die before they reach the age of five. There are two main, interrelated causes behind these shocking figures: first, the lack of timely diagnosis of HIV, and secondly and consequently, the lack of access to treatment.

Care and support programmes seek to address both these issues. Table 1 shows the number of children accessing HIV testing and treatment services within CHAHA. The high numbers of children who are tested positive demonstrates that the programme is identifying the children most vulnerable to HIV. Without this testing, their life expectancy would be

#### Figure 2: Facilitating HIV Testing and Disclosure with Children and Adolescents, India HIV/AIDS Alliance, 2009



much lower. Care and support then, would appear to increase the survival of children by facilitating early diagnosis.

Figure 1 compares a baseline and midline of a sample of children across four states where CHAHA is being implemented. In two states, Andhra Pradesh and Manipur, the data does not point to a significant difference in ART adherence, but in the two states and in total, an increase in adherence is evident. The programme has adjusted to ensure a thorough tracking of children according to national guidelines to promote adherence.

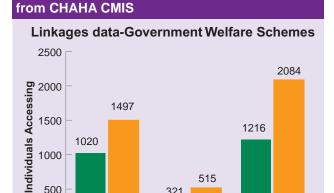
### 2) Support to parents and children for testing and disclosure

Parents experience deep reservations about disclosing HIV status to their children, and once the status is disclosed, children need support in coming to terms with the news. Interviews with adolescents in 15-18 age group revealed that parents who disclosed their HIV status to children were mainly those who had come in contact with the NGOs. Figure 2 also shows that NGOs, alongside parents, play the most significant role in disclosure.<sup>3</sup> Care and support programmes provide support to both parents and children in coping with HIV status and planning for the future.

### 3) Increased access to long-term government support and programmes

Care and support programmes seek to build bridges between people living with HIV (PLHIV) and government schemes and entitlements. This is a crucial part in facilitating sustainable support. For bureaucratic or logistic reasons, entitlements can be difficult to access. Care and support programmes increase not only the capacity of people to demand services but also of the service providers to provide them. Figures 3 and 4 show how uptake of government entitlements has increased for children who are part of the CHAHA programme. CHAHA is often the only initiative to help children and their families access these government services.

<sup>3</sup> Chaturvedi, Vaishakhi M., K. Vijay, Facilitating HIV Testing and Disclosure with Children and Adolescents, India HIV/AIDS Alliance, December 2009



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**Government Schemes** 

Old age

pension

Ration

Cards

Till December 2009

500

0

Widow

pension plan

Till March 2009

Figure 3: Linkage with Government Schemes

#### 4) Contribution to critical areas to improve child mortality and morbidity

The lives of young children can be saved if they have access to two crucial entitlements - co-trimoxazole

#### Figure 4: Linkages to HIV & Health Services, **CHAHA Baseline and Midline**

Services Available and Functional 100 91 90 83 80 76 80 72 68 70 62 60 50 50 40 30 20 10 0 ICTC ART Centre PHC Pvt Institutions BL ML

(CTX) prophylaxis and supplementary nutrition. Both are essential to strengthen a child's immunity. CHAHA has focused its advocacy in 2009 on ensuring that children do have access to these entitlements.<sup>4</sup> Initial data collection suggests that this focused advocacy is having a positive effect. Over a period of time, the access to CTX prophylaxis and double nutrition<sup>5</sup>



<sup>4</sup> See 'Advocacy in CHAHA', page 44

<sup>5</sup> Double nutrition/ration means double the quantity of meals already provided at the Anganwadi centre (under the ICDS) and in primary schools (under the Mid-day Meal Scheme), to meet the special nutritional needs of children; GO issued by Government of Andhra Pradesh, Lr. No. 2052/J3/2009, dt. 03.04.2009

is increasing among children below two years and below six years respectively, in CHAHA. Community awareness, negotiations with service providers, reporting to policymakers and supporting them in implementing existing good policies are some of the strategies leading to slow but steady change.

#### Conclusion

We do believe that this data points to a compelling argument in favour of care and support programmes for children. Most evidently, it outlines that government and civil society have separate but mutually complementary roles to play. Civil society generates the demand for services, and the government ensures the supply. If civil society organisations (CSOs) stop their work within communities, especially marginalised communities, then we can expect the update of services to decline, thereby affecting the government's targets in the response. This is part of a wider argument as to why not all HIV services can be mainstreamed. With widow and orphan - headed households especially, there is still a need to reach out and support people in overcoming barriers to exclusion, including those of self-stigma. This goes beyond the mandate of health systems and falls into the responsibility of those charged with community mobilisation. Our experience in 2009 has convinced us of the validity of this case, and advocating for it will be a focus for us in 2010.

#### The CHAHA Programme Update

Core indicator	Achievement (as of December 2009)
Number of CLHIV (children living with HIV) and CAA (children affected by HIV/AIDS) under 18 years of age benefiting from a minimum package of care and support services	35947
Number of CLHIV and CAA receiving nutritional services including nutritional counselling and demonstration services from the implementing NGO	14586
Number of households of CLHIV and CAA covered by basic support	18552
Number of children referred for Paediatric ART to a healthcare institution	1382
Number of CLHIV and CAA provided with educational support and/or vocational training	5992
Number of households provided income generation support	3568
Number of children support groups formed	572
Number of sensitisation meetings held in communities	1988

n 2009, we embarked on a truly rewarding exercise and listened to stories of around 500 children and caregivers from our Global Fund programme on care and support for children – CHAHA – in Andhra Pradesh, Tamil Nadu, Maharashtra and Manipur states. It was in keeping with the Alliance's community-based approach and our tradition of listening to and learning from the communities.

The methodology used was the Most Significant Change (MSC) technique which is a form of participatory monitoring and evaluation. In this, children and their parents talked freely about changes in their lives, while some children even drew the change. At a time when development is being increasingly driven by numbers for the need to reach ever larger percentages of target groups, using the MSC technique was our attempt to understand and respect the people behind the numbers generated by project reports. While the goal of projects often is to "saturate" districts or towns with services, the real risk in such an environment is that numbers will become an end in themselves. It is too easy to assume that a person reached is a person better off, whereas in fact, as these stories tell, even well intended assistance can have mixed effects.

The process involved the collection of Significant Change (SC) stories at the field level, systematic selection of the most significant of these stories by the communities, Sub-Sub Recipient (SSR) and Sub-Recipient (SR) organisations in all four states. Finally, the most significant of the shortlisted stories were selected at the national level by a group of selectors from Alliance India, the composition of which was an adequate representation of experienced professionals from various areas such as the Programmes, Policy, Monitoring and Evaluation, and Finance and Administration.

Four domains of change were identified for the study in consultation with the partner organisations. Domains of change were the broad categories in which people could share their stories. MSC adheres to asking open-ended questions without providing any leads and prompts in order to take into account various perceptions of change. Domains of change defined the periphery in which the community could give their response but did not show the path on what to say. Domains were selected based on the kind of changes through the CHAHA programme that Alliance India and its partner organisations



wanted to measure. This was largely influenced by the programme objectives.

The four domains for this study were:

- Quality of life: Change in quality of people's lives was identified as a domain as, amongst others, it also reflected the first Strategic Direction (SD1) of CHAHA – to improve care and support services for children living with and/or affected by HIV.
- Level of participation: This domain was chosen to reflect on SD2 of CHAHA – to create a supportive environment for reducing stigma and discrimination'. It can be inferred that positive changes in the level of participation would also indicate better coping mechanisms to deal with stigma and discrimination.
- **3. Negative changes:** This domain was selected essentially so that we are not comforted by "good news" and the "good stories", because this may deter us from further enquiry and learning.<sup>6</sup> This domain helped us understand the gaps in the programme.
- Staff capacity: This domain was chosen to reflect SD3 of CHAHA – to create a supportive environment for civil society strengthening and institutional capacity building.

We found out the following:

#### Domain 1: Change in Quality of Life

### Children and caregivers have developed positive attitude and self-confidence

For many children and caregivers, the ability to overcome feelings of hopelessness and being able to interact with others has been a relief. Their stories reveal the confidence that they have regained due to the support provided by CHAHA and it has improved the quality of children's lives by instilling confidence through training, children support groups and counselling. The stories also reflect that, unlike before, children have been able to develop positive attitude towards their HIV positive parents. "The aunts and sisters of CHAHA project advised me to be brave and courageous. This has enlightened my life. The Most Significant Change is that I have the courage to live alone in the society even if my community people have no affection for me. For this reason, I succeeded in bringing a big change in my life."

... A 17 year old boy from Manipur

### Children appreciate the support towards continuing their education

The second recurring theme in this domain, from the children, is the fact that they were able to go back to schools. In all the stories told by children, they appreciated the support towards continuing their education.

The most important change for me is that now my mother can pay my school fees on time and I can attend my school properly. When I grow up and get a job, I will build a house like this".

... A young boy from Maharashtra

### Improved well-being: better health, being able to socialise, making friends and saving money

Being able to go out, mingle without fear, being able to overcome shyness, make friends and better health are important changes experienced by many children and caregivers from all the states. The programme has improved the well-being of children and their caregivers, who can now interact with dignity, save money and worry less about basic survival needs. "My child is not afraid of people anymore. Before when their friends played they didn't join but now they play together. Now without them the other children will not play. The most important change for me is that my child became a leader among his friends."

... 34 year old H. Premila Devi from Manipur

#### **Domain 2: Level of Participation**

### Children and caregivers have developed leadership skills

Many stories show that children and caregivers have been able to disclose their status, interact with people and generally overcome feelings of being shunned and stigmatised by their neighbours or the communities they live in. The stories reflect that several storytellers are voluntarily spreading the message of prevention, care and treatment and becoming role models for others.

"Recently I met two PLHIV in my village and introduced them to CHAHA programme. I participate in sensitisation meetings and explain about the difficulties faced by PLHIV. I have applied for six widow pensions from our village on behalf of women living with HIV. Wherever I go for work, I talk to women about HIV and provide them counseling, guidance and information on HIV/AIDS."

> ....30 year old P. Rammanamma from Andhra Pradesh

### Regained confidence to re-enter society

Many stories from both caregivers and children showed the confidence they got by being part of the programme – the confidence to essentially face the world with growing pride and confidence. Several "The Children's Support Group (CSG) in CHAHA helped me identify my talents and I am now participating in competitions, compared to before. I was not taking ART tablets regularly, now I am taking the tablets regularly, heeding the advice of CHAHA. Since my parents and I had this infection, my schoolmates and neighbourhood children never used to play with me. Now we all play together. Though there are still some children who don't talk to me but I have many friends."

... Tamilarasi, a young girl from Tamil Nadu

stories talked about the feeling of hopelessness that the storytellers experienced earlier, some had recurring suicidal thoughts. It's increasingly evident in the stories that increase in the level of confidence led to a decline in incidents of stigma and discrimination.

#### **Domain 3: Any Negative Change**

#### Fear of disclosure in the community with Outreach Workers (ORWs) visiting their house

Some storytellers, both children and caregivers, said that their already existing fear of being threatened

"Five days after the death of my daughter Jhansi, the ORW came to our house and everyone came to know that my daughter died of HIV/AIDS. I had a petty shop and also sold tiffins in the morning. After the death of my daughter, my elder daughter suggested me to stop selling tiffins as no one will buy because a family member died of HIV. But I did not listen to her. However, after a few days I had to close the shop as no one was coming to buy from us."

> ...55 year old Vemula Sam<mark>r</mark>ajy<mark>a</mark>m from Andhra Pradesh

and isolated by community members and families once they become aware of their HIV status, is compounded by the CHAHA programme staff visiting them.

#### Unkept promises and its effects on children

Few stories in this domain show the disappointment experienced by children who were somewhat assured for certain services by the programme staff but did not receive them.

"When my mother went to the hospital, XXX madam told us about the CHAHA project. They told us that through this project, we will get education and other support. After we joined the project, they brought rice and provisions for us. They told my mother 'don't send your daughter to work'. They stopped me from going to work and admitted me in school and helped me join computer science group. I was hurt by the project. They asked me to join school. They said that after you join, we will help you by providing provisions for your family. I was disappointed because they did not help as promised. We did not

have money for admission in school. In school, they asked for medical certificate as I had missed a year. We needed Rs. 500/for getting the certificate, we expected this support from the project but did not get it. That disappointed me. The significant point is that when I needed Rs. 500/-, the project couldn't help me and they failed to support

when I needed it the most. My mother is sick. I used to get Rs. 500/- by going to work but I stopped going because the NGO asked my mother not to send me to work."

> ... P. Nandhini, an 11<sup>th</sup> standard student from Tamil Nadu

#### Domain 4: Changes in Staff's Capacity

### The field staff is reflective, powerful and the backbone of the programme

Most stories show the deep level of reflection, a seriousness of purpose, and the field staff's tremendous contribution in making a significantly large programme like CHAHA work. The stories also reflect a great sense of pride which the staff feels. Several staff members reported about the change they experienced at personal level, which has directly impacted their work, like being able to control their anger, internalising the values of child participation and applying to their own children.

"As a father of two children, my only dream was to raise them to what I want them to become in the future. Asking them their needs and desires was not my priority. Instead I only directed and forced them to do things. But today I have changed my thinking. I have learnt that parents must leave options for their children to make their own decisions. This change has only come because of my role in CHAHA programme."

> ...Peter Dilbung, Assistant Prog<mark>ramm</mark>e Coordinator from Manipur

#### Enhanced skills in several areas such as interpersonal communication, networking and knowledge on HIV/AIDS

The staff at Project Coordinator (PC) and Assistant PC levels reported that their most significant change has been their enhanced programme management skills that encompass better communication with partners, ensuring timely implementation of activities and generally more enhanced interpersonal relationship skills. Many other staff members including ORWs experienced that their skills in facilitation have improved significantly with the introduction of the Life Skills Education (LSE) sessions, they "The important thing is since I am positive, I felt good while working with others like me. I forgot my sorrows and difficulties when I listened to their stories and struggles.

When I visited the home of one lady, she was in terrible grief. She used to ask why God has given her such a disease, why is he not giving her death instead. Then I disclosed my status to her and she was surprised to hear my story. She calmed down. She could not believe that I also live with HIV. We got solace after sharing our stories. We felt relieved and our confidence also increased. She left the thought of committing suicide after knowing about me." ...An ORW from Maharashtra have themselves been becoming more confident in facilitation and in interacting with children using different methodologies. Most stories talk about their significantly enhanced self-confidence, especially in meeting and networking with doctors and government officials. Seen in the light that more than half the staff is from the community itself (i.e. living with HIV), there are positive indicators that we are achieving the objective of institutional and community capacity building.

#### Lessons Learnt

- Doubts about the future, an unnamed fear, and the general poignancy in the stories are indicators that organisations working in the field of HIV/ AIDS should re-think their strategies of working with the orphans and most vulnerable children.
- More support from the programme in terms of land, house, continuous education support, job for children above 18 years, and a business with a huge investment—such demands, apart from highlighting the abject poverty that most of the children and families are living in—also



indicate people have high expectations from the programme. This reflects on the need for ensuring sustainability of any income generating venture by a comprehensive value chain analysis, i.e. assessing Income Generation Programme (IGP) in terms of its feasibility, viability and sustainability through a market analysis. At the same time, it is important to communicate well with the communities and counsel them on limiting their expectations from, and dependency, on the programme.

- There is a need for developing a better understanding of community mobilisation aimed at reducing stigma and discrimination, at both community and programme staff levels. Evidently, families' stigmatisation by neighbours, and disclosure of HIV status due to the frequent visit of the programme staff, highlight the need for doing things differently.
- Working on gender and sexuality is imperative with young people, especially as they are at the

crossroads of adulthood and go through different emotions and experiences.

