

Supporting Community Action on AIDS



CHAHA
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We are grateful to the National AIDS Control Organisation and State AIDS Control Society officials and staff at tertiary and district ART centres, and NGOs for their cooperation in steering the project ahead.

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For more information on the International HIV/AIDS Alliance and its work in India, please visit our website on www.aidsalliance.org; and to access Alliance India's resources and publications, please visit its virtual resource centre, Setu on www.aidsallianceindia.net, or write to:

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The Alliance in India

The International HIV/AIDS Alliance is a global partnership of nationally-based organisations working to support community action on AIDS in developing countries. The national partners help local community groups and other non-government organisations to take action on AIDS, supported by technical expertise, policy work and fundraising carried out across the Alliance.

The vision of the Alliance is of a world in which people do not die of AIDS. This means a world where communities have brought HIV under control by preventing its transmission, and where they enjoy better health and higher quality of life through access to comprehensive HIV prevention, care, and support and treatment services.

Established in 1999, the India HIV/AIDS Alliance comprises a Secretariat in New Delhi, five lead partner organisations (the Linking Organisations within the global Alliance) and their networks of over 100 community-based non-governmental organisations (NGOs) and community-based organisations (CBOs) across five states – Andhra Pradesh, Tamil Nadu, Manipur, Maharashtra and Delhi. The Alliance's project office in Hyderabad was formally launched in April 2008 as the fifth lead partner (or Linking Organisation) in India. Alliance India has also been working closely with a state partner organisation in Manipur.

In 2007, the Alliance in India supported over 120 community-based projects through its NGO and CBO partners to prevent HIV infection; improve access to HIV treatment, care and support; and lessen the impact of HIV. The last including 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/or affected by HIV.

Funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) was awarded to the Alliance in July 2007, whereby the partnership in India has been broadened to include two new project-based lead partner relationships with two external organisations and their networks of implementing NGO partners.

Abbreviations

AIDS:	Acquired Immuno Deficiency Syndrome
ART:	Anti Retroviral Therapy
CAA:	Children Affected by AIDS
CBO:	Community Based Organisation
CLHIV:	Children Living with HIV
CMIS:	Centralised Management Information System
DAPCU:	District AIDS Prevention and Control Units
DCC:	District level Coordination Committee
GFATM:	Global Fund to Fight AIDS, Tuberculosis and Malaria
HCBCS:	Home and Community-Based Care and Support Programme
HIV:	Human Immuno-deficiency Virus
ICDS:	Integrated Child Development Scheme
ICTC:	Integrated Counselling and Testing Centre
IDU:	Injecting Drug User
IGP:	Income Generation Programme
MSLM:	Mutual Sharing and Learning Meeting
MSM:	Men having Sex with Men
NACO:	National AIDS Control Organisation
NACP:	National AIDS Control Programme
NGO:	Non-Governmental Organisation
OI:	Opportunistic Infection
ORW:	Outreach Worker
PCA:	Participatory Community Assessment
PCR:	Participatory Community Review
PCU:	Programme Coordination Unit
PLHIV:	People Living with HIV
PR:	Principal Recipient
SD:	Strategic Direction
SR:	Sub-Recipient
SRH:	Sexual and Reproductive Health
SSR:	Sub Sub-Recipient

A message from the Country Director

It is a matter of great satisfaction that The Global Fund Round 6 programme titled “CHAHA” (meaning ‘a wish’ in Hindi) has completed its first year of implementation. CHAHA is an expanded child-centred community-based care and support project in line with the strategic priorities of the National AIDS Control Programme Phase III. It operates in the four high prevalence states of Andhra Pradesh, Manipur, Maharashtra and Tamil Nadu. The goal of the project is to reduce HIV related morbidity and mortality in adults and children and to address the impact of HIV on children.

The impact of HIV on children touches all aspects of their lives - employment, education, community standing, dignity as well as health. It can shatter the economic infrastructure of families, resulting in children lacking essentials such as adequate food and shelter. The Outreach Workers of CHAHA encounter on a daily basis children whose lives have become isolated, excluded and further impoverished due to HIV.

CHAHA is about working with children, families and communities to overcome this isolation, exclusion and impoverishment. To address immediate survival needs, CHAHA includes a spectrum of services that supplement nutritional intake, support children getting back to school and alleviate urgent shelter and medical needs. Yet beyond that CHAHA is about promoting inclusion and rights – to health care, to entitlements, to economic independence and community participation.

Our services are often woefully inadequate against the needs we encounter, yet this first year has seen an array of successes in securing access to treatment, to education and to employment. Crucially it has also seen some victories in challenging the stigma and discrimination that so inhibits families affected by HIV.

This Annual Report attempts to cover a range of information about the project: its achievements, lessons learnt and challenges.