There is an urgent need to focus on the issues of numerous grandparents who are the sole caregivers of their orphaned grandchildren (whose parents died of AIDS), particularly due to their perceived inability to continue providing care for their children until they become selfreliant. Many grandmothers from Tamil Nadu and Andhra Pradesh asked, "(we) just want to know if our grandchildren will still be treated for free when they grow up...We are afraid when they grow up, they will no longer be given treatment. Will the organisation continue to look after them? What will happen to them when we die? They are so young and we may die any day now." Stigma and ostracism towards HIV positive individuals make it all the more difficult for them to find someone they can trust who would be willing and able to provide care for their grandchildren.

#### Main Recommendations

Enhanced role of community and religious leaders, especially in terms of new and collective role of decision-making around allocating resources, planning programmes, defining policies, ensuring right to quality services, and limiting stigma and discrimination.

Review the strategy of working with young people and children that should include recognising the specific needs of children in different age groups; providing them a safe, non-judgemental and enabling space; and a comprehensive sex education along with information on sexual and reproductive rights, gender equality and skill development.

Enhanced use of the gender lens, while designing such programmes for children, which includes analysis of gender, sexuality and power, and how these dynamics affect access to and control over resources – education, food, medical facilities and government schemes.

Better coordination between various players—both government and non-government—at all levels that will help reduce duplication of efforts, garner improved support from various actors, and help build an overall climate of shared sense of purpose.

To read the full report: 'Stories of Significance, Redefining Change", please log on to: <u>www.aidsallianceindia.net</u> and to read the 500 Significant Change stories, please order a CD at <u>setu@allianceindia.org</u>

### **Operational Research Summary**

In 2009, Alliance India conducted Operational Research (OR) on two issues, as part of the CHAHA Programme.

One of the ORs explored the specific challenges and barriers that confront families, children and adolescents with regard to testing for HIV and disclosure of their HIV positive status. The other OR focused on identifying barriers to sustainable access for children and families to ART centres, in both rural and urban India. Both the studies used a mix of qualitative and quantitative methodology. The former was conducted in Andhra Pradesh and Manipur, while the latter in Maharashtra and Manipur.

### The Fact File...

- According to the National AIDS Control Organisation (NACO), 33,000 newborns in India get HIV from their infected mothers every year. Over 50% of these children die within two years of birth while 80% of them die within five years (www.hivaidsonline.in)
- In India, it is only since the third phase of the National AIDS Control Programme (2006-11) that facilities for testing infants have been made available. At present, there are only 19 qualitative Polymerase Chain Reaction (PCR) machines in India, a number that is insufficient to test the growing number of infants born to HIV positive mothers. (www.hivaidsonline.in)
- In India, adults had access to ART from April 2004. ART was made available to children in November 2006. (Barriers to Sustainable Access of Children and Families to ART Centres in Urban India, India HIV/AIDS Alliance, December 2009)
- NACO has identified 32,803 HIV positive children in the country. It provides support and treatment to 8,887 of them, through the 126 ART centres established in the country. (<u>www.hivaidsonline.in</u>)
- The interventions planned under NACP-III target both infected and affected children, including orphans. The programme aims to reach all the 65,000 infected and affected children by 2012. (The Statesman, April 20, 2008)

### Challenges and barriers that confront families, children and adolescents with regard to testing for HIV and disclosure of their HIV positive status

#### Findings

#### **Factors Preventing HIV Testing**

The **stigma and discrimination** associated with HIV and AIDS is the biggest barrier to testing. The high reported incidence of discrimination with families affected by HIV within the neighbourhood adds to their reluctance to test.

**Financial constraints within the family** was cited as another powerful barrier to testing. Concerns were reported about high travel costs to testing centres and loss of wages during this period, which together place a high financial burden on the family.

**The fear of unsolicited disclosure within the neighbourhood** is another deterrent. Issues of breach of confidentiality and its potentially negative aftermath were mentioned as a factor especially for parents of children in the 0-6 age group.

Lack of knowledge among parents on HIV and AIDS makes it difficult for them to explain to their children (7-14 age group) about the importance of testing. Almost all children in this age group were merely told to accompany their parents to testing centres on the pretext of routine check-up. Lack of awareness and sensitivity on the part of healthcare providers is another limitation that is often cited.

Various factors like parents' inability to overcome shock/grief resulting from their own positive status, fear of their children testing positive, and disillusionment emanating from the viewpoint that ART will only extend life and is not a cure for HIV, are contributory factors towards **low motivation levels** among parents in getting their children tested.

**On the supply side, certain issues related to healthcare service providers are** seen as important barriers. This includes lack of enabling environment at testing facilities, long drawn procedural issues, and breach of confidentiality by service providers. On the flip side, service providers complained of increasing burden due to high HIV caseloads and lack of specialised training for counsellors as reasons for deficiencies at their end.

#### **Issues Related to Disclosure**

**Challenges and dilemmas:** Parents/caregivers feel that children in the 0-6 age group are too young to understand the meaning of their HIV status. In most cases, parents experience guilt for not being able to disclose. In many cases, the decision on whether and when to disclose, creates confusion and anxiety among parents. When they actually decide to disclose, many experience an inability to deal with the issues during and after the process of disclosure. The lack of counselling and guidance/training by ICTC staff on disclosure only adds to the complexity that parents/caregivers are often faced with.

**Channels of disclosure:** Parents, NGO staff, ICTC staff, overhearing and suspicion were the common channels through which disclosure to children and adolescents is made. In order of preference, parents, NGO and ICTC staff figured as the preferred channels of disclosure. While most said that parents are best placed than others to assess the opportune time for disclosure, many parents/caregivers viewed NGO staff as trustworthy and skilled at disclosure.

**Immediate psychosocial effect of disclosure on children and adolescents:** The study brought forth pain, fear, worry and helplessness, in that order, as common emotional responses post disclosure. Children experienced pain about their parents' health condition and their own limitations to support their family by earning a livelihood. Parents often forewarn children to keep the information to themselves lest hostility and discrimination within their neighbourhoods, make their lives even more difficult. Several other uncertainties and worries that children routinely face are: financial insecurity, life after parents' demise, possible eviction by landlord, discontinuation of education, and denial of marital opportunities, especially in the case of girls.

#### **Key Recommendations**

**Modify healthcare service delivery** by expanding the number of testing centres and days of functioning, filling up gaps in infrastructure, equipment and human resource at ICTC, working out feasible and flexible timings appropriate for families, and monitoring the scheduled timings of the ICTC staff in terms of presence and punctuality.

**Improve diagnostic services for children below 18 months** by creating awareness and informed demand for DNA-PCR testing facilities, or alternatively, adopt the Dried Blood Sample method for children to enable Early Infant Diagnosis.

**Capacity building and training** for parents, healthcare providers, counsellors and ORWs from NGOs requires scaling up. There is a need to develop appropriate training tools with practical guidance notes for disclosure to children. There is an urgent need to train counsellors in child-centric counselling, and strengthen the knowledge of counsellors and healthcare providers in order to deal with young adolescents, especially young girls.

Establish improved and focused counselling services by using services of professionally skilled counsellors and reallocating budget commensurate with their qualifications and experience, using child-centred counselling techniques including play therapy, storytelling, drama, dance/movement, drawing and art, supporting children in pre and post-disclosure phases.

To improve the supply side response, there is a need to organise regular refresher training courses for counsellors in tune with the needs of different age groups of children, scaling up youth-friendly testing and counselling facilities and integrating these with adolescent reproductive health programmes. There is also a need to develop a systematic plan to aid parents in disclosure including post-disclosure issues, and focussing on positive attitude and positive living for parents and children.

Strengthen Information, Education and Communication (IEC) coverage by disseminating IEC materials widely to intervention sites. Awareness about the importance of using IEC materials regularly with children and their families should be increased by facilitating special observation time periodically. Such steps will intensify the use of these materials by ORWs, counsellors and in support groups and training sessions.

#### Identifying barriers to sustainable access for children and families to ART centres

Findings	Key Recommendations		
Barriers and Bottlenecks Faced by CLHIV and Families in Accessing Treatment Services, Both in Rural and Urban IndiaStigma and the resultant discrimination which exists at various levels, i.e. within the family, community, institutions (including schools and healthcare facilities) and the wider community.	Deepen communication and decentralised response in addressing stigma and discrimination by designing and implementing intensive child-focused IEC, separately targeting rural and urban population through an appropriate mix of media, disseminating appropriate information on HIV and AIDS, paediatric diagnosis and ART through mass media and other communication campaigns, and involving local opinion leaders, village elders, faith-based organisations, women's collectives and youth clubs.		
<ul> <li>Economic constraints caused by inadequate availability of financial resources in poor and child- headed families resulting in inadequate access and adherence to ART.</li> <li>Infrastructural issues related to the location of ART centres at long distances, insufficient number of ART centres to cater a large population, non-availability of transport and travel time.</li> <li>Unsatisfactory support from parents and caregivers owing to long-winded procedures at ART centres and infrastructural issues and costs involved in reaching the ART centre.</li> </ul>	<b>Ease the infrastructural bottlenecks</b> by decentralising ART services by increasing the number of ART centres close to small and medium towns with services like HIV testing, CD4 count and prognostic support, and establishing new Link Centres where new ART centres cannot be set up. This would also mean facilitating direct referral of children from the counselling centres to the ART section/department to save them from the trouble of waiting in long queues at different counters, encouraging flexible timings at ART centres, and using vernacular signage with standard pictorial description of various services at ART centres keeping in mind the widespread illiteracy in certain areas.		
Lack of awareness about Paediatric ART and HIV/AIDS. ART has for long been primarily adult focused and there has been lack of child focused IEC on HIV and AIDS combined with inadequate awareness about existing paediatric ART services and Community Care Centres (CCCs), treatment options and benefits, and issues related to adherence. Lack of adequate <b>capacity and accountability at ART centres</b> due to inefficient administrative procedures, non-availability of trained professionals on paediatric ART, inadequate paediatric counselling and scattered sites for the process from registration to treatment.	<b>Coordinate and converge for improved diagnostic and treatment services</b> by improving coordination between State AIDS Control Societies (SACS) and district health departments. NACO can develop guidelines, training manuals and standard operating procedures on EID and Exposed Baby Care (EBC), keeping in mind the rural realities. In addition, PPTCT and paediatric ART services should be integrated for early detection and follow-up. Given the present realities, diagnostic services like PCR, DNA and viral load tests should be made available at district level, free of cost to all children as this will reduce the dropout rate. Further, simple and cost effective mechanisms should be developed so that ART can be provided along with Directly Observed Treatment Short Course (DOTS) up to the sub-district level.		
Lack of coordination, collaboration and convergence between agencies, departments and related programmes, more particularly Integrated Child Development Scheme (ICDS), Reproductive and Child Health (RCH), and Tuberculosis (TB) with Prevention of Parent-to-Child Transmission (PPTCT), HIV and paediatric ART.	Augment capacity and responsiveness at ART centres by strengthening operational facilities and providing a comprehensive package of services (counselling, HIV testing, PPTCT, ART, follow-up) under one roof. Keeping in view the staff constraints, medical officers posted at ART centres should preferably be a pediatrician wherever post graduate specialists are not available. Further, opportunities should be created for the entire staff, i.e., lab technicians, pharmacists, nurses, medical officers to undergo refresher training to keep them updated with the best paediatric practices. Capacity building of gynaecologists, both in government and private sector, and development of uniform treatment protocols is essential.		
The two pieces of OR were widely disseminated to various stakeholders and organisations, and through various e-forums. Two policy briefs were also developed based on these two studies. To read the reports – 'Facilitating HIV Testing and Disclosure for Children and Adolescents', 'Barriers to Sustainable Access of Children and			

HIV Testing and Disclosure for Children and Adolescents', 'Barriers to Sustainable Access of Children and Families to ART Centres in Rural India' and 'Barriers to Sustainable Access of Children and Families to ART Centres in Urban India' in detail, or the policy briefs – 'Breaking Barriers: Facilitating HIV Testing and Disclosure for Children and Adolescents' and 'Breaking Barriers: Improved Access to ART Centres is the Key to Fight Against HIV/AIDS', please visit our virtual resource centre, SETU, at <u>www.aidsallianceindia.net</u>, or ask us for the printed copies at <u>setu@allianceindia.org</u>.

Name of the Child: Vaishnavi Dehare Sex: Female Age (March 2009): 3 years Place: Nagpur, Maharashtra

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Sub Recipient – MAMTA Sub-Sub Recipient - BAJSS

Vaishnavi is a child living with HIV. She used to live with her mother (Vandana), father (Pramod) and a 3 month old baby sister (Damini) till her father passed away in March 2009 - just 10 days after we had first met them. That time Vandana was very angry with Pramod for having given her the infection, but now she breaks down often partially because of her loss and partially because of her fear of how she will support her two daughters (Vaishnavi, 4 years and Damini, 14 months) in a situation where she has no family support and no source of income and in an environment where she is facing stigma of not just being HIV positive but also being a mother of two daughters and not sons.

### Year 2009

We met Vaishnavi and her mother, father and baby sister in their rented house in Nagpur. When Vandana was pregnant with Damini, she had to undergo an HIV test and her result came positive. As a result, her husband and daughter were also tested and both of them were diagnosed living with HIV. Vandana did not get proper medical attention or care after the doctors learnt her status. She delivered Damini lying on the floor of the hospital. Pramod was working as a daily wage labourer in a factory and earning Rs. 1700 – 1800 per month. But the entire month of March he had been sick with a CD4 count of 19. Vandana's greatest worry that time was how she would pay the monthly rent of the room which was Rs. 800 if Pramod doesn't go for work. Little did she realise that he would pass away 10 days later.

## Year 2010

We met Vandana again in 2010 but this time at her sister's and brother in-law's house. She stayed with her own parents but they couldn't house her and the children beyond a point because of resistance from her brother and sister in-law. Her own sister is also under a lot of pressure from her husband and mother in-law to turn them out and Vandana said there are frequent fights in her sister's house. She said she would need to move out of there too, soon. Her in-laws have completely disowned her. Outwardly, Vandana smiled and played with her children but her eyes spoke volumes of her state of mind. She is unable to work because she has two small children. She has no cash inflow except for what her younger brother gives her occasionally. She has no savings, policies, bank account or even a ration card. *"It is only CHAHA that gives my children food to eat and sends my daughter to school"*. Three months from now, Vandana will get Damini tested for HIV (in India, due to non-availability of PCR, children can only be tested after 18 months of age). And six months from then, funding for CHAHA programme would come to a stop.



### A Blind Spot in HIV Prevention – Female Anal Sex

#### Have We Been Afraid to Ask?

In 2009, we asked ourselves the question: have we been too scared to ask about female anal sex? The question is pertinent for two main reasons. First, because from an HIV perspective, unprotected anal sex is dangerous. HIV permeates the mucus membrane around the anus more easily than other parts of the body due to its absorptive function. Secondly, because there is evidence to show that anal sex among heterosexual couples is on the rise. The 2005 CDC survey showed that in the United States (US), 38.2% of men between 20 and 39 years and 32.6% of women between 18 and 44 years have engaged in heterosexual anal sex, whereas the CDC's 1992 National Health and Social Life survey found that only 25.6% of men between 18 and 59 years and 20.4% of women between 18 and 59 years had practised it.7

# More Common than You Might Think

These figures are not unique to the US according to the online 2005 Durex Global Sex Survey. Greece and Chile top the list of nations practising heterosexual anal sex (55%) and most western European countries are not lagging far behind.<sup>8</sup> A survey of 5000 households in Brazil revealed that 50% of urban couples and 40% of rural couples consider anal sex to be a regular part of sex life.<sup>9</sup> It is hypothesised that in absolute numbers, there are more heterosexual couples practising anal sex than homosexual couples.<sup>10</sup>

There are consistent reasons why in the past and to the present day, heterosexual couples have chosen to practise anal sex. It allows for sex without the risk of pregnancy. It allows for sex while preserving the appearance of virginity (it leaves the hymen intact, which is essential in cultures where blood stained sheets need to be displayed the morning after the wedding). It allows men to avoid contact with menstrual blood if they happen to be deterred by it. And importantly, even though evolution has provided no natural lubrication to facilitate entry, the anus is rich in nerve endings, and therefore, can be a source of great physical pleasure.