I take immense pleasure in putting on record the untiring efforts of all of our partners implementing CHAHA. It is because of their high commitment levels that the project has generated a wealth of experience and knowledge that will in turn lead to more and better support for children in our second year.

I hope that this report will be used widely as a learning document by all those working in the field of HIV, and more particularly by those engaged in care and support services for children and families.

Alexander Matheou

Director

India HIV/AIDS Alliance

Understanding the problem

According to the National AIDS Control Organisation's (NACO) sentinel surveillance of 2007, India is estimated to have a total of 2.5 million PLHIV, with an approximate national adult HIV prevalence of 0.36 per cent. The epidemic is concentrated in some 200 districts, most of which fall in six states – Andhra Pradesh, Karnataka, Maharashtra, Manipur, Nagaland and Tamil Nadu – where HIV-prevalence is more than one percent. Also, these states contribute around 64% of all PLHIV to India.



The 2007 estimates from NACO say that 70,000 children below the age of 15 – or 3.8 per cent – are living with HIV. More than 21,000 children contract HIV every year through parent-to-child transmission. In addition to children living with HIV (CLHIV), there are those who are directly affected by HIV, a result of either the death of their parents or the family trauma due to HIV. Overall,

children who are affected by HIV fall into two categories – CLHIV, and children who have a parent (or two) who are HIV positive, living or dead.

Some AIDS orphans are adopted by their grandparents or extended families, but many are left without any support. Households headed by children are an upcoming feature in some areas, with older children having taken the responsibilities of their siblings and themselves.

In India, in addition to the impact of HIV on the health of children, there are further repercussions. Children affected by HIV face

multiple hardships – not only through losing their parents but also on account of losing them to AIDS, which is often associated with widespread stigma and discrimination. They give up their childhood due to the burden of the family, often giving up school in order to earn and care for their sick parents or their siblings after the death of their parents. AIDS orphans have fewer chances of gaining education and getting access to healthcare.

Care and support response to these children has so far proved quite inadequate, inappropriate and often inaccessible - including with reference to the access to anti-retroviral drugs, Opportunistic Infection (OI) prophylaxis and other health services. This situation remains exacerbated by the widespread stigma and discrimination faced by these children in their schools and communities.

In the light of the prevailing scenario with regard to services and linkages for children living with and/or affected by HIV, the National AIDS Control Programme Phase III (NACP-III) has given importance to scaling up child-focused services. NACP-III plans to do this through measures including early diagnosis and treatment of HIV exposed children; comprehensive guidelines on paediatric HIV care for each level of the health system; special training to counsellors for counselling HIV positive children; linkages with social sector programmes for accessing social support for CLHIV; outreach and transportation subsidies to facilitate anti-retroviral therapy (ART) and follow up; nutritional, educational, recreational and skill development support; and by establishing and enforcing minimum standards of care and protection in institutional, foster care and community-based care systems.

Alliance India's Focus on Children through CHAHA

Acknowledging that the HIV epidemic in India is generating an increasing and disproportionate need for the care and support of CLHIV and those affected by HIV, the India HIV/AIDS Alliance (or Alliance India) initiated an expanded child-centred home and community-based care and support (HCBCS) programme in the year 2007, in line with the strategic priorities of NACP III. The project named CHAHA (meaning 'a wish' in Hindi language), receives funding support from Round 6 of the Global Fund to Fight against AIDS, Tuberculosis and Malaria (GFATM). As a civil society Principal Recipient (PR), Alliance India has been implementing this project along with its consortium of 8 Sub-Recipients (SRs), in the states of Andhra Pradesh, Tamil Nadu, Maharashtra, and Manipur. CHAHA is working closely with different stakeholders and Government Ministries to find ways to help keep children with their parents or extended families. It envisages extending care and support to 64,000 children living with and/or affected by HIV and their families (especially women-headed households), within a span of five years.

Previously, in the year 2000, Alliance India initiated the Abbott Fund-supported HCBCS programme for PLHIV and their families, along with its NGO partners in Tamil Nadu, Andhra Pradesh, and Delhi states. The Alliance has been considered a pioneer in advancing home-based care and support to PLHIV and their families in India. Based on its long experience in care and support programming, Alliance India has reviewed the gap in services for CLHIV and children affected with HIV. Additionally, the key findings from the Baseline Study conducted by Alliance India have helped assess the issues related to affected children and families during the designing of the CHAHA programme.