#### Female Anal Sex and Sex Work

It doesn't take a great leap of imagination to assume that if experimentation with anal sex is on the increase among heterosexual couples, then there is almost certainly an increase in demand for anal sex from clients of Female Sex Workers (FSWs), which from an HIV prevention perspective, should ring all sorts of alarm bells around usage of lubricants and condoms, and the risk that non-usage of either of them entails.

The reasons why a client may want anal sex from a FSW are unlikely to have anything to do with the first three of the four traditional incentives for female anal sex outlined above. There are unlikely to be any practical incentives at all - he will want it as a matter of taste. But for the FSW, the motives for agreeing may be varied. A Ukrainian sex worker listed four main reasons why she and her colleagues preferred to offer anal sex over vaginal sex. First and most importantly, sex workers can demand higher payment for anal sex. Secondly, men tend to climax faster when practising anal sex allowing the sex worker to end the transaction in a shorter period of time. Thirdly, anal sex can be offered all throughout the month with no breaks. Finally, and most significantly from an HIV prevention perspective, there is a misconception that it is safer to have anal sex with a non-regular male partner than to have vaginal sex with him.<sup>11</sup>

There are the more sinister reasons also, such as a total lack of choice, for economic reasons or due to physical coercion and rape.

For India HIV/AIDS Alliance, who with the support of the Bill and Melinda Gates Foundation-funded

<sup>7</sup> Mosher, Wiliam, Ch Andhra, Anjani, Jones, Jo. "Sexual Behavior and Selected Health Measures: Men and Women 15–44 Years of Age, United States, 2002" CDC Advanced Data, September 15, 2005

<sup>11</sup> Interviewed by the author

<sup>&</sup>lt;sup>8</sup> Durex Global Sex Survey 2005 (<u>http://www.durex.com/cm/gss</u>): This survey puts European countries at the top of its list and Asian countries at the bottom, but this is not a reliable sexual behaviour survey. It is filled in online and does not adjust to account for access to internet or the culture of completing such surveys.

<sup>&</sup>lt;sup>9</sup> Morris, Desmond "The Naked Women" Vintage Books, 2005

<sup>&</sup>lt;sup>10</sup> http://en.wikipedia.org/wiki/Anal\_sex

Avahan Project oversees a prevention programme reaching out to over 50,000 FSWs in Andhra Pradesh, the prospect of widespread female anal sex among sex workers has serious implications. At the moment, FSWs are supported with condoms and prevention advice that pays scant attention to anal sex. Both the lubricants, essential for safer anal sex, and the anal sex prevention advice, are disseminated to MSM communities only. Female anal sex could be a significant route of HIV transmission that is at the moment only being partially mitigated by condom distribution. And if so, prevention interventions need to be adjusted accordingly.

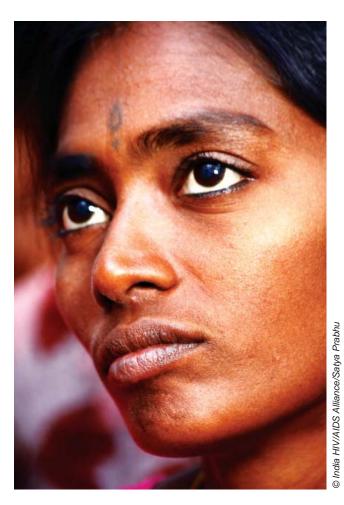
#### **Asking Female Sex Workers**

In an attempt to get a clearer picture of the prevalence of anal sex among FSWs, Alliance India conducted two stages of operational research. First, by interviewing 100 FSWs in focus groups and one-to-one interviews in the city of Hyderabad and two sites in the rural district of Nalgonda in Andhra Pradesh, and secondly, by conducting a survey (ongoing) of 500 FSWs in 10 districts of Andhra Pradesh. The findings below come from stage one of the research only.

Of 50 FSWs interviewed in urban-based focus groups, 80% claimed that they practise anal sex. Nearly half of all clients who approach FSWs, request for anal sex. Participants claimed to have an average of 12-15 clients per week, of which a third involve anal sex encounters. For every 10 sex acts, participants claimed that three were anal sex acts. From an average 10 clients, 3 will seek exclusively anal sex, while around two out of 10 will want both anal and vaginal sex.

In rural focus groups, all participants had offered anal sex to clients, but some described being permanently deterred by the pain it caused. As in Hyderabad, around 50% of clients request anal sex and around 60% of FSWs agree to offer it regularly. Several participants claimed to have at least one anal sex encounter per day.

FSWs suggested that the clients' motives for seeking anal sex are various, including boredom with wives and regular partners, the refusal of wives and partners to experiment with anal sex, the desire for novelty and thrill, enhanced sensation, homosexual inclinations



or preferences, and the inspiration of pornography accessed through internet, MMS, magazines or films. Pornography was considered the most significant driver of the demand for anal sex from clients. In rural focus groups, particular significance was also given to alcohol consumption and that clients are more likely to want anal sex when drunk.

Participants claimed that their own motivations were different, and in fact, anal sex was demand, not supply driven. Participants stated that they did not seek anal sex and thought badly of those who wanted to purchase it. Many described the pain it had caused them. Nevertheless, FSWs can demand higher rates for anal sex and therefore, there is a financial incentive to practise it. There is also a strong business case for accepting clients for anal sex—demand is high, and to refuse would be to deter half of your potential clients, something few FSWs can afford to do. This is particularly true in the case of regular partners, many of whom also seek anal sex. Participants also explained that the number of clients diminishes with age and therefore, refusing clients' requests ceases



to be an option. In terms of the number of anal sex acts, however, participants underlined that younger sex workers still have more anal sex because they have a larger number of clients overall. During menstruation, women see anal sex as a way of being able to continue to attract clients and earn money throughout the month.

In urban focus groups, participants claimed that during anal sex, only two-thirds of clients use condoms, that a large number of clients demand anal sex without a condom, and that it is actually difficult for the FSW to confirm condom usage because the client is not visible during the act of anal sex. Participants explained that sex work is a demand driven business, and economic necessity often means that client demands are met, whatever the risks involved. They underlined that clients demonstrate very low awareness about risks and prefer to believe that FSWs are exaggerating or simply bargaining for a higher price.

In rural focus groups, all participants thought that

vaginal sex was more dangerous than anal sex from the perspective of HIV transmission, and many rated it as a lower threat than oral sex. Nevertheless, participants claimed high condom usage despite apparent lack of awareness of risk, even with regular partners, of whom 50% ask for anal as well as vaginal sex.<sup>12</sup>

Participants spoke of irregular use of lubricants, which are essential to the prevention of condom breakage and reducing the risk of cuts and bleeding. Some participants did report using water-based lubricants, but the majority referred to using coconut oil, saliva, petroleum jelly, hair oil, or relying on the lubrication of the condom.

#### **Conclusions and Next Steps**

The combination of frequent anal sex, infrequent condom usage, lack of access to appropriate lubricants, the presence of economic and physical coercion, and low awareness of the risks associated with anal sex, present a serious threat to the health

<sup>&</sup>lt;sup>12</sup> The insistence of all participants to claim 100% condom usage in the rural focus groups, even when referring to forced sex, suggests that this response was motivated by the expectations of the prevention programme in which they participate. With regular partners especially, there is strong evidence to prove lower condom usage. For example, see "Population Council. 2008. Patterns of Mobility and HIV Risks among Female Sex Workers: Andhra Pradesh. Population Council: New Delhi, pg 38"

of FSWs and their clients, and are likely to be a significant contributor to HIV transmission.

Three actions can be taken to mitigate the risks. First, there are dangerous misconceptions about the health risks involved in anal sex that need to be addressed when running prevention campaigns with FSWs. Information campaigns with FSWs should include education about the risks of anal sex and practising safe anal sex. Clinics need to ensure that patient examination involves checking for anal Sexually Transmitted Infection (STI). Secondly, FSWs must have access to lubricants along with condoms. It is widely recognised that this is true for MSM but it is evidently equally true for FSWs for all the same reasons. Thirdly, it is unlikely that the India/Andhra Pradesh context is in anyway unique regarding the prevalence of female anal sex with sex workers, and therefore, other prevention programmes need to consider whether sufficient attention is being given to protect sex workers and their clients with regard to anal as well as vaginal sex.

#### Main Recommendations

- FSWs should be given lubricants as well as • condoms within prevention programmes.
- Anal sex education should be part of prevention • programmes for FSWs.
- Further research should be conducted to test these initial findings and the results should inform prevention programmes in India and globally.

To read the full Issue Brief - 'A Blind Spot in HIV Prevention', log on to www.aidsallianceindia.net

Core Indicator for Avahan	Achievement (as of December 2009)
No. of old individuals reached by 1-1 HIV/STI prevention communication	104,925
No. of KPs reached through one-to-one contact	73099
FSW	49517
MSM	23335
IDU	247
No. of new individuals visiting clinics	11,286
No. of old individuals visiting clinics	217,205
No. of STI consultations	240,354
No. of referrals (VCCTC, Care & Support, Hospitals etc.)	38,256
No. of condoms distributed	26294461

### Learning from the Results of Monitoring and Evaluating Community - Led Violence Response among Female Sex Workers in India

ost Female Sex Workers (FSW) in India at some time or another suffer from violence from ruffians, partners, pimps and madams, and from the police. This heightens the risk of HIV transmission because women under the threat of violence are less likely to have negotiating power over condom usage, are more likely to be cautious of leaving their homes and accessing health services, are more likely to suffer from withdrawal and depression, and therefore, less likely to adopt health seeking behaviour.

In order to challenge and counter this violence, the Avahan project of the Bill and Melinda Gates Foundation in India has invested in building the capacity of partner organisations, and especially FSWs themselves, to protect women against violence, to sensitise the usual perpetrators of violence and hold the actual perpetrators of violence to account. Various initiatives have been tried around India to this end, but they all work on a common premise that individual FSW is less likely to seek recourse for violence than collectivised women, and therefore, FSWs should be supported to collectivise into groups that can provide mutual support in protection, sensitisation and advocacy work. Cross-cutting approaches have been to invest in advocacy training for FSWs, to support the formation of Crisis Response Teams from among FSW and NGO partners, and to proactively seek to sensitise the media and the police on issues of FSW rights.

The response has to date touched many hundreds of lives in positive ways, but there has been an ongoing challenge in assessing to what extent this advocacy has in fact been reducing violence towards FSWs. As a Lead Partner in this project, Alliance India has had to try to understand and address this.

The challenge can be roughly broken down into two areas. First, we have had to appreciate that advocacy in terms of holding people to account has limited potential in reducing violence against FSWs, and secondly, we have had to appreciate the limited possibilities of collecting data from FSW on incidents of violence.



#### **Accountability and Violence**

The main perpetrators of violence against FSWs are intimate partners, clients, pimps/madams, ruffians and police. Among these, the police force is the only one that can actually be held to account, and this is where the most apparent advocacy successes have been.

With the police, it is possible to have structured meetings, to name and shame through media, and to work with authorities within the police force to influence subordinates. Yet, even here it would be naïve to assume that an input of advocacy will necessarily result in an output of sensitised behaviour. There will be too many other factors at play, shaping attitudes and behaviours. But if we are looking (as we are when we prepare project reports), we might still nevertheless find incidents of sensitised attitudes. And this is how we have tended to report.

As for the rest of the perpetrators, then, an advocacy aimed at accountability is not realistic. Partners, clients, pimps and ruffians may have entrenched patriarchic and sexist attitudes as well as selfish economic interests that motivate them to commit violence, and that may be abhorrent, but they are not accountable to anyone to think differently. Here, the best form of advocacy is sensitisation, which sadly, can often only happen after the violence is committed. In some parts of India, particularly the north-east, the situation is further complicated by the role of insurgent groups in violence, which again have no official accountability, that can be a platform for an advocacy campaign.

In advocacy, two issues need to be balanced – people's capacity to demand accountability, and an organisation's or group's ability to be held to public account. In the case of community violence response, we have had to acknowledge that the latter is for the most part not an option, and therefore, it is people's capacity that needs to be the focus of our support.

# The limitations and incentives of reporting on violence

In monitoring and evaluating community-led violence response, we are only able to hear one side of the changing experience of violence, that of the FSW. It is much less realistic to understand attitude changes in pimps, partners or ruffians as we have no methodology to access such information.

Yet while FSW may be active in reporting cases of violence perpetrated by the police, they may be far less willing to do so against intimate partners or pimps, either for fear of reprisal or out of loyalty.

In other words, there may be a number of motives why a FSW would choose not to report a case of violence, meaning that there are significant limitations in our ability to monitor it. The consequence of this is that despite widespread understanding of the frequency and presence of violence in the lives of FSWs, actual reporting of incidents has remained extremely low.

#### **Ways Forward**

Having recognised that advocacy to hold people to account has only a limited role on responding to violence to FSWs and that FSWs will often choose not to report incidents of violence, Alliance India has considered its options to support FSW and at the same time to understand whether such support is working.

We have come to a few tentative conclusions. First, given that motives and attitudes towards violence are so deeply engrained, it would be naïve to expect a cause and effect relationship between sensitisation and change of behaviour, especially for individuals and groups who are not accountable to anybody. Violent behaviour is too complex a phenomenon to expect an input/output approach to measurement of work. That is not to suggest that sensitisation is not needed, but rather to underline that it must be understood as a long-term, collaborative effort with boundaries well beyond a project. More immediate emphasis should be placed on protection. The women we interviewed in Manipur claimed that the biggest contribution to reducing incidents of violence had been the opening of a night shelter in Imphal that allowed them to hide from ruffians and police. In Andhra Pradesh, confidence itself was described as the greatest form of protection. From the focus groups at least, it appeared that the FSWs trained as ORWs and peer educators had brought violence down in their lives to nearly zero incidents per year, and they attributed this to feeling more confident to stand up for themselves.



The form of protection may vary depending on the context but what is consistent is that women who feel more protected are less vulnerable to being intimidated by the threat of violence and are therefore, more able to avoid it. This would imply two actions. First, that a variety of protection options be considered in consultation with FSWs based on their own interpretations of the threat of violence in their own contexts, and secondly, that monitoring tools need to focus on qualitative data that assesses how empowered the FSWs feel to protect themselves against violence.

A second conclusion is that we need to acknowledge the limitations in the possibilities of gathering accurate data on incidents of violence. Reporting violence is emotionally painful and may not be in the interests of FSWs for a number of legitimate reasons. Yet while FSWs may not be willing to report violence on a case by case basis, they may well be willing to discuss trends in their experiences of violence. A monitoring tool that covered FSWs' perception of risk, and periodically measured, from the perception of FSWs, changes in the frequency of violent encounters with different groups, should provide a more reliable indication of empowerment and progress than seeking to track actual incidents one by one.

A final conclusion is that the most effective way to monitor community-led violence response may

actually be to measure our own performance as Lead Partners and donors in support of community violence response. How well have we sought to understand violence in all its forms? How well have we sought to appreciate the power dynamics and motives that drive both violence and its reporting? How much have we used our own influence to shape community and police perceptions? How much have we considered and applied the various options for protection? How well have we adapted training to deal with clients, ruffians, pimps and police? How closely do we stay in touch with FSWs once they are collectivised into support groups? And how do we ensure that empowerment and confidence building is an ongoing process?