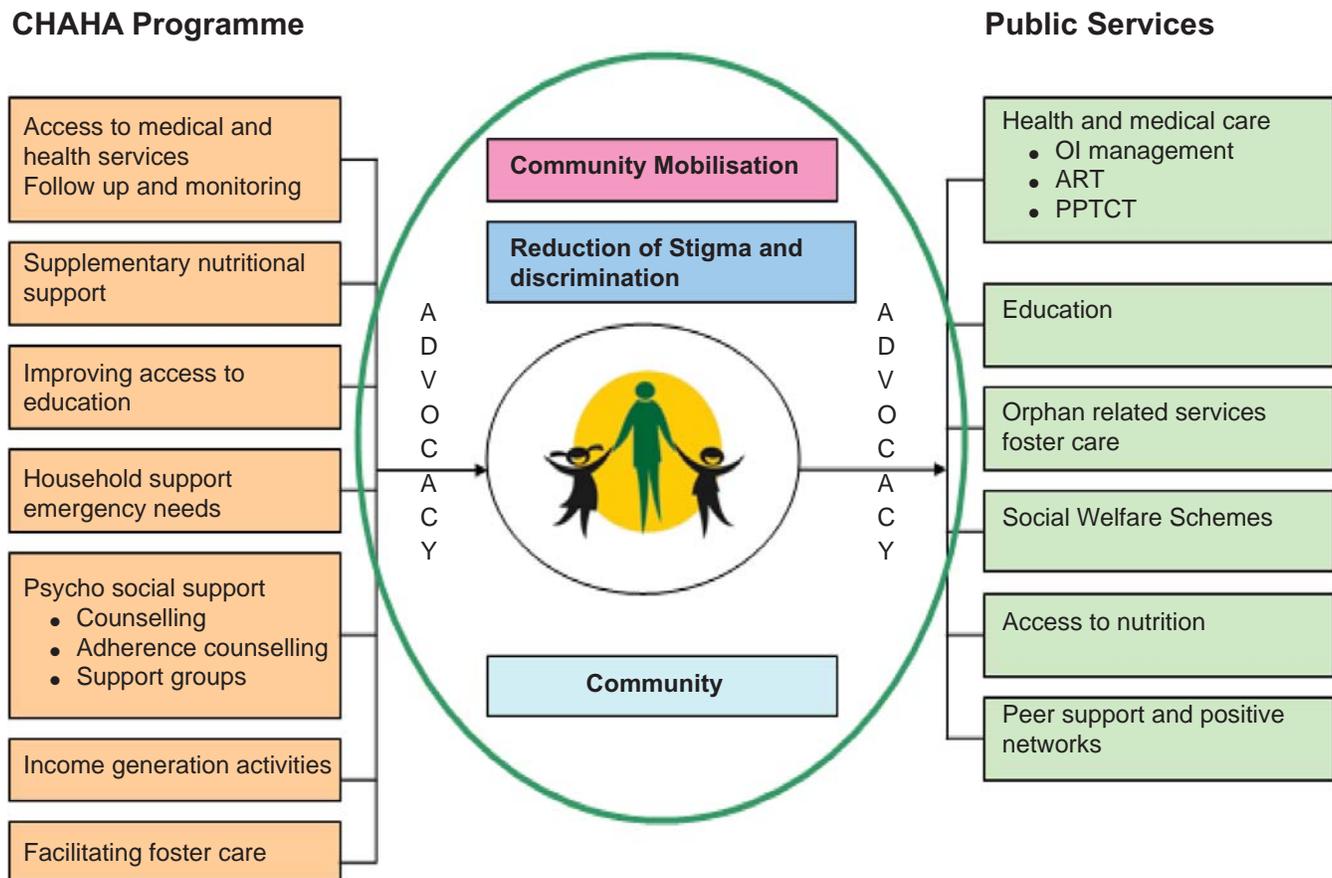
Adopting a holistic approach, CHAHA reaches out to the needs of the children affected by HIV in an integrated manner, as a member of the family, which is also taken as an integral part of the community. This approach is based on the significance that the Alliance attributes to a community-driven response to HIV, with the belief that family involvement and active engagement and leadership of the community is a prerequisite for any HIV intervention.

Baseline Findings, CHAHA Programme, 2007

- More than four fifth of the affected children currently attend schools. More than one tenth of the children reported discrimination while about 1 to 6 percent children were expelled from educational institutions
- A little less than one third of the children reported they receive supplementary food; mostly from their school
- About four fifth of caregivers to CLHIV or CAA are parents
- About one fourth of the caregivers who are living with HIV report that they have experienced discrimination
- About one third of the CLHIV are reportedly taking ARV

This is evident from the fact that communities have been involved in all Alliance India's interventions – from the programme design stage to evaluation through practices such as Participatory Community Assessment/Review (PCA/PCR), formation of support groups and linkages with PLHIV networks, and participatory methods of undertaking programme evaluation, as well as training and capacity building of NGOs and CBOs at the grassroots level.