Such an approach of self-monitoring informs us how our own behaviours and approaches are working. It is also a reminder of our own accountability and who the interventions are for. Crucially, it further empowers the FSWs themselves to control the type of support they need to mitigate the risks of violence, which is itself a development goal.

To read the think piece – 'Learning from the Results of Monitoring and Evaluating Community-led Violence Response among Female Sex Workers in India', please log on to <u>www.aidsallianceindia.net</u>

# The Idea of Round 9 – Why Prevention for MSM, TG and Hijra should be CBO-led

s part of the effort to meet the Millennium Development Goals (MDG) and Alliance India's own vision of supporting community action on AIDS, the Global Fund Round 9 proposes to work with the most-at-risk populations of Men who have Sex with Men (MSM), Transgender (TG) and Hijra populations in the country.

According to the HIV Sentinel Surveillance 2007, the prevalence of HIV among MSM stands alarmingly at 7.4%. The reported situation at state level is grim as well with more than 5% HIV prevalence in Karnataka (17.6%), Andhra Pradesh (17%), Manipur (16.4%), Maharashtra (11.8%), Delhi (11.7%), Gujarat (8.4%), Orissa (7.4%), Tamil Nadu (6.6%) and West Bengal (5.6%). Despite the national programme giving priority to MSM in its Targeted Interventions (TI), it is only able to cover 73% of the 2.35 million MSM/Hijra/TG populations in the country as of March 31, 2009.

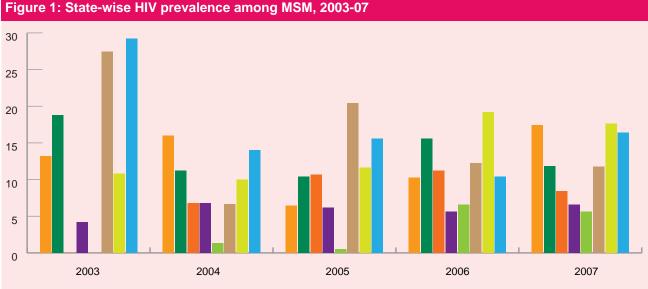
{Source: Annual Report 2008-09, National AIDS Control Organisation (NACO)}.

Furthermore, the report of the AIDS Commission in Asia predicts that out of all HIV cases, MSM would account for 50% of the infections by 2015.

# Why HIV prevalence continues to be high among MSM?

Based on the rising prevalence rates among MSM, numerous gaps in the current programming for the community have been identified. To begin with, the reach in terms of geographical coverage is low, though there is insufficient data to validate exact figures.

Additionally, most of the current programming through government-run TIs and those of other donors has shown partial and variable success in community



	2003	2004	2005	2006	2007
AP	13.2	16	6.45	10.25	17.4
Mahrashtr	a 18.8	11.2	10.4	15.6	11.8
Gujarat		6.8	10.67	11.2	8.4
TN	4.2	6.8	6.2	5.6	6.6
WB		1.33	0.54	6.6	5.61
Delhi	27.42	6.67	20.4	12.27	11.73
K'taka	10.8	10	11.61	19.2	17.6
Manipur	29.2	14	15.6	10.4	16.4

#### Source: HIV Sentinel Surveillance and HIV Estimation 2007, A Technical Brief, NACO

mobilisation and reach. One reason is that the institutional capacities to address the specific needs of MSM/TG/Hijra issues remain weak. This has brought to light the need for technical support and handholding of NGOs to deliver quality programming for the community.

The traditional definition of 'hotspots' within the TIs is also limited to public "cruising" spots with inadequate attempt to reach emerging sex sites such as massage parlours and various social networking sites which offer to the community increased opportunities for social and sexual contact. Also, reaching out to elderly MSM, non-feminised MSM and partners of MSM/TG/Hijra has often proven to be difficult, and is therefore, neglected within the TI approach, which tend to focus on kothis (feminised MSM) that form only a part of a larger community whose needs are currently underserved.

While prevention remains the mainstay of the HIV response in India, it is well recognised that care and support services are critical for arresting the growing prevalence rates across the world. These would require care services and positive prevention for HIV positive MSM, specialised counselling for mental health and psycho-sexual support. This approach is currently a major gap within the national response.

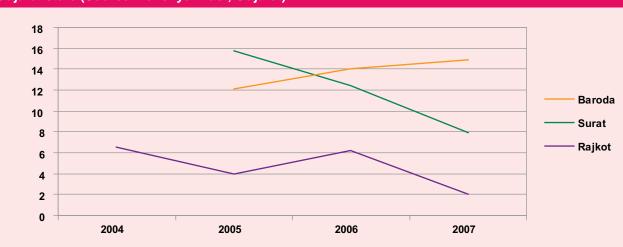
There is also limited legal support in case of violation of human rights of MSM/TG/Hijra which often force them to operate in secrecy, only further distancing them from the services being offered.

For certain sections of the community (like kothis and hijras), opportunities for socio-economic development are still limited which often forces them into sex work, further increasing stigma, vulnerability and marginalisation. This widespread stigma and discrimination within the healthcare system only adds to their inhibition to access services openly. A significant gap in the services for MSM/TG/Hijra is the non-provision of lubricants, absence of clear, specific and innovative communication strategies, and lack of adequate and specific materials targeting behaviour change within the community. Finally, lack of credible research and data to understand the sexual practices of the community, and documentation of proven community-led interventions remains a gap.

# Why should MSM prevention be CBO-led?

It is well recognised that Community-Based Organisations (CBO) are strategically well placed to address the issues of the community. The Sonagachi Project run by the CBO, Durbar Mahila Samanwaya





### Figure 2: Graph on HIV prevalence rates amongst MSM communities in Baroda, Surat and Rajkot in Gujarat state (Source: Lakshya Trust, Gujarat)

Samiti, formed and managed by a group of FSWs is a successful example. Alliance India has also embarked on community-led responses towards HIV prevention and impact mitigation, involving the communities right from programme designing to even evaluation stage. The formation of CBOs results in rapid saturation of coverage since there is greater trust, understanding of community issues and therefore, the opportunity to offer quality services, which the community can access without stigma in a safe and supportive environment.

The HIV prevalence figures in regions where CBOs have led the interventions clearly show that this approach has been successful in reducing prevalence rates among MSM, TG and Hijra population. For instance, in Gujarat, the Lakshya Trust, an MSM CBO, has been working with MSM/TG/Hijra populations in three cities – Baroda, Surat and Rajkot – since 2001. HIV prevalence figures from these cities demonstrate the effectiveness of community-led interventions, making the programme successful and sustainable. (*Refer to Figure 2*)

#### Challenges

CBO formation and strengthening is a long and difficult process. Capacity building of CBOs falls out of the remit of SACS and local district units, which limits their involvement in giving technical and financial support to local CBOs. Institutional building and strengthening is often not perceived as a priority by MSM, TG and Hijra communities themselves either.

Rising HIV prevalence within MSM communities is attributable to low awareness and unsafe sexual practices, insufficient coverage and extremely slow pace of scale up. A hostile social environment, lack of services, and poor mobilisation of communities are contributory factors. CBOs cannot be built overnight – they need careful facilitation, mobilisation, mentoring and handholding support, and specific skills for working with MSM/TG/Hijra groups which are not widely available. Finally, there is lack of capacity and platforms for advocacy to counter discrimination and to enable the communities to access services. Besides, there is a need for greater coordination of CBOs with the state and national HIV control programme, which is critical.

#### The Idea of Global Fund Round 9

Through Round 9, Alliance India aims to strengthen CBOs (new as well as existing), build their institutional capacity and work towards policy development and advocacy. The objectives of Round 9 are:

- Strengthen community systems that reach MSM/ TG/Hijra populations in India.
- Increase the number reached by communitybased activities and services for MSM/TG/Hijra populations.
- Strengthen the relevant health system resources and increase the involvement of community systems.

Table 1:		
Stage 1: Start up	Stage 2: Strengthen and develop	Stage 3: Towards sustainability
Basic sexual health Drop-in centre Support groups	Sexual health outreach attains 'Pre TI' level Friendly services and referral system Trauma and violence rapid response Community level awareness raising and preparedness	TI takes over: Outreach work Condom promotion and distribution BCC STI referrals Drop-in centre Stakeholder sensitisation 'Package 2' takes over: Support groups Friendly services, referrals and tracking Community level awareness raising and
		preparedness

 Increase knowledge and advocacy related to MSM/TG/Hijra populations.

The National Programme seeks to set up 300 CBOled TIs of which 90 are on the ground. Hence, Round 9 will facilitate three key processes:

 Setting up 110 new CBOs across 14 states. In total, 110 CBOs will be facilitated and supported in 14 states of India reaching 1,47,250 new community members. The newly created CBOs will be supported in a step-wise manner for progressively expanded community-based activities during the start up, strengthening, and sustainability phases. This will include 'Pre TI' activities that will lead to TIs that can be funded by SACS. (Refer to Table1)

- Strengthening of 90 existing CBOs across 13 states through additional services offered to the communities—for the existing CBOs implementing TIs—to expand community level programming, and offer services that respond to MSM/TG/Hijra priorities, which also focus on reducing vulnerabilities. An outreach and service delivery package (Package 2) has been envisaged. (Refer to Table 2)
- 3. Providing support for organisational development of all 200 CBOs (110 new and 90 existing)



across 17 states - the CBOs will be strengthened programmatically, organisationally and institutionally by developing new activities and systems. Basic CBO management will be supported through development of operational guidelines and manuals for management and for reporting. Partnerships will be established with existing initiatives to support the management of CBOs {for instance, with Indira Gandhi National Open University (IGNOU), Indian Institute Management (IIM)

#### Table 2:

Stage 1: Expand and add

- Expand outreach
- Life skills
- Mental health
- Priority issues of TG and Hijra populations
- Community level awareness raising and preparedness

#### Stage 2: Diversify

- Trauma and violence rapid response
- Specialised prevention for married MSM/TG/Hijra and MSM/TG/Hijra living with HIV
- Effective and confidential local referrals and tracking

#### Stage 3: Mature

- Peer financial saving groups
- Outreach and referrals for female partners and spouses
- CBO-led learning and advocacy in their local environment

and United Nations Development Programme (UNDP)}. Further strengthening will focus on institution building (vision, purpose and sustainability), CBO leadership development, key stakeholders relationships (notably SACS, DAPCU, local leaders) and external support to help the process of CBO registration.

### Policy development and advocacy

An inadequate policy framework to cover MSM, TG and Hijra issues is a major contributor to the prevalent stigma and discrimination against the community. The aim of policy development efforts within Round 9 will be: to increase knowledge on priority issues related to MSM, TG and Hijra communities in India, and to support stakeholders in translating this into better policies, guidelines and programmatic decisions.

There is an immediate need for saturating the coverage of MSM/TG/Hijra communities as the

current programmes are not able to reach out to the entire MSM/TG/Hijra populations. In Round 9, the attempt will be towards increased coverage.

Further, the current programmes focus largely on prevention services, resulting in major gaps in care, support and treatment (CST) services for MSM, TG and Hijra living with HIV. Through the provision of CST services in Round 9, this gap will also be addressed.

Thus, the idea of Round 9 is not only to provide effective and appropriate interventions among MSM, TG and Hijra populations, but also to address the barriers to access services, reach the 'bridge' and 'hidden' populations including their female partners, and increase knowledge and sensitivity regarding their issues within the broader social framework through advocacy with various actors including the police, judiciary and media, and sustained efforts for policy change at multiple levels.

## The Sashakt Project Update

The Sashakt project supported by UNDP India was initiated by Alliance India in September 2009 as a pilot programme for the upcoming Global Fund Round 9 programme, which is scheduled to start from July 2010. The project aims to strengthen community institutions, capacity and systems for MSM, TG and Hijra communities in India. This will enable the community to advocate for their rights and play a role in the national response to the HIV epidemic in India. The project will develop four new CBOs and strengthen two existing ones across six states (Manipur, Orissa, Uttar Pradesh, Madhya Pradesh, Maharashtra and Tamil Nadu). The project is being implemented in close coordination with the national and state governments. By the end of 2009, the process of CBO formation was initiated at four new sites, with capacity building through mentoring, technical workshops, provision for infrastructure and human resources. The existing CBOs are being provided additional human and technical resources in order to address specific community needs and to reach out to more community members.

# Why Harm Reduction Needs more Focus on Poverty Reduction: *The Case of Female Injecting Drug Users in Manipur*

t is easy for Female Injecting Drug Users (FIDUs) to fall off the radar screen of harm reduction programmes in India. In all states, they constitute a small minority of IDUs, and even where their numbers are comparatively large, such as in Manipur, women still represent only around 5-7% of the IDU community.

The natural consequence of this is that harm reduction services are mostly taken up by men, even if they are not strictly targeted at men. Men fill the needle exchange points, the drop-in centres and the counselling rooms. Women who seek to access these services can be easily intimidated by the gender imbalance. Male partners of FIDUs often dislike the idea of their wives or girlfriends spending time at these sites, and restrict access. The services themselves, adapting to the needs of the client majority, develop little or no capacity to address specific female needs, such as pregnancy and child care.

We should be concerned about this for two main reasons. First, because FIDUs are entitled to

protection and access to services even if their numbers are relatively small, and secondly, because FIDUs experience a number of additional vulnerabilities on top of those experienced by males, including heightened risk of HIV infection.

Primarily, this is because women are more frequently rejected by their families once they inject drugs and are often forced to migrate to new towns, and from there, many support themselves, (and often their male partners too) through sex work.

Three years ago, India HIV/AIDS Alliance, through partnership with Social Awareness Service Organisation (SASO), began to address the specific needs of FIDUs through establishing a drop-in centre for women, where they could access counselling, clean needles, Oral Substitution Therapy (OST), condoms and referrals to other services. In 2009, the project reached out to 270 FIDUs, of which 61% are HIV positive. This customised approach to women was widely acknowledged as innovative and important, but in 2009 we learned just how much braver this support is going to have to become if it is



to look beyond mitigating immediate health risks and aspire to support women to lead safer lives.

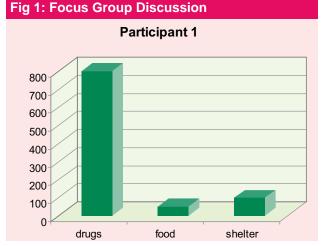
The fact that the project rarely influenced the cycle of injecting drug use and sex work for women was not in itself as failing, as it aspired to mitigate the risks of these activities rather than stop them. But the fact that is was the same women using the services year in year out, and that relapse after detoxification was around 97%, was a clear enough sign to suggest that something about the intervention was inadequate. It may have been having some impact on reducing the risk of HIV transmission on a day-to-day basis, but it was not addressing the vulnerabilities that presented a sustained risk to the women and their partners.

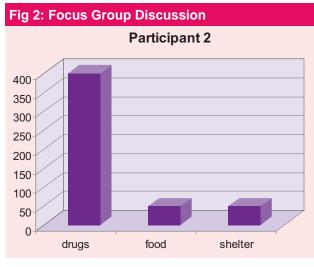
In focus groups, the FIDUs themselves articulated three root causes of their relapse after detoxification. First, after detoxification, they return to the same temporary shelters or street - based life from which they practised sex work and injecting drug use, and peer pressure and drug availability act as strong incentives to relapse.

Secondly, they perceive themselves, due to health problems, appearance and local reputation, as unemployable and therefore, financial necessity and boredom drives them back into sex work and injecting drug use.

And thirdly, the trauma of having hurt and severed links with loved ones, and the sense that all bridges back home are burnt, leads to depression and hopelessness that is alleviated in injecting drugs, that in turn can only be funded by sex work.

Having identified these issues, in theory at least, it was not difficult to sketch out what more sustainable support should look like.



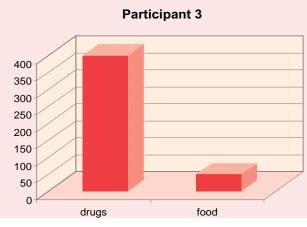


The women are living on the street or huddled together in wooden shack hotels. Violence and abuse is common. It is not an environment in which to sustain detoxification. Some type of shelter, away from these sites of injecting drug use, sex work and violence would be needed.

Almost all the income earned from sex work is spent on drugs. The three figures (1,2 & 3) show the daily income and expenditure of three typical participants in the FIDU focus group:

The women were clear that if they were not injecting drugs, then their daily spending needs would reduce dramatically. However, none of the women felt physically or emotionally ready to consider other employment, and none could imagine anyone giving them credit or an opportunity to earn money outside of sex work. Yet, not working post detoxification inevitably led to hopelessness and boredom that resulted in a return to injecting drug use. Clearly, some type of investment in vocational training and





confidence building was going to be necessary in any sustainable strategy for the women.

Finally, most women interviewed expressed feelings of shame for having hurt their families. Some saw no road back, but most felt that a reunion would be possible only after a full recovery from injecting drug use, and only if they could come home with something to offer – a job and some money. Depression about apparent burned bridges with families appeared to be another cause of relapse. The FIDUs requested that future projects include mediating between women and their families.

What was clear from these consultations was that our harm reduction would need to include more poverty reduction if it were to address these root causes of relapse. Crucially, it was evident that the three causes cannot be addressed in isolation, and only a harm reduction that embraces the relief and development challenges of shelter, vocational training and family linkages can hope to break the cycle of injecting drug use and sex work for FIDU.

Yet, if that message has come across to us loud and clear in 2009, the way forward remains an unfamiliar terrain. It is not a new idea to promote greater emphasis on poverty reduction within harm reduction interventions, but actual experience is still quite scarce and has had mixed results. The poverty reduction argument is strong, but in practice, it involves stepping over the borders of organisational strategies and crossing departmental mandates, both within the government and in NGOs. Health programme managers and donors are uncomfortable with the complicated and unpredictable horizons involved in moving into development agendas, and their mandate may stop at mitigating HIV risks, which can be seen as best served by condoms and clean needles.

At the same time, those responsible for poverty reduction are nervous about the viability of successful interventions with IDUs, and anyway, demand from other communities for poverty reduction support is high, and there is no strategic pressure to focus on IDUs in particular.

Yet, there is good news too: Alliance India, together with SASO, received a grant from the Elton John Foundation to pilot ways of reducing relapse among FIDUs in 2010. It will require working with new partners and cultivating new skills, but by the next annual report, we hope to be well on the way to building a case to show how extra time and money given for poverty reduction among IDUs can play a crucial role in breaking the cycle of injecting drug use and sex work, and can provide viable options for alternative and safer lives.

Core Indicators	Achievement (as of December 2009)
Number of clients registered/enrolled in the project	281
FIDUs	220
Spouses	27
Children	34
Number of FIDUs attended night shelter	34
Number of fresh needles and syringes provided	28526
Number of condoms provided	26759
Number of clients tested positive for Hepatitis C	38
Number of PLHIV put on ART	37
Number of clients put on OST	18

## The Female Injecting Drug Use Project Update

# Linking Sexual and Reproductive Health Rights and HIV/AIDS: A Community-Centred Approach to Achieving Universal Access

ince June 2008, Child Survival India (CSI) has been implementing a community-based programme to facilitate integration of SRH and HIV/AIDS information and services with the support of Alliance India and the Hewlett Foundation. The programme has adopted a comprehensive understanding of Sexual and Reproductive Health Rights (SRHR) addressing the full range of issues and needs, including maternal health, Reproductive Tract Infections (RTI) and STIs including HIV, menstrual hygiene and the underlying determinants and sources of vulnerability such as gender dynamics and violations of SRHR. While the project has been implemented on a small scale, its successful impact on health seeking behaviour, the effectiveness of health services and health outcomes presents important lessons for both larger scale programming and for the development of policies.

The programme specifically aimed to increase access to health and social services for vulnerable groups – adolescent girls, poor and illiterate women and men, and marginalised groups such as sex workers and PLHIV – in the project area, a relocated slum community in Holumbi Kalan phase I in Northwest Delhi. The community (approximately 12,000) consists mostly of migrant workers and their families. The programme aimed to increase informed demand for services by addressing community and individual level factors, while also working to ensure accessible, acceptable, available and good quality health services.

Supporting the community to increase demand: Various strategies were adopted to increase community demand. These included support groups and counselling with the involvement of peer educators, community sensitation and mobilisation, workshops in schools, and sensitisation of community gatekeepers and family members. A particular emphasis was made on engaging men and addressing the inherent power dynamics and inequalities that acted as barriers to ensuring infomed demand among those most vulnerable and affected by sexual and reproductive ill-health and HIV.

Creating available, accessible, acceptable and good guality health services: Geographical barriers as well as issues affecting acceptability and accessibility of services by those most in need were addressed. These included improving referral systems by introducing community group support sessions within government Antenatal Clinics (ANC) to increase access to VCT and PPTCT services, community solutions to provide transportation for emergency services, and training and sensitisation of healthcare providers to overcome HIV-related stigma and discrimination. Access to supplies was increased through establishment of community-based supplies of condoms, contraceptives, iron pills and other basic medical needs, and through community-led production of low cost sanitary pads.

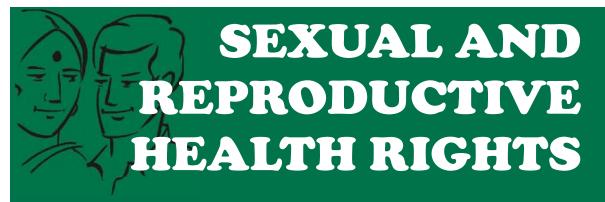


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### Challenges

Though the programme made desirable impact in one year, several challenges were faced during the implementation:

- A social audit conducted with the community and other stakeholders, raised huge demands from the community in terms of scale up and intensified activities to reach more number of people. However, with the current funding, it is difficult to meet their demands.
- SRH and HIV services are provided by two different healthcare providers within the health system. Healthcare providers in HIV services were trained and sensitised on HIV whereas healthcare providers in SRH services were not oriented or sensitised on HIV issues. As a result, bringing them together for capacity building trainings for convergence was very difficult.
- The funding for this project ended in October 2009, and the project had to be supported through unrestricted funds from the International HIV/AIDS Alliance until December 2009.



- 1. The right to life should be invoked to protect women whose lives are currently endangered by pregnancy.
- 2. The right to liberty and security of the person should be invoked to protect women currently at risk from genital mutilation, or subject to forced pregnancy, sterilisation or abortion.
- 3. The right to equality and to be free from all forms of discrimination should be invoked to protect the right of all people, regardless of race, colour, sex, sexual orientation, marital status, family position, age, language, religion, political or other opinion, national or social origin, property, birth or other status, to equal access to information, education and services related to development, and to sexual and reproductive health.
- 4. The right to privacy should be invoked to protect the right of all clients of sexual and reproductive health care information, education and services to a degree of privacy, and to confidentiality with regard to personal information given to service providers.
- 5. The right to freedom of thought should be invoked to protect the right of all persons to access to education and information related to their sexual and reproductive health free from restrictions on grounds of thought, conscience and religion.
- 6. The right to information and education should be invoked to protect the right of all persons to access to full information on the benefits, risks and effectiveness of all methods of fertility regulation, in order that any decisions they take on such matters are made with full, free and informed consent.

- 7. The right to choose whether or not to marry and to found and plan a family should be invoked to protect all persons against any marriage entered into without the full, free and informed consent of both partners.
- 8. The right to decide whether or when to have children should be invoked to protect the right of all persons to reproductive health care services which offer the widest possible range of safe, effective and acceptable methods of fertility regulation, and are accessible, affordable, acceptable and convenient to all users.
- 9. The right to health care and health protection should be invoked to protect the right of all persons to the highest possible quality of health care, and the right to be free from traditional practices which are harmful to health.
- 10. The right to the benefits of scientific progress should be invoked to protect the right of all persons to access to available reproductive health care technology which independent studies have shown to have an acceptable risk/benefit profile, and where to withhold such technology would have harmful effects on health and well-being.
- 11. The right to freedom of assembly and political participation should be invoked to protect the right to form an association which aims to promote sexual and reproductive health and rights.
- 12. The right to be free from torture and ill treatment should be invoked to protect children, women and men from all forms of sexual violence, exploitation and abuse.

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### **Lessons Learned**

As the programme continues into its second year, it has already generated important lessons for its continuation, future programming and policy development.

Overall, the project showed that a communitycentred approach delivers results for those most in need. Empowering community members to take an active role in addressing the underlying factors of vulnerability has helped overcome barriers at the individual, family and community levels. Only when inherent dynamics and inequalities, including those linked to gender, income and violations of SRH rights that make communities vulnerable to HIV and sexual and reproductive ill-health are overcome, sustainable health outcomes can be achieved.

The direct involvement of individuals as peer educators and in the self-sustaining production and distribution of commodities ensured that skills and structures were built within the community for the long-term. Furthermore, integrating SRHR and HIV along the continuum of services has tangibly improved lives by linking community and health systems by creating a user-friendly, needs-based approach to reducing vulnerability and improving access to accessible, adequate, appropriate and good quality services.

Furthermore, supporting not only direct service provision but also strengthening existing health and community systems linked with advocacy and capacity building, increased the impact and sustainability of the efforts.

Community systems can play a crucial role in strengthening existing health systems—through creating informed demand, capacity building of healthcare providers, improving referrals and sensitisation to make services more accessible to key populations.

# Achievements and Impact, based on a social audit and ongoing monitoring and evaluation of the project:

- Increased knowledge of SRH issues among support group members and their families
- Increased knowledge of existing health services and their locations
- Increased health seeking behaviour for symptoms related to STIs and RTIs
- Increased number of referrals of high risk deliveries to healthcare services
- Increase in reported condom use
- Increased number of pregnancies registered with the health system and in the number of women accessing ANC services and counselling
- Improved access to commodities and supplies as demonstrated by take-up from community-based outlets
- Increased sense of community and support among members of support groups, in particular among PLHIV
- Expressed recognition of and support from Mahila Panchayat members for women's SRHR and incorporation of related issued into legal aid services
- Community leaders working as proactive advocates, facilitating and supporting community members to access services, including in cases of deliveries
- Increased number of referrals from general health services to HIV testing and treatment services
- Increased number of women voluntarily accessing HIV testing and PPTCT services.
- Improved coordination between various health services

Name of Child: M. Melody Devi Sex: Female Age (March 2009): 10 years Place: Moirang College, Mairembam Leikai, Bishnupur, Manipur Sub Recipient: SASO Sub-Sub Recipient: Dedicated People's Union (DPU)

Melody's is HIV positive. Her deceased father was an injecting drug user. Melody's both parents were HIV positive. She became an orphan in January 2009, a month before she was registered in CHAHA programme.

A shy and reticent girl, Melody is studying in Class V. She stays with her elder brother Kingson, 12, and grandmother, 85. While Melody wants to become a doctor, her brother wants to become an officer in the Indian army.

# Year 2009

Kingson said in a demure tone, "I've always been fascinated by the rigours and disciplined life of a soldier. Can there be anything better than a spectacle of a military parade?"

The children seemed shattered with the bereavement of their mother. They told us that they had learnt embroidery from her. The biggest dilemma after losing their parents was how to generate a small income for sustenance from their learned skill at a time, when pursuing studies was also a priority. With a meager family income and an old and ailing grandmother, it wasn't easy to imagine proper care and support for the orphan children. Perhaps the saving grace was their paternal aunt who was scampering up and down between her in-laws' and mother's house to provide physical and emotional support. But it was tough!

The outreach worker from CHAHA realised the children's desire to pursue their dreams and that this would

require continued educational support. She, therefore, entered into a Memorandum of Understanding (MoU) with the local Little Bird School arranging for complete fee exemption for the children. This was perhaps the first programmatic step to a sustainable solution.

The family did not have a ration card for access to cheaper public distribution system (PDS), and death certificate for their parents or their own birth certificates, which are so important for claiming certain rights and entitlements provided by the state. The programme in early 2009 decided to provide additional support on further needs assessment, through various linkages and involving Melody in the children's support group.

In 2009, it seemed pretty obvious that the real test will be when the paternal aunt would be unable to stay longer with these two children She seemed to be preparing the children for the long haul!

# Year 2010

Melody is on pre-ART counselling. She recently reported throat infection, skin rashes and fever and one instance of diarrhea. She was in hospital for a short duration. Melody has been promoted to the next class and so has been her brother, Kingson. Both have been fairly regular to school. Kingson was tested for HIV and was found negative.

The family is convinced that education is crucial to both children. The children have abandoned the idea of earning a livelihood by stitching and embroidery. The Little Bird School continues to provide free education to the children. Both children have also been linked to some or the other NGO in the area. Melody and Kingson are now part of a local children support group and they have greater opportunities to share and learn from other children of their age. Given that the grandmother is too old to provide active care to children, their paternal aunt has moved in the house with her children and spouse. She is helping the family by earning wage labour. She plans to shortly start a small roadside eatery.

In this visit of ours over a period of one year, we found that community level sensitisation has worked well with the family. The children do not face any discrimination at school or the neighbourhood.

We also learned from the programme staff at SR and SSR, linking this family to PDS may be a good beginning but more needs to be done so that the rights and entitlements can be accessed by all such families. Anita, the Programme Coordinator at DPU said, "further to providing direct services, linkages are crucial to enable families' access to government schemes and services."

These crucial discussions apart, Melody reminisced, "I sang on Teacher's Day in my school and was acclaimed for my performance. I really enjoyed it". It seemed that Melody has been true to her name!



# **Advocacy in CHAHA**

A dvocacy and policy work is an integral part of Alliance India to achieve its objectives in India. Central to achieving the objectives is the involvement of Civil Society Organisations (CSOs) and networks, and strengthening their ability to advocate for programmes and policies for the affected population.

In 2009, Alliance India developed an advocacy strategy focusing on two key themes aimed at better implementation of the Children and AIDS Policy Framework developed by NACO and the Ministry of Women and Child Development (MWCD). The policy aims at providing comprehensive care and support services to children living with and affected by HIV.

The themes are:

All children less than five years born to mothers living with HIV, with unknown HIV status or living with HIV, must receive Co-trimoxazole Prophylaxis (CTX) before their ART is started.

Children living with HIV (up to 14 years) should have access to supplementary nutrition through ICDS and Mid-Day Meal scheme.

Alliance India's advocacy efforts for the two themes were aimed at consistently negotiating and lobbying with government departments to implement the policy, and ensuring that the end users have access to services by the end of 2010. NACO realised that this is an important issue for advocacy. Though NACO trained the ART medical officers on CTX provision, it was not monitored well due to supply related issues with regard to CTX.

### Rationale

It is estimated that 70,000 children below the age of 15 are living with HIV and 21,000 children contract HIV every year through mother-to-child transmission (Updated NACO estimates 2007). Most of these children will die before their fifth birthday. Research studies have shown that Pneumocystis Jiroveci Pneumonia (PCP) has been identified as the leading cause of death in infants living with HIV. Due to difficulty in diagnosing HIV in infants, CTX is recommended for all HIV exposed children born to mothers living with HIV, starting at 4-6 weeks after birth and continuing until HIV has been excluded and the infant is no longer at risk of acquiring it through breastfeeding.