Figure 1



Keeping affected families at the centre and as part of the community would not only support the effectiveness of services to mitigate the impact of HIV/AIDS in terms of improving health-seeking behaviour, but also create a conducive, non-stigmatised and supportive environment for children and families. Enhanced community action will also empower and enable these

families to take control of their lives, and help facilitate their access to public services as long-term and sustainable structures. Due to the comprehensiveness of the services and support provided to children and their families, the impact focuses on all round development.

The CHAHA programme is providing a comprehensive package of care and support services to the affected children and families through four main strategic directions (SD). These services include the following (*summarised in Figure 1*):

Strategic Directions

- SD1:** To improve care and support services to children living with and/or affected by HIV and AIDS
- SD2:** To create a supportive environment for reducing the stigma and discrimination
- SD3:** To create a supportive environment for strengthening of civil society and institutional capacity building
- SD4:** Information systems and operational research

Improving Access to Healthcare: Limited or lack of accurate information, fear of disclosure, discrimination from healthcare providers, and paucity of resources are reasons enough for affected children and families not to access

the existing health care services available at the district and state level. To address this and improve their health seeking behaviour, the programme on one hand, sensitises service providers at the healthcare centres towards the issues of PLHIV, while on the other the target population are referred and linked to the healthcare systems. These systems include HIV testing, OI prophylaxis and management, ART, prevention of parent to child transmission (PPTCT), Community Care Centres, sexual and reproductive health (SRH) care, and vaccination. A host of outreach workers (ORW) regularly update the target population with healthcare information as well as accompany them to the service providers, and undertake follow-up and monitoring of families. Improving access to services synergises national and Alliance India's efforts towards universal access; and in the case of HIV promotes adherence, and tracks and reduces the number of individuals discontinuing medical treatment, thereby reducing the HIV related morbidity and mortality.

Till June 2008 through CHAHA programme, 99% CAA (8253) has been reached with regard to the set targets of 8333 children.

Nutritional Support: Lack of adequate and balanced nutrition compounds the problem of HIV in terms of response to HIV-related treatment and other health outcomes. In the case of children, the impact is more critical given their added nutritional demands towards growth and overall development. For PLHIV and CLHIV, it increases the risk of OI and prolongs recovery from acute illness. The diminishing ability of parents to earn due to HIV also has a direct bearing on the procurement of food for themselves and their children. Although the Government of India, through its Integrated Child Development Scheme (ICDS), provides nutrition to children in the age group 0-6 years as well as mid-day meals to school going children, this may be insufficient in

comparison to their nutritional requirements. It is especially the case for CLHIV and/or those receiving ART. This gap is being bridged by providing supplementary nutrition to children through CHAHA. Additionally, through nutritional counselling and community-based demonstrations, affected families are given information on the optimum utilisation of limited resources to cook nutritious food, with low-cost and locally available materials.

CHAHA is able to provide supplementary nutrition support directly to 3473 children (CLHIV or CAA), slightly more than the set targets of 3333 children to cater to the high demand from the community.

Education Support: As mentioned before, most children affected by HIV suffer lapses in their formal education as they drop out of schools or become irregular, due to factors like poor health, insufficiency at home and/or loss of parents to AIDS. While the circumstances that force children to drop out of schools vary and need to be addressed holistically, facilitating access to schools and formal education has also required immense efforts by the programme for children who have completely dropped out or are struggling to stay in schools. These efforts have included sensitisation of



Finding a home, away from home...

Nengnu (name changed), 12 and Hengkip (name changed) 14, were born at Moreh in Manipur. Both their parents died due to AIDS related condition in 2003 and 2006 respectively. The father had been an injecting drug user. After the death of their parents, they had no one to support them. As per the custom of the place, one of their fraternal uncles who had no children took them into his home.

While they were at their uncle's home, they were counselled and taken for blood test by an organisation in Moreh. The test indicated Nengnu to be reactive and she was put on ART. One of the CHAHA staff from Sneha Bhavan (Alliance India's SSR) met her at the centre and thought it worthwhile to visit the family for inclusion in the CHAHA programme. On visiting the family, her uncle and aunt told the ORW that both the girls were no longer with them and they did not care where they had gone. After a long search, the staff found them at one of their aunt's (the father's sister) house. An informal discussion with the girls made them reveal that they were made to sell wine till late at night by their uncle and aunt who were also in a habit of beating the girls when drunk. Both sisters also expressed their desire to go to school as they had never attended one.

Nengnu discontinued her ART after they left their uncle's house as she feared he might trace her at the ART centre. The CHAHA staff took her to the ART centre for continuation of her treatment. The staff also interacted with the new caregivers who said they were willing to take care of the children.