The reasons for the slow implementation of CTX include the difference in causation and burden of HIV related infections between well-resourced and resource-limited countries, the potential for drug resistance and the lack of guidelines. Until more recently, there has also been concern over the limited evidence base for the efficacy of CTX, particularly in areas with high levels of bacterial resistance to the drug; recently, more data has become available from



resource limited settings on the efficacy of CTX in reducing morbidity and mortality among adults and children living with HIV (Data on the effectiveness of CTX comes from randomised clinical trials. observational studies cohort and analyses programme from several African countries, India and Thailand). CTX prophylaxis based solely on HIV exposure, without confirmation of HIV status, is likely the only option in resource poor settings and remains a trade-off between possible benefit to the infant, versus the risk of resistance to antibiotics and antimalarials.

According to the Paediatric ART Guidelines developed by NACO, CTX is a simple, well-tolerated and costeffective intervention for PLHIV.

The importance of proper nutrition for children living with HIV, especially those who are on ART, is also an obvious need. Children born to a mother living with HIV are more likely to have low birth weight. CLHIV need extra food for better nutrition to gain weight and counter common infections. However, care and support programmes like CHAHA have their own constraints. For instance, through CHAHA, Alliance India can provide nutrition to only 20% of children. One of the steps taken by Alliance India was working with government systems and facilitating linkages with schemes such as ICDS and government schools where food is provided to children below poverty line.

Considering the above context, situation assessment was conducted in CHAHA implementation areas to understand the provision of CTX to HIV exposed children. It was realised that healthcare providers are hesitant to give CTX to HIV exposed children due to fear of contraindications. Also, there are supply related issues as the drugs should be replenished once in a month. Alliance India decided to advocate with healthcare providers on the benefits of CTX to HIV exposed children, and consistently worked with NACO at national level to support the advocacy work.

## **Activities**

- Monthly data collection on number of children below 18 months, and number of children in 0-6 and 6-14 age groups to track the number of children in the programme area, and number of children referred to services. This data was also used as an evidence to advocate with healthcare providers at district level.
- Regular meetings with ART medical officers, Chief District Programme Officers (CDPO) and teachers, and link these children with ART centres, ICDS and Mid-day meals to access CTX

prophylaxis and supplementary nutrition.

- Meeting district officials/DAPCU, SACS, WCD, National Rural Health Mission (NRHM) and NACO to provide evidence and elicit support to address the above issues.
- Development of IEC material in regional languages on CTX prophylaxis and double nutrition to carry out advocacy activities at district and state levels.
- Focused activities at district level on special events like International Women's Day, Global AIDS Week of Action and World AIDS Day, involving district officials, positive networks and communities.

## **Challenges**

Initially, convincing the healthcare providers took some time due to lack of clarity on the paediatric ART guidelines by them, and lack of confidence among the programme partners to deal with technical issues. These issues were addressed through regular meetings with healthcare providers and through monitoring and technical support visits to the implementing NGOs. These efforts were supported with IEC materials developed in consultation with NACO, which enhanced the confidence level of the programme partners and acceptance by the healthcare providers. Also, the data received from the implementing NGOs was analysed that was used by them during meetings and special events that helped them deal with the healthcare providers confidently about the issue.

### **Progress till Date**

The above activities in CHAHA programme area resulted in increased number of children accessing the services from ART centres, ICDS and government schools. Figure 3 (Page 46) shows the increasing trends in accessing the services by the communities.

The analysis of data from September to December 2009 shows an upward trend in children accessing CTX. The number of children receiving CTX has increased from 21% (September 2009) to 31% (December 2009), which is 10% increase. (This analysis is based on the quarterly targets fixed for

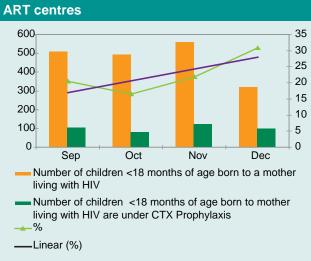
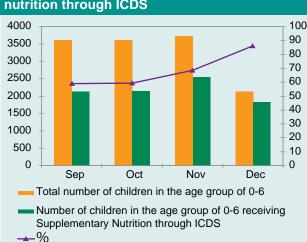


Figure 3: Number of children receiving CTX from

each implementing NGO). The X-axis of the graph shows the number of children and Y-axis shows the percentage increase in children accessing CTX.

This was possible due to the efforts made by Alliance India through service mapping at state and district levels to identify the right people for advocacy and direction provided to the implementing NGOs. Also, the implementing NGOs were trained in basics of and skills in advocacy, which they used by developing state specific advocacy plans. These plans were reviewed quarterly and provided feedback to strategise the advocacy work for greater impact. The ART medical officers were invited to take sessions on CTX for ORWs and counsellors which helped in increased understanding about the issue among the implementing agencies. The coordination between



## Figure 4: Children receiving supplementary nutrition through ICDS

the Accredited Social Health Activist (ASHA) (frontline worker in NRHM), Anganwadi Worker (AWW) (frontline worker in ICDS) and CHAHA ORW in identifying children and referring them for CTX, resulted in increase of children receiving CTX.

Figure 4 shows the number of children registered in the CHAHA programme and number of children receiving supplementary nutrition through ICDS. The number of children receiving supplementary nutrition has increased from 59% (September 2009) to 86% (December 2009) which amounts to 27% increase (This analysis is based on the quarterly targets fixed for each implementing NGO). The X-axis of the graph shows the number of children and Y-axis shows the percentage increase in children accessing supplementary nutrition. Consistent efforts made by Alliance India and its partners in service mapping, establishing good relations with the ICDS officials, participation in the monthly meetings of ICDS projects by the implementing NGOS, and coordination between the AWW, and the CHAHA ORW resulted in increase in the number of children receiving supplementary nutrition.

## Next Steps

While the focus for advocacy in 2009 was sensitising healthcare providers, the focus for 2010 will be on educating the community to generate demand for services. This will be done through capacity building of volunteers, ORWs and counsellors by the implementing NGOs, who will be in direct contact with families. They will identify the pregnant women in the community and provide information on accessing CTX for HIV exposed children, and track the number of children receiving CTX. IEC material will be developed in regional languages to educate the communities. The activities carried out in 2009 will be continued this year along with community education. State level consultations are planned later this year involving stakeholders to disseminate the advocacy work, highlighting that community mobilisation and demand generation is essential for accessing care and support services, and for buy in by the government to continue the service provision to children.

# The South Asia Technical Support Hub: Meeting the Challenges of Providing Technical Support to Civil Society Organisations

he International HIV/AIDS Alliance works on the philosophy of strengthening the capacities of civil society organisations (CSOs) and communities to address their needs, particularly on HIV and AIDS, and also related areas that include SRHR, TB and Health Systems' Strengthening (HSS).

The Alliance recognises that CSOs are the key actors who understand the needs of communities and are actively engaged with them to build their capacities in order to improve their access to healthcare services and meet their basic rights. The importance of civil society is also in bringing different perspectives to forefront and playing a pivotal role in steering the AIDS response.

Recent increases in support to civil society responses towards HIV and AIDS through national and international commitments and funding mechanisms (for instance, the Global Fund and World Bank) has led to challenges in getting this money channelised most effectively, directly to NGOs and CBOs.

The capacity of NGOs and CBOs to be involved in national mechanisms and to deliver quality programmes is variable, requiring both financial and technical support, to ensure an involvement and response that is sustainable, effective and capable of being scaled up.<sup>13</sup>

The Alliance understands this changing scenario and the importance of addressing the emerging challenges of quality programme implementation. To meet such challenge, the Alliance Regional Technical Support Hub (TSH) for South Asia was established in 2008 hosted by Alliance India, to improve access of CSOs to high quality technical support and scaling up national and regional HIV and AIDS responses across the South Asia region. In 2009, the Alliance Secretariat continued to decentralise its technical support function to the Hub. **The Vision** of the TSH is 'to build the capacity of civil society to respond to HIV/AIDS in the South Asia region'.

# Need for providing technical support

It is important to recognise that CSOs will remain at the forefront of AIDS response. However, it is also important to recognise that many of these CSOs have limitations in delivering quality programming and require guidance and technical support.

The South Asia TSH has been able to introspect over the key learnings of providing technical support in the region over the past one year. Some of the key learnings have highlighted that even though civil society understands issues and also recognises that there is a need for capacity building, there are few technical agencies that are able to offer technical support which speaks directly to the communities.

Another important learning is that most of the technical support in the region is centred on programmes funded by big donors, while the technical support available to CSOs revolves around the needs of projects, which often do not have technical support built-in in terms of bridging capacity, skill and quality gaps that often exist. This limits CSOs to implement programmes with limited capacity often resulting in less than optimal impact.

Alliance India prided itself that its contribution to the response was community ownership, consciousness raising, grassroots leadership, constituency building – issues not always on the tip of the tongue of TS purchasers, but issues that are at the heart of sustainability and development.

The niche identified by the Alliance's South Asia TSH is to focus on community mobilisation and community-centred approaches for building capacities of CSOs.

<sup>13</sup> Meeting the challenges of providing financial and technical support to NGOs and CBOs in the context of increased funding, International HIV/AIDS Alliance, Brighton, UK

## Role of South Asia Technical Support Hub in meeting the challenges

The South Asia TSH believes that to meet its vision of providing quality technical support to CSOs, it needs to work on the principles of leveraging from its experiences of implementing and delivering various community-centric programmes for the most-at-risk populations like Orphan and Vulnerable Children (OVC), MSM, IDUs, FSWs and PLHIV. It utilises the expertise of a cadre of TS providers who are mostly community-based practitioners or the communities themselves (apart from the more regular consultants), and uses community-based approaches right from conceptualisation to evaluation of the technical support provided. This may also involve exchange trips, coaching and mentoring besides using more standard approaches of workshops and trainings.

The South Asia TSH follows a multi-pronged strategy to build its regional focus within the South Asia region. The strategy includes nurturing and mentoring civil society in the region, particularly in Bangladesh, Nepal, Bhutan and Maldives, in order to help identify their strengths, provide technical support to overcome weaknesses and enable them to position themselves as key actors in the region for high quality implementation, advocacy and engagement in policy work.

Capacity building of CSOs should help them to recognise their strengths, build a common perspective to address their issues and strengthen systems. The ultimate objective of the technical support provided through the Hub is to strengthen leadership and capacity of PLHIV and key populations most affected by the epidemic, and to meaningfully engage in the AIDS response at all levels.

## Way forward

The strategies outlined above can be achieved only if the Hub takes a pragmatic approach in identifying potential donors and organisations that are inclined to work with the Hub on a long-term basis. The Hub also realises that while short-term assignments could be important and generate resources, it would be more impactful to engage in long-term strategic initiatives playing to its core strengths.



The South Asia TSH is in the process of developing a cadre of key TS providers who have a strong community focus and good understanding of the grassroots implementation realities. This will not only help CSOs to get the technical support they need but also ensure quality by following quality standards for technical support which Alliance India has developed.

The South Asia TSH will work on the philosophy of south-south cooperation, where the TS providers are preferably from the region and have substantial experience in the implementation of communitycentred projects. Toolkits and Best Practice guides developed by the Alliance will be key resources that will guide the technical support to ensure quality and standardisation.

The Hub has developed and begun deploying a rigorous Quality Assurance (QA) mechanism that spans the project lifecycle through planning, delivery, evaluation and follow-up. These quality tools will be the benchmarks for all technical support assignments.

The TSH will also work with donors such as the Global Fund (GFATM), UN agencies and other bilateral agencies as they are recognised as important drivers in shaping national programmes and policies through increased investment in technical support, in the scenario where actual implementation of programmes shifts to the government. Working with these donor agencies will also help influence their perspectives on the need and added value of technical support based on an approach which is cognizant and inclusive of communities and community-based practitioners, which is also Alliance India's approach in technical support provision.

This approach will also help the South Asia TSH to identify its niche and help establish itself as a premier organisation focused on providing quality technical support to build sustainable capacities within CSOs in the South Asia region.

The most crucial point that came from reflection on our learning of providing TS in 2009 was that our criteria for success should not be the number of assignments run but the nature of the assignments; and confidence that the TS really did contribute to greater civil society capacity and community ownership in the HIV response. Name of the Children: Raman and Laxmanan (twin brothers) Sex: Male Age (March 2009): 10 years Place: Puddukotai, Tamil Nadu Sub Recipient – TASSOS Sub-Sub Recipient - TMSSS

Raman and Laxmanan are twin brothers affected by HIV, and study in a local government school. Their mother, Parvathi, passed away in 2007, and they lost their 5-years old sister to AIDS in 2008. Their father, Karppiah is 31 years old and is HIV positive.

# Year 2009

The grandparents were worried that they do not quite understand what is happening around them or perhaps nobody is telling them the problem. The responsibility of providing care and support to the two young kids was not easy for them. The grief of losing a young daughterin-law followed by the loss of a grand-daughter were too much to bear for the old couple.

The grandparents worked as labourers. But their income was far from enough to support the family. We did not meet their son, Karppiah, as he had almost abandoned the family. But his parents informed us that his income was practically of no help. Also, his dependence on alcohol further exacerbated the economic situation in the family. In 2009, the children were difficult to be engaged in a conversation. Perhaps the scars of loss of their mother and younger sister, indifference from their father, and extreme poverty, had a telling effect on their psychosocial well-being. We saw both of them shirtless and were told that they wear a shirt and slippers only when they go to school.

The overall well-being of the twins and their primary caregivers was marked by extreme vulnerability owing to extreme family poverty, in that year.

# Year 2010

The children and the family continue to be in a state of distress. This is despite the fact that the CHAHA programme continued to provide nutrition, household and income generation support to the family. Our volunteer photographer, Donna, originally a medical Doctor, checked the twins and said that they are malnourished and perhaps anaemic. This was confirmed when Raman confided that they do not get enough to eat-"When the school is closed, my grandmother provides us some boiled rice once in the day that we eat with water. We get to eat vegetables once in a week. We look forward to go to school as we get mid-day meals there."

The extent of poverty facing the family translates into an issue of survival with dignity. Hunger and malnutrition are stark realities that this family faces along with countless others in different parts of the country. The grandparents reported that even with a BPL (Below Poverty Line) card, they are unable to access rice (Rs. 1 per kg) provided by the government. "We do not have enough money to lift our full monthly quota of grains from the PDS (public distribution system)", said the frail-looking grandfather. This is true even as CHAHA has stepped up its efforts through the provision of a goat under IGP. The family

now owns three goats from the one given under CHAHA.

The psychosocial impact of happenings around them has left the children shattered. "This morning my grandmother was beaten up in our presence by a woman in the neighbourhood. This is emotionally very disturbing for us", he said with an alarm.

## Epilogue

It would be a shame if this case is seen as depiction of hungry and malnourished people as examples of indolent and passive beneficiaries and not citizens imbued with strong spirit. This should, in fact, spur more action and strengthen a case for concerted action, from both government and civil society.

The challenges facing OVC (orphan and vulnerable children) in neighbourhood, families and in institutional settings like school are multi-faceted. There may not be easy answers and quick-fix solutions to intricate issues of survival, emotional well-being and sustainable care and support yet it is a challenge that requires projects and programmes to sit back and take notice.



# **Information Updates**

## SETU – Sharing Learning

Alliance India's virtual resource centre, SETU, was designed with the purpose of being a Virtual Resource Centre in 2006. For three years, it served as a one-stop shop for anybody looking for resources on HIV/AIDS in India and recorded close to 30,000 visitors with more than 80,000 page views. Meanwhile, Alliance India was expanding its vision, and the nature of the response was changing with greater focus on TB, SRH, HSS and the shrinking health financing owing to the global recession. Alliance India also became host to the Regional TSH for the South Asia region to support civil society development in South Asia, with the core purpose of building national and regional capacity to respond effectively to HIV/AIDS.

In 2009, keeping with the changing needs of the organisation and the context we work in, SETU was revamped and its scope expanded to becoming a South Asian knowledge portal and a dynamic forum for knowledge sharing. It also has a thematic focus on TB, drug use, children, care and support, HSS and Health Financing apart from the expanded geographical focus on Afghanistan, Pakistan, India, Nepal, Bhutan, Bangladesh, Myanmar, Sri Lanka and Maldives.

The objective of the new SETU is to become The Hub for all South Asian resources, discussions and to become a 'one-stop-shop' of technical support (resources, publications, training, knowledge sharing, links to other websites et al) for NGOs and CBOs in South Asia. It is a dynamic and buzzing portal for dialogue, knowledge sharing, showcasing Alliance India's work, learning and achievements. It will also aim to help policymakers (national, regional and global) by disseminating our research findings, facilitating discussions on pertinent and relatively untouched issues like female anal sex, and economic rehabilitation for FIDUs. It is mainly aimed at developing an open, networked and informed society that can use knowledge to make change and has been conceptualised as a people's portal which will be expanded in various phases to include collaborative features for active collation and exchange of data, research and information from people working in the field, in organisations, with government departments and with donors.



The primary audience for the new SETU is: NGOs, CBOs and experts in South Asia—to contribute in the discussion forums, posting their own experiences, sharing their knowledge and seeking/providing technical services, and international donors and policymakers (including governments, donor agencies such as UN, Global Fund, World Bank and DFID) who work on HIV and other public health issues – for content sharing, fundraising and developing linkages.

The new SETU has been developed using Drupal, an open source content management system that allows users to easily publish, manage and organise their content. The choice of an open source platform for SETU reflects the strong belief that knowledge must be widely accessible and freely shared between a vibrant community of knowledge providers and seekers.

Please visit our new knowledge portal for South Asia, SETU, at <u>www.aidsallianceindia.net</u>, and join our discussions, access the resources and read more about Alliance India's work.

## Web-Based CHAHA CMIS Software

Monitoring and Evaluation (M&E) being a key component of the CHAHA programme, the monitoring system in CHAHA was initially based on various records and registers maintained at the implementing NGOs' level (SSRs), and data was reported through excel format to SRs and then to Alliance India, the Principal Recipient (PR). A need was felt to monitor and track the status of each and every activity till the end of project duration for effective programming. Therefore, in 2009, Alliance India introduced and developed a software for the CHAHA M&E system to track and record the information. The web-based Management Information System (MIS) platform was launched in September 2009. The outputs from the software are:

- Tracking of all registered children in CHAHA and services provided to them at each level (SSR, SR and PR).
- Generating timely and consistent feedback at SSR level to specify the need of each child for better and effective management of the programme.
- Reviewing progress of the programme at any point of time (irrespective of ending of a quarter) and providing specific feedback.
- Providing quality (error free), consistent and timely data flow from SSR to SR and then to PR.

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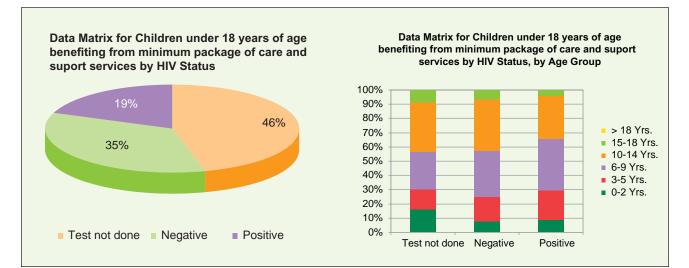
Supporting community action on AIDS in developing countries

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M&E Data Checklist	20/06/2009	07-Mamta	40-K	ripa	D-Gracy Nazareth	Ajay Dhotre	Informed mother about his se	none	Follow up	
SSR Quarterly Plan							lection and asked their need		schedule	d.
Output and Reports	19/03/2009	07-Mamta	40-K	ripa	D-Gracy Nazareth	Ajay Dhotre	to provide support	given school	Follow up	E/ 1
Registration Register								fees worth	schedule	
Registration Summary								Rs.3 42 under	for next month	
Individual Child Register								education	monut	
Referral Register		52552	18.60		0.000	1		support		-
Counseling Register	07/03/2009	07-Mamta	40-K	ripa	D-Gracy Nazareth	Ajay Dhotre	Informed mother about his se lection and asked their need	none	Follow up	
Direct Support Register							s.		Solieouie	-
Weekly Meeting Checklist	20/01/2009	07-Mamta	40-K	ripa	D-Gracy Nazareth	Ajay Dhotre	Alliance survey growth moni	none	Follow up	
Staff Movement Register	09/01/2009	07-Mamta	40-K)		D-Gracy Nazareth	Alexy Diverse	toring study Confirmed about optimal use		schedule Follow up	
Meeting Register	09/01/2009	U/-Mamta	40-10	ripa	D-Gracy Nazareth	Ajay Dhotre	of services.	none	schedule	
Child Support Group Meeting	17/12/2008	07-Mamta	40-K	ripa	D-Gracy Nazareth	Ajay Dhotre	follow up visit	none		0
Register	23/10/2008	07-Mamta	40-K	ripa	D-Gracy Nazareth	Ajay Dhotre	to provide support	given rations		
Grants and Expenditure								worth Rs.163	schedule	d.
SSR Quarterly Report								u nder nutrition		
M&E Data Checklist								support		
SSR Compiled Report	15/10/2008	07-Mamta	40-K	ripa	D-Gracy Nazareth	Ajay Dhotre	Informed about his selection in the 6th quarter and aske	none	Follow up	
Individual Child Lifecycle							d their needs.		schedule	
Child Tracking Sheet	22/09/2008	07-Mamta	40-K	ripa	D-Gracy Nazareth	Ajay Dhotre	follow up visit	none		E
Query	25/08/2008	07-Mamta	40-K	ripa	D-Gracy Nazareth	Ajay Dhotre	Informed mother about his se	none	Follow up	
■ To Do							lection and asked their need s.		schedule	
	12/08/2008	07-Mamta	40-K	ripa	D-Gracy Nazareth	Ajay Dhotre	follow up visit	none		6
	<u>11/07/2008</u>	07-Mamta	40-K		D-Gracy Nazareth	Ajay Dhotre	Confirmed about optimal use of services.	none	Follow up schedule	d
	30/06/2008	07-Mamta	40-K	rina	D-Gracy Nazareth	Aizy Dhotre	to provide support	aiven rations	Eoliow up	E

As an example of the data generated from the software, the chart in Figure 5 generated from the software, shows the distribution of children according to their HIV status and by age group. These are self-generated figures that can be produced at any level

of the software to provide implementers with more insights.

This allows the implementing NGOs to focus on increasing testing among children.



The CHAHA CMIS software can be accessed at www.chahacmis.org

# India HIV/AIDS Alliance Accredited to the International HIV/AIDS Alliance, 2009-13

The Alliance is a network of organisations working towards a common vision of a world in which people do not die of AIDS. The Alliance has its presence in 40 countries working through a model of linking organisations (LO), which are local NGOs, HIV and AIDS being either their exclusive focus or a component within various programmes.

All of the LOs and partners within the Alliance have to pass the accreditation process. This allows all LOs of the Alliance, their donors and their partners, to feel confident of a quality assurance that comes with the Alliance Brand. The system assesses Alliance member organisations against high institutional and programmatic standards to improve their HIV responses and accountability to the communities they serve. It is also used to assess organisations seeking membership of the Alliance.

The accreditation process is a tool which consists of 10 Components, 38 Standards, and 157 Criteria. Under each standard, the criteria are segregated into essential and desirable categories. For an organisation to pass the accreditation, it is mandatory to meet the essential criteria and a majority of the desirable criteria. For a new organisation to be part of the Alliance, it is necessary to go through the accreditation process.

The process begins with the completion of a Self-Assessment Form (SAT) which is submitted to the Assessment unit at International HIV/AIDS Alliance Secretariat in U.K. A review team is then constituted comprising three members with different areas of expertise, for instance, Programme, Finance, Policy and Governance. The field review team then visits the organisation and meets a wide range of stakeholders ranging from government, communities, implementing partners and donors. Subsequent to the visit, the team submits a detailed report to the accreditation committee. The decision to accredit or not, rests with the accreditation committee which has representatives from LOs.

On being accredited, the organisation gets a certificate and is entitled to use the partnership logo

#### Accreditation Structure

In order to be accredited to the Alliance, each LO and the secretariat must meet all the 38 standards. A standard is met by meeting all 'essential' criteria and a majority of 'desirable' criteria in the standard 10 COMPONENTS 10 COMPONENTS 38 STANDARDS Stan expenses 157 CRITERIA

#### **The Components**

- 1. Governance
- 2. Strategic planning
- 3. Alliance Values
- 4. Programmes
- 5. Monitoring and evaluation
- 6. Policy, advocacy, networking
- 7. Financial Management
- 8. Resource mobilisation
- 9. Human resources and security
- 10. Communication, knowledge sharing, information technology

**Standards** are statements about expected quality. Each standards has a number of criteria

**Criteria** are used to measure whether a standard is being met. Criteria are either 'essential' or 'desirable'

alongside their organisational logo. The accreditation is equivalent to the ISO (International Organisation for Standardisation) certification obtained by Industries which indicates adherence to minimum standards by an organisation.

In India, there are four LOs, one state partner, one project office at Hyderabad (AP) and a Secretariat in Delhi. In 2009, Alliance India Secretariat in Delhi underwent the process. It took the Delhi Secretariat over nine months to prepare and be assessed. The review team visited Delhi in November 2009 for four days and reviewed documents and met staff and partners. The team found that Alliance India met all 38 standards and fulfilled majority of the desirable

criteria required for an organisation to be accredited.

On December 18, 2009, the Alliance India Secretariat was successfully accredited into the Alliance. The process allowed us to reflect on our performance and to update our systems. It also allowed us to see ourselves through the perspective of other stakeholders and ensure that our practice reflects our policies. Ultimately, we hope the process will help build confidence in donors and partners in Alliance India's capacity.

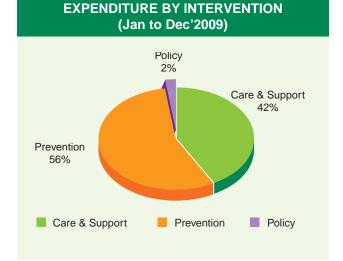
If you wish to refer to accreditation documents, please visit our website at: <u>https://intranet.aidsalliance.org/</u>global/projects/accreditation/default.aspx

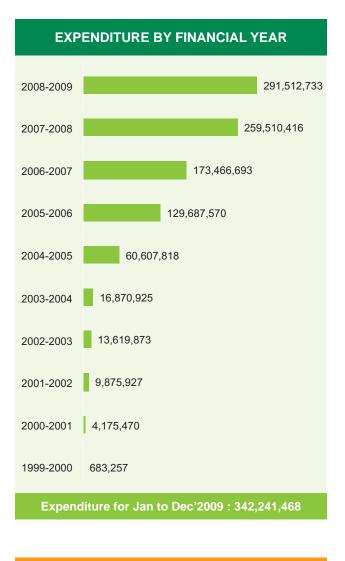
# **Financial Summary**

The Income of India HIV/AIDS Alliance has grown significantly from 2007 onwards, and we are grateful to all our donors for showing this level of commitment. Expenditure at the end of December 2009 stood at more than INR 342 million, allowing us to increase grants to partner organisations to the tune of 68% during January to December 2009.

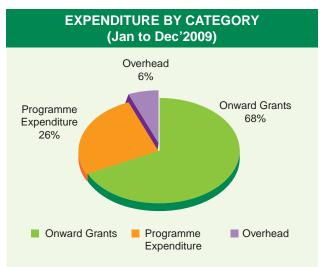
The major funding has been from restricted source while the proportion of flexible funding that the Alliance has received has decreased over time.

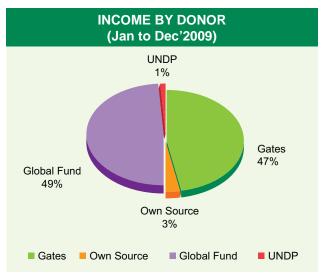
The increase in funding has helped expand our programme reach and area of operations.





**CURRENCY: INDIAN NATIONAL RUPEE (INR)** 





# **Resources and Publications**

#### **Study Reports**

Facilitating HIV Testing and Disclosure for Children and Adolescents

Based on an Operational Research conducted in Andhra Pradesh and Manipur, the report discusses the barriers and challenges in facilitating testing and disclosure for children in 0-6, 7-14 and 15-18 age groups, and puts forth recommendation and action agenda for the same.



rs to Sustainable Access of an and Families



Barriers to Sustainable Access of Children and Families to ART Centres in Rural India Barriers to Sustainable Access of Children

and Families to ART Centres in Urban India

Both the reports bring out the barriers that children and families face in accessing ART centres in rural and ctively as the titles suggest

urban India, respectively, as the titles suggest. The study, conducted in Maharashtra and Manipur, puts forth solutions as well.

# Stories of Significance: Understanding Change through Community Voices and Articulations



The report provides findings from a participatory evaluation conducted with children and their caregivers in the CHAHA programme, by means of the 'Most Significant Change' technique. The study explored the change in the overall quality of life of the community through a process of 'significant change' story collection and story selection.

#### **Policy/Issue Briefs**



Breaking Barriers: Facilitating HIV Testing and Disclosure for Children and Adolescents

Breaking Barriers: Improved Access to ART Centres is key to the Fight against HIV/ AIDS

Providing practical action agenda, both the policy briefs are crisp evidence-base for advocacy with the government.



#### A Blind Spot in HIV Prevention – Female Anal Sex

This Issue Brief is based on insights drawn from a number of relevant studies and publications from India and other places around the world, on anal sex among FSWs, and supplements it with findings from interviews and discussions with sex workers conducted in the city of Hyderabad and two sites in the rural district of Nalgonda, in Andhra Pradesh.

### **Toolkits**

#### All Together Now! Community Mobilisation for HIV/AIDS (Hindi)

Adapted into Hindi to help organisations use it for Indian communities, this toolkit is about how to mobilise communities for HIV/AIDS prevention, care, support and treatment, and impact mitigation.



# Tools Together Now – 100 participatory tools to mobilise communities for HIV/AIDS (Hindi)



Adapted into Hindi to help organisations use it for Indian communities, this toolkit provides some 100 PLA tools that can be used for mobilising communities with regard to HIV/AIDS.

#### The Magic Bus – A Flipbook on Basics of HIV/AIDS

It is an illustrative flipbook that helps children to learn the basics of HIV/ AIDS and its treatment. It beautifully weaves stories in simple language using cartoons that a facilitator can use to build awareness. The flipbook is also available in Marathi, Telugu and Tamil versions.



#### The Magic Place – At the ICTC and ART Centre



Its is an illustrative flipbook that helps children to learn beyond basics of HIV/ AIDS and includes HIV testing, living with HIV, importance of nutrition, treatment and adherence, amongst others.

#### Newsletters

#### Together Now, Issues 2 and 3



Two issues of the bi-annual newsletter were produced in the year. The second issue (April 2009) was based on the theme, 'Psycho-social Support', while the third issue (December 2009) was based on 'Community Mobilisation' as the theme. Both the issues, in their respective themes, focused on the experience of Alliance India in various projects and programmes, discussions on various approaches, and a critical inquiry into its own work.