An informal meeting was organised with the elders from both the villages where the girls' aunt (current caregiver) and uncle reside. Uncle's consent in a public forum (as per the custom of the land) was essential to ensure that the girls are not troubled in their new caregiver's home. The caregivers and the children are quite happy to be together, the community also has a sense of concern and responsibility for the children. CHAHA programme is providing foster care along with nutrition support to the children after counselling and facilitating admission of the girls to a neighbourhood school.

district and school authorities on HIV issues, advocacy with schools and community to ensure the children the right to attend schools, provision of private tuitions for long-time drop-outs to bring them at par with other children

of the same age and readmit them into the appropriate standard, and provision of books, notebooks, pens, pencils and school uniforms when required. Besides, counselling, nutrition support, household support, income generation support, and various community-mobilisation initiatives also constantly encourage children and families to prevent children's formal education from getting affected.

CHAHA has provided educational support and/or vocational training to 1427 children (CLHIV or CAA), exceeding the set targets of 1333 children to cater to the high demand from the community.



Psycho-Social Support: The impact of HIV on children can be psychologically profound, as

they do not possess the coping mechanisms of adults. Dealing with their issues and expressing themselves require special skills that can be provided to the affected children by the counsellors. Within the programme, periodic need-based counselling is provided by trained counsellors to children and families through one-to-one interactions and home-visits. Additional techniques for children are employed to make them comfortable such as art and craft, pictures and participatory interactive games. The counsellors, trained for the general population as well as specifically for children, are easily available to the community – on the telephone by the ORWs in case of emergencies, and also contactable by families directly when required.

Household Support: The needs of children and families affected by HIV are varied. Household support is needs-based and provided to meet both the emergency and sometimes the basic needs of the families of children. This includes nutrition in dire situations, travel for medical emergencies, funds for hospitalisation and for treatment and diagnostics, and sometimes for last rites for family members who die due to AIDS. Such support not only prolongs the parents' lives but also ensures an improved family atmosphere due to the emotional security and stability gained.

CHAHA has provided household support to 4484 households of CLHIV or CAA, again more than the set targets of 4167.7

Income Generation Activities for Adults: The affected families for most part either suffer deterioration or complete loss of income due to illness or death of parent(s). This leads to an amplification of a host of related concerns as malnutrition and other health problems, loss of education for children, inaccessibility of healthcare, and lack of treatment amongst others. Income generation activities then have been made an important part of the CHAHA



Geeta – A Self Sufficient Tailor

Geeta (name changed) is a 15 year old girl, living with her mother and younger brother in Metpally (Karimnagar district, AP). She lost her father many years ago. The family of 3 members is solely dependent on the mother's income, who works as daily-wage labour. But all the days are not the same. When her mother falls sick, Geeta has to stop going to school and look after her mother and brother. CHAHA identified her during one of her mother's illness bouts. ORWs supported her in looking after her mother and had her join the community care and support centre. Geeta had to stay with her mother till recovery; meanwhile, her name was removed from the school because of absence.

The ORW went to the school to find out the reason for cancelling her admission. Since she was absent for more than 4 months and the annual exams were near, the school administration said it wasn't possible to let her appear for them. They promised that she could join the same class in the following academic year. For the remainder of the academic session CHAHA staff motivated Geeta to explore other options of vocational training. She showed interest in stitching and was provided the requisite support to join a tailoring school to learn the skill during her holidays.

Geeta enjoys her tailoring classes and is happy that she didn't waste her free time. On one of the visits she told the ORW – *"if you could provide some support for purchasing a sewing machine after completion of the tailoring course, I can earn and support my family and my self. I also can take care of my family well, without depending on any body"*.

intervention to help affected families become economically independent and for their all-round development, as well as to decrease their dependence on government systems and programmes. The activities range from trading, flower selling, vegetable vending, to petty shops and other businesses, for which support is managed by the implementing partner in the form of loans, and repayment of the same without any interest and is channeled into a revolving fund. Improved financial status of affected families helps rebuild their self-confidence as they may be otherwise socially excluded.



The CHAHA project is able to provide income generation support to 862 households of CLHIV or CAA, against the set target of 833.

Foster Care: One of the most significant challenges faced by Alliance India in previous care and support interventions has been the growing number of children without family care, as a result of AIDS-related deaths. Although there are government systems and processes in place, most of them rely on institutionalising children in orphanages or stay homes, which today is not a well-accepted strategy as it may

not be in the best interest of the children. Thus, the CHAHA programme is attempting to work closely with government systems to sensitise them about the rights of affected children. Sensitisation of the community members and other stakeholders is also being undertaken. As a result, not only extended families but also families with no relation to the affected child have come forward to take care of children supported by the programme. This demonstrates community potential in taking action to mitigate the impact of HIV, if supported and empowered.

Community Involvement and Mobilisation:

The continuing stigma and discrimination around HIV is a prevailing concern. CLHIV and CAA are either denied admission in schools or forced to drop out due to the HIV positive status of their parents. Healthcare providers discriminate against the PLHIV, manifested in their refusal to treat them or even touch them. It is also hard to find employment due to this nature of discrimination and/or limited opportunities, compounding the economic suffering of affected families. Family or community members also show reluctance in performing funeral rites for those who died of AIDS. As the involvement of the community including the general community is an essential strategy for reducing stigma and discrimination for PLHIV, community mobilisation, awareness and sensitisation, formation and facilitation of children and adult support groups, and linkages with positive networks are some of the important steps being taken in the CHAHA programme.

Various awareness building and sensitisation programmes on HIV and related issues are being undertaken for the community. Events to promote World AIDS Day and World AIDS Orphans Day are being organised. Key community stakeholders like community gate-keepers, Panchayat leaders and district and block development authorities are being regularly involved in the programme. All these

activities have proved to be of immense value in not only reducing stigma at community level, but also in encouraging the community to support the children and families affected by HIV. Evidences from field sites show how communities have come together to mobilise resources for affected families, help them in accessing health service and provide nutrition support. Also, community leaders, and block and district level authorities have been instrumental in facilitating their access to social welfare schemes like widow pension plans, issuance of BPL (Below Poverty Line) card to avail the Public Distribution Schemes, and *Avaas Yojna* that entitles the poor to housing facilities.

Till June 2008, 389 sensitisation meetings have been conducted in the community with decision makers and key stakeholders.

With the formation of various support groups, Alliance India has been emphasising the building of social capital in the community; and in particular the engaging, empowering and mobilising of the community through knowledge-sharing to advocate for change at various levels. Various children and adult support groups have been formed within the CHAHA programme with this purpose, which undertake periodic meetings. This provides the affected children and families an important platform to access relevant information, share and relate personal experiences and problems, receive peer support, establish social networks, and for recreation. The membership of the children's support groups is not restricted to only those affected by HIV. The group sessions are facilitated by counsellors and ORWs imparting life skill education to children. Thus, the support group strategy is an important means to reduce stigma and to provide psycho social support to the affected population.

Till June 2008, 126 children's support groups have been formed.

Linking the affected families and children with district-level PLHIV networks also facilitates pooling together requisite support and information for affected communities, helping them improve the availability and access to HIV related services through a strong advocacy agenda. Such linkages improve the lives of the affected families as they receive peer support,



and counselling in general, as well as in specialised areas as positive living, ART and its adherence.

Strengthening Civil Society and Institutional Capacity Building: Building the capacity of staff and organisations at every level of implementation, and establishing linkages with NACO and State AIDS Control Society (SACS) as well as other governmental and non-governmental authorities has been a key feature of the CHAHA programme. This is especially in line with the NACP III mandate of strengthening infrastructure, systems and human resources in prevention, care, support

and treatment programmes at all levels; and of mainstreaming and forging partnerships to facilitate a multi-sectoral response, engaging a wide range of stakeholders including the private sector, civil society, PLHIV networks and line ministries to scale up HIV initiatives. Capacity building of partner organisations has also been a part of the general strategy of the Alliance.

A number of workshops, exposure visits and seminars intended at capacity building have been organised by Alliance India and its SRs. The areas of focus include programme and finance management, technical training for implementing staff on issues relating to children and HIV, monitoring and evaluation, and knowledge management. Another important approach has been to provide continuous technical support to implementing partners and staff in the form of personal visits by the

staff from Alliance India and SRs to support programme management, strategic direction and workplans, monitoring and evaluation, and financial management.

The CHAHA programme is in synchronisation with the principle of Three Ones, with regard to networking and linkages with various government institutions. At the national level, Alliance India coordinates with NACO on the progress in responding to HIV, and provides quality feedback on issues and concerns from the SRs, SSRs and the communities. Monitoring data and qualitative reports are shared with NACO at a quarterly basis and the PR officially updates NACO during Global Fund coordination meetings.

A similar approach is undertaken at the state level where qualitative reports and quantitative

CHAHA Program's Key Indicator: Targets and Achievements, June 2008

Indicator Description	Target	Achieved	% Achieved
Number of CLHIV and CAA under 18 years of age benefiting from a minimum package of care and support services	8,333	8,253	99
Number of CLHIV and CAA receiving nutritional services including nutritional counseling and demonstration services	3,333	3,479	104
Number of households of CLHIV and CAA covered by basic support	4,167	4,484	108
Number of children referred for pediatrics ART to a healthcare institution	417	409	98
Number of CLHIV and CAA provided with educational support and/or vocational training	1,333	1,427	107
Number of households provided income generation support	833	862	103
Number of Children support groups formed	105	126	120
Number of sensitisation meetings held in communities	350	389	111
Number of participants attended the sensitisation meetings held in communities	3,500	3,991	114
Number of NGO/CBO staff trained	250	637	255

data is shared on a monthly basis. The CHAHA programme represented by the SR is invited to attend regular coordination meetings at SACS. At the district level the SSR are members of the District level Coordination Committees (DCC) where they update the District AIDS Prevention and Control Units (DAPCU) or the District AIDS Nodal Officers. The SSR are instrumental in organising coordination meetings on behalf of the authorities in a number of districts.