To access all the above resources and <u>Aliane</u><sup>®</sup> publications and others, please log on to our knowledge portal for South Asia, SETU, at www.aidsallianceindia.net; or to order hard copies, please write to setu@allianceindia. org



# **Linking Organisations**



#### Lepra Society, Andhra Pradesh

LEPRA Society was established in 1988 as an Indian partner of LEPRA, a UK-based charity serving the needs of people affected by leprosy. As leprosy

has become less common, the Society has broadened its reach to address tuberculosis, malaria, disabilities and HIV. LEPRA Society runs numerous HIV-related programmes in Andhra Pradesh and Orissa on the eastern coast of India. These are: the Avahan initiative funded by the Bill & Melinda Gates Foundation; the AP Counsellors project, in collaboration with the Andhra Pradesh State AIDS Control Society and UNICEF, which supports quality counselling services in more than 300 centres for HIV testing and preventing parent-to-child transmission of HIV; and the PPTCT plus project that works to enhance access to HIV services among the general population and promote follow-up services for HIV-positive women in eight districts of Andhra Pradesh, covering more than 5,000 villages. Currently, Alliance India and Lepra, together, run the CHAHA programme in Andhra Pradesh.

#### Contact details:

LEPRA Society Post Box No.1518, Krishnapuri Colony, West Marredpally, Secunderabad 500 026, Andhra Pradesh, India TEL: +91 40 2780 2139/2780 7314 FAX: +91 40 2780 1391 EMAIL: info@leprasociety.org WEB: www.lepraindia.org



#### MAMTA Health Institute for Mother and Child, Delhi

MAMTA, a national nongovernmental organisation, has been working since 1990 with vulnerable communities of women, children and adolescents to address their health and development

concerns. It works through networking, capacity building, direct intervention, advocacy and research in close association with the Government and public health systems, civil society, research institutions and the community at large. MAMTA has built the capacity of over 150 CBOs in 11 states on issues related to SRH, HIV/AIDS and care and support, with a special focus on young people, children and women. It has also contributed significantly to policy and programme formulation at state and national levels especially on the issue of HIV/AIDS. Mamta is working in partnership with Alliance India for providing care and support to children and families living with or affected with HIV/AIDS. Maharashtra is one of the high prevalent states of HIV. The programme (CHAHA) is being run in Nagpur, Amravati, Thane and Chandrapur districts of Maharashtra with the six partner organisations of Mamta.

#### MAMTA HIV/AIDS & TB projects

SI. No	Name of the Project	Duration	Supporting Agency	Geographical Reach
1	Community Based Care & Support	2001- 2010	Abbott Fund- USA	Delhi (Slum based)
2	СНАНА	2007- 2011	India HIV/ AIDS Alliance Global Fund Round 6	Maharashtra-4 Districts Nagpur, Amaravati, Chandrapur and Thane
3	ACSM Project TB-Advocacy, Communication & Social Mobilization.	2009- 2011	UNION/World vision USAID	Bihar- Jamui, Aurangabad, Begusari, Gopalgand,Kaimur and Khagaria
4	Targeted Intervention Project-MSM		DSACS/ NACO	East Delhi: Seelampur
5	Composite TI Project MSM & FSW		HSACS/ NACO	Mewat district- Haryana
6	North East "Capacity building initiatives for CSOs"	2009- 2010	UNAIDS	North East Region: Assam, Meghalaya, Mizoram, Manipur and Nagaland.

#### Contact details:

MAMTA Health Institute for Mother and Child (MAMTA) B-5, Greater Kailash Enclave-II, New Delhi 110048, India TEL: +91 11 2922 0210, 2922 0230 FAX: +91 11 2922 0575

EMAIL: mamta@ndf.vsnl.net.in

WEB: www.mamta-himc.org/



#### Palmyrah Workers Development Society (PWDS), Tamil Nadu

PWDS is a community development organisation based in Tamil Nadu, Southern India. Since 1977, PWDS has been providing integrated

services in the areas of health, income generation, women's issues, rural development, education and habitat. PWDS views HIV not only as a health issue, but as a development issue that should be addressed with a development agenda.

PWDS's home and community-based care and support

project – the first of its kind in Tamil Nadu – is implemented by eighteen partner organisations in ten districts, in partnership with Alliance India with funding from Abbott Laboratories. In 2001-2008, the project reached more than 22,000 people living with HIV, affected children and their families.

PWDS implements the CHAHA programme in ten districts of Tamil Nadu to reduce the impact of HIV on children and families.

#### Contact details:

**PWDS** 

Crystal Street, Marthandam. 629165, Kanyakumari District, Tamil Nadu, India TEL: + 91 4651 270 241, 273 942 FAX: + 91 4561 270 138 EMAIL: palmarts@sancharnet.in WEB: www.pwds.org



#### Vasavya Mahila Mandali (VMM), Andhra Pradesh

VMM has been working to help women, children and youth in Andhra Pradesh, southern India since 1969. It implements HIV-related programmes in ten districts, mainly centred on the

needs of women living with HIV, young people, maternal and child health, safe motherhood, integration of HIV services into the wider sexual and reproductive health field, trafficking, domestic violence and harassment.

VMM supports a network of non-governmental organisations, community-based groups, associations of people living with HIV and government hospital staff to provide comprehensive HIV-related services.

In CHAHA, VMM with its six SSRs has registered 3606 children and all children availed support services on need based till December 2009.

Services	Children affected by HIV	Children living with HIV
Children registered	3117	489
Nutrition	1188	254
Education	501	75
OI treatment	0	137
Referral to ART	0	143
IGP	40	18
Referral to Social welfare sche	emes	
Widow pension plan	278	
Old age pension plans	78	
Housing schemes	84	
Disabled pension	4	

#### Contact details:

Vasavya Mahila Mandali (VMM) Atheist Centre, Benz Circle, Vijayawada 520 010 Andhra Pradesh, India TEL: +91 866 247 0966, 247 3056, 248 9784 FAX: +91 866 247 03056 EMAIL: vasavyamm@sify.com WEB: www.vasavya.com

## **State Partner**



#### Social Awareness Service Organisation (SASO), Manipur

SASO was formed in 1991 by a group of former injecting drug users (IDUs) seeking to lessen the impact of drug use in Manipur and other parts of Northeast

India. SASO provides home and community-based care and support to IDUs and their families. MSM, and others affected by HIV. It focusses on addressing the economic, social and human impact of the HIV/AIDS epidemic in relation to drug use, through advocacy and increasing awareness on social, gender and human rights issues. Activities include needlesyringe exchange programmes, oral substitution theraphy, condom promotion. STI management, support groups and communication campaigns. Some of these interventions are specifically tailored to the needs of female injecting drug users. To increase the accessibility affordability of services. SASO has established community-based drop-in-centres linked to health clinics, and a night shelter for vulnerable and homeless IDUs. SASO's programme approach to community participation and local leadership has led to increased community involvement and greater acceptance of IDUs and people living with HIV. The organisation won the UNAIDS Civil Society Award in 2006.

Contact details: Social Awareness Service Organisation Uripok Sinam Leikai, Opp. Common School Imphal - 795001, Manipur Telephone: 0385-2411408/2414011 Fax: 0385 - 2411409 E-mail: saso.imp@gmail.com, sasoimph@rediffmail.com

# **Our Partners**

#### **CHAHA Programme**

#### Andhra Pradesh

#### LEPRA Society Sub Recipient Sub-Sub Recipients

GRAM Abhyudaya Mandali Peoples Action for creative education Hyderabad Leprosy Control and health society Divya Disha Ravicherla Integrated Development and Educational society Women's Organisation for Rural Development

#### Vasavya Mahila Mandali (VMM) Sub Recipient

#### Sub-Sub Recipients

Deepthi Socio Educational Society Gramasiri Rural Activities in National Development Society Youth Club of Bejjipuram Green Vision ARDAR (Association for Rural Development and Action Research Rural Environment and Education Development Society

#### Plan India - Sub Recipient

#### Sub-Sub Recipients Arthik Samata Mandal Janakalyan Welfare Society Rural Energy for Environment Development Society GUIDE Society for Help Entire Lower & Rural People Social Activities for Rural Development Society Chaitany Jyothi Welfare Society

#### Alliance for AIDS Action Sub Recipient Sub-Sub Recipients

Rural Education and Community Health Lodi Multipurpose Social Service Society Jagruthi

#### Maharashtra

#### MAMTA-HIMC Sub Recipient

#### Sub-Sub Recipients

Bharatiya Adim Jati Sevak Sangh RTM SAP Mandal Janhitay Mandal Kripa Foundation Jeevan Vikas Sanstha Nagpur Multipurpose Social Service Society

#### Plan India Sub Recipient

#### Sub-Sub Recipients

Committed Communities Development Trust

Community Aid & Sponsorship Programme (CASP)

Network of Maharashtra by people living with HIV/AIDS (NMP+)

#### Sub Recipient

#### Sub-Sub Recipients

Santhome Charitable Trust of Kalyan Sangli Mission Society- Miraj Sangli Mission Society- Kolhapur Sarva Seva Sangh Paramprasad Charitable Society, Satara Paramprasad Charitable Society, Solapur

#### Manipur

#### Social Awareness Service Organisation

#### Sub Recipient Sub-Sub Recipients

Manipur Network of Positive People (MNP+) Dedicated People's Union (DPU) Sneha Bhavan- Imphal East Sneha Bhavan-Chandel Sneha Bhavan – Thoubal

#### **Tamil Nadu**

## Palmyrah Workers Development Society (PWDS) Sub Recipient

#### Sub-Sub Recipients

Anbalavam Centre for Action and Rural Education (CARE) Community Action for Social Transformation (CAST) Centre for Social Reconstruction (CSR) GRAMIUM Native Medicare Charitable Trust (NMCT) Peoples Association for Community Health Education Trust (PACHE Trust) Scientific Educational Development for Community Organization (SEDCO) Society for Rural Development and Protection of Environment (SRDPE) Society for Serving Humanity (SSH) Village Reconstruction and Development Project (VRDP) Women's Organization in Rural Development (WORD)

## Tamil Nadu Social Service Society (TASOSS) Sub Recipient

#### Sub-Sub Recipients

Centre for Education and Empowerment of the Marginalised (CEEMA) Madurai Multipurpose Social Service Society (MMSSS) Tiruchirappalli Multipurpose Social Service Society (TMSSS) Thiruvannamalai Social Service Society (TVMSSS)

#### **Avahan Project**

#### Andhra Pradesh

Alliance India, Andhra Pradesh Lead Partner (Project Office)

#### Implementing NGOs

Centre for Rural Action Chaitanya Rural Education and Development Society

#### THE LEPRA SOCIETY

Mass Education & Organisation Society Spandana Cultural Organisation For Progressive Education Kallumarri Rural Education & Development Societv Rural Integrated Development Society Society for Integrated and Rural Improvement Socio-Economic & Cultural Upliftment In Rural Environment Action for Integrated Rural and Tribal **Development Social Service Society** Association for Needy and Kindle the Illiterate through Action Gram Nava Nirmana Samithi Modern Architects for Rural India Rural Education And Community Health Self Employed Welfare Society Sarvodaya Youth Organisation Jagruthi PRAGATHI Chaitnya Educational and Rural **Development Society** People's Action for Social Service People's Action In Development **Rural Reconstruction Society** Sneha Society for Rural Reconstruction Serve, Train, Educate People Society Collective Order for Rural Reconstruction Education **KRUSHI SAMSTHA** Forum for Rural Development Jana Jaagriti Human and Natural Resources **Development Society** SAMPURNA

#### Sashakt Project

Uttar Pradesh: India Naz Foundation International, Lucknow West Bengal: Solidarity and Action the HIV Infection in India, Kolkata Maharashtra: Humsafar Trust, Mumbai Tamil Nadu: South India AIDS Action Programme, Chennai

#### **Project Action**

Uttar Pradesh: MAMTA in Uttar Pradesh, implementation in Ettawa and Allahabad Manipur: SASO in Manipur, implementation in Imphal East and West Bangladesh: HASAB in Bangladesh – implementation in Dhaka Sadar, Khulna Sadar, Sylhet Sadar, Rajshahi Sadar

#### Sexual and Reproductive Health Rights (SRHR) and HIV/AIDS Project

Delhi: Child Survival India, Delhi

# **Our Trustees**

**Peter Freeman CBE** (UK) is <u>the Chair of the</u> <u>Alliance's Audit Committee</u>. Before he retired from the Department for International Development he held a number of senior positions, including Director of Multilateral Aid, Director for Africa and Director of Finance and Aid Policy.

**Callisto Madavo** (Zimbabwe) trained as an economist joined the World Bank in 1979. Between 1996 and 2005 he was Vice President for the Africa region, responsible for directing Bank activities in 25 sub-Saharan African countries.

**Nafis Sadik** (Pakistan) served as Executive Director of the United Nations Population Fund, with the rank of Under-Secretary-General, from 1987 to 2000. A physician by training, she is currently the UN Secretary-General's Special Envoy for HIV/AIDS in Asia and the Pacific.

**Steven Sinding** (USA) is <u>Chair of the Alliance Board</u>. He was formerly the Director General of the International Planned Parenthood Federation and is a professor at Columbia University. Prior to his time at IPPF, he was director of the Population Sciences programme at the Rockefeller Foundation.

Jens Van Roey (Belgium) has long experience in health care at district level in resource-poor settings, and for many years has been active as a technical advisor on HIV/AIDS programmes at community, national and international level. He is currently Medical Advisor for HIV/AIDS to the Médecins Sans Frontières Access Campaign.

Jan Cedergren (Sweden) has worked in development cooperation for almost 40 years. He has been Director of Operations Department, OHCHR (United Nations Office of the High Commissioner for Human Rights), Director General for International Development Cooperation, Swedish Ministry for Foreign Affairs and Deputy Director General. Jan has travelled extensively in Africa, Asia and Latin America.

**Carole Presern** (UK) has more than 25 years experience in governance, management, international health policy and health in developing countries. She has worked for the UK Foreign and Commonwealth Office and the UK Department for International Development on issues including health and AIDS policy, human rights, policy development and managed diverse health programs. She has been a UK board member for the Global Fund to Fight AIDS, Tuberculosis and Malaria, and of UNITAID.

**Fatimata Sy** (Senegal) is <u>Vice Chair</u> of the secretariat board and sits on the secretariat's Finance and Audit Committee. She is Liaison with GFATM for the USAID West Africa Regional Office in Ghana and has 20 years experience in development and public health programming, including more than 10 years in HIV and AIDS programmes. She has worked for USAID, the World Bank and FHI and has considerable experience in designing, managing and evaluating programmes in several African countries.

**Kevin Ryan** (Australia) is currently the volunteer Project Director of the global HIV education programme, 'Positive Lives' as well as a trustee of the HIV information charity NAM. Kevin was previously a partner on the international board of a leading London law firm and a past president of an international business association. He is HIV positive and combines a professional legal career with work as a volunteer lawyer with a variety of organisations.

**Alvaro Bermejo** (UK) is the Executive Director of the International HIV/AIDS Alliance

## Thanks to

The Global Fund to Fight AIDS, Tuberculosis and Malaria The Bill and Melinda Gates Foundation International HIV/AIDS Alliance UNDP UNAIDS European Commission The Hewlett Foundation National AIDS Control Organisation, Government of India State AIDS Control Societies in Andhra Pradesh, Maharashtra, Tamil Nadu, Manipur and Delhi





Lepra India www.lepraindia.org



Mamta - Health Institute for Mother & Child www.mamta-himc.org



Palmyrah Workers Development Society www.pwds.org





To order copies of this document, please email: setu@allianceindia.org or write to:

#### India HIV/AIDS Alliance

#### Delhi Secretariat

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#### **Project Office**

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