Thus all the agencies – governmental and non-governmental – working in the field of HIV get together to share information, concerns and challenges, reflected at the state level by the SR. The district level committee meetings now also see participation by other departments.

Strengthening the Information System:

Efforts are being made to strengthen a nationwide strategic information management system. Development, testing and implementation of monitoring and evaluation tools across all levels of programme implementation is being

undertaken. This covers both quantitative and qualitative data for effective monitoring of the programme activities and for informed decision-making. The indicators and the data collected are in conjunction with the national requirements, and data is shared at the state and national level, and fed into the Centralised Management Information System (CMIS).

Furthermore, Alliance India has initiated the process of conducting Operations Research centred on three identified themes – sustainable access to ART by positive children; HIV testing and disclosure with children of all age groups; and capturing good practices – in one year of CHAHA programme implementation. These themes have been decided upon through a consultative and analytical process involving NACO, Population Foundation of India, Programme Coordination Unit, SRs and SSRs to ensure alignment with the national priorities.



Managing the CHAHA Programme

With the belief (supported by evidence) that HIV related services and activities are particularly effective when implemented in partnership with locally-based organisations, Alliance India has been implementing its various programmes through a number of intermediary NGOs, providing them with programmatic, technical and financial support. The Alliance has also formed strategic alliances and partnerships with a range of stakeholders and institutions including NACO, SACS, other government ministries/departments, health professionals, NGOs and research/academic institutions.

Alliance India has employed a participatory project cycle management approach for design and implementation of its projects, upholding a track record of successfully managing complex process projects. Managing a project of the size and magnitude of CHAHA has entailed securing a good management structure to ensure functioning as per the proposed plans and strategies. As a PR, Alliance India has set up many systems for smooth implementation

and quality assurance of CHAHA programme. An overview is provided here.

Programme Coordination Unit (PCU): Located in Delhi, the unit has been designed functionally and comprises competent professionals to facilitate effective programme delivery, ensure quality of services as well as reporting and systems that are participatory, community friendly and in the best interest of children. The unit also works towards influencing the larger policy environment in favour of CLHIV and CAA. The unit comprises of the following teams: (1) Care and Support Team responsible for day to day management and reporting; (2) Monitoring and Evaluation Team that maintains systems of data flow, transfer and monitoring of the pace of the programme; (3) Knowledge Management Team that captures the programme process, best practices, lessons learnt, challenges and impact of the programme, for ensuring appropriate knowledge-sharing among partner NGOs; (4) Finance Team that handles fund disbursement and accountability related issues; and (5) Policy, Advocacy and Communication Team that strategically pushes the advocacy agenda and brings external stakeholders on a common platform to influence policies. The unit directly reports to Alliance India's Country Director.

Sub-Recipient (SR) and Sub Sub-Recipient (SSR): The SRs and SSRs in various states are supported by Alliance India (PR) for effective implementation of the programme. This approach also fulfils Alliance's organisational goal of strengthening local and state level capacities. The SRs are responsible for capacity enhancement of their respective SSRs, in addition to overseeing the smooth implementation, reporting and advocacy initiatives at state level. The SSRs' role is to deliver high quality services to children



and their families, building local capacities, networking at village/block/district level, and timely and accurate reporting. Sub-grant agreements with SRs were preceded by their assessment undertaken by Alliance India, using a specially designed Capacity Analysis Tool. The assessment was based on the SRs' demonstrated expertise in HIV work, and their willingness and availability to undertake an intermediary role in supporting other NGOs/CBOs with less experience and capacity. A similar exercise was conducted by the SR for selection of each SSR.

Coordination with the Government and other Stakeholders: The CHAHA programme's implementation framework draws heavily on the national operational guidelines formulated by the government to complement the National Policy Framework for Children and AIDS. The programme focuses on establishing strong referrals and linkages at the community level. Coordination with various government and local bodies and also linking the people with government schemes and programmes is imperative for long-term sustainability of the programme. To ensure the same, all SRs and SSRs participate in state and district coordination meetings and facilitate access to government schemes by the community. The PR also regularly meets with key players in the government, donor and partner organisations to discuss needs, issues and challenges and inform the country policy and programme framework.

Grants Management: All SRs have signed a grant agreement with the PR and grant disbursement is carried out through this mechanism. Funds are disbursed at the beginning of the quarter with a buffer of one month for smooth implementation. Quarterly financial reports are received from the SRs at the end of each quarter, which are reviewed and feedback is provided to the SRs. Audit of the SRs' project accounts is done on a quarterly basis by an external audit firm. Financial reporting to the Global Fund is the role of the PR and the responsibility for this function lies

with the Director (Finance and Administration) at Alliance India.

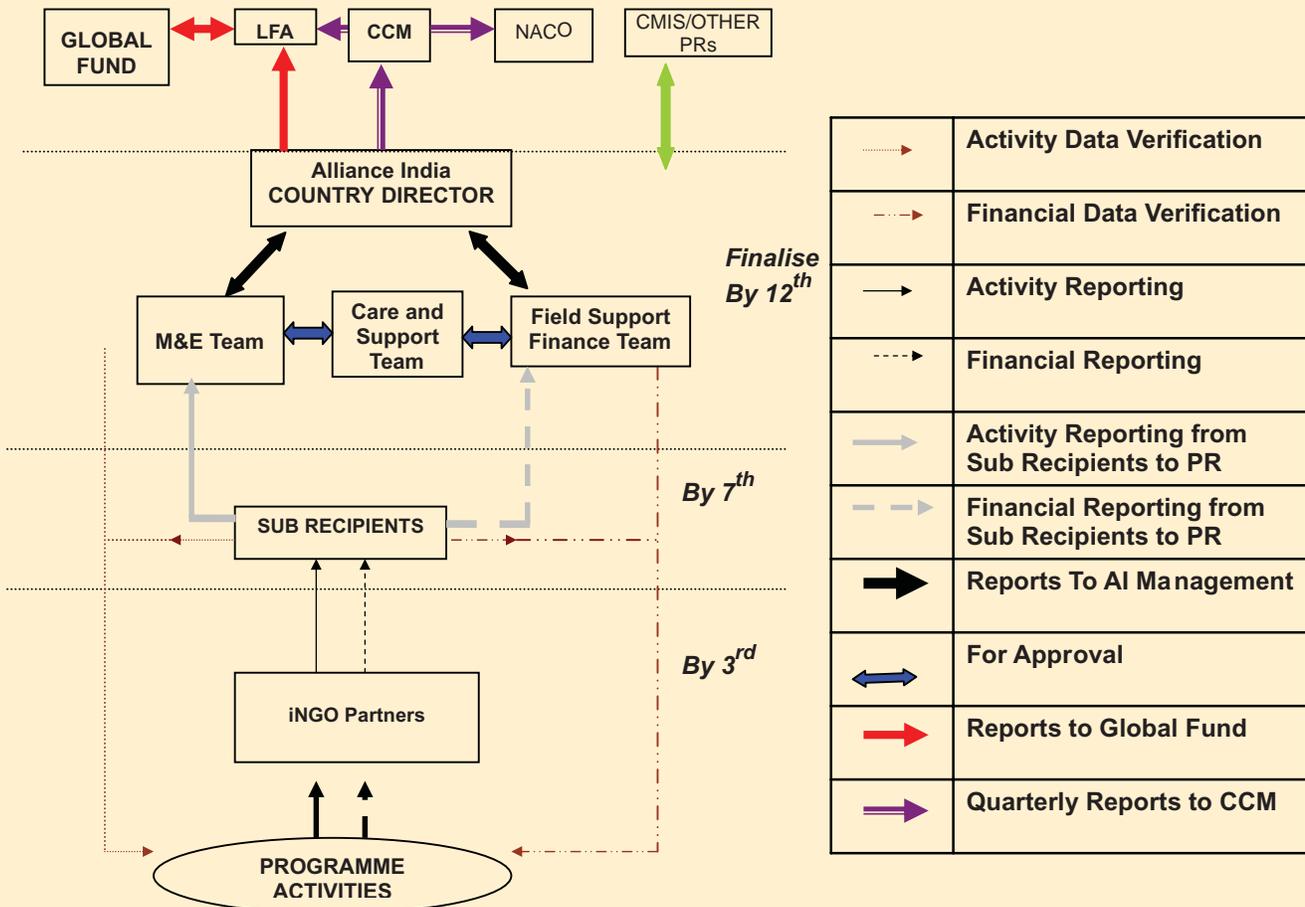
Monitoring and Evaluation: Periodic reports from partners on key indicators and on the functioning of the project are aggregated by the PR on a quarterly basis and submitted to the Global Fund. A uniform reporting system has been established at the SSR level, with comprehensive training and a standard operational guideline. Quality, correctness and timeliness of reports are ensured by SR and PR through technical support visits, and electronic and telephonic communications. Progress report of the programme is incorporated by NACO in the CMIS. Progress reports are also sent to the Alliance Secretariat in Brighton, UK for feedback and quality assurance. Evaluation of the project is to be conducted against baseline indicators and mid-term survey is being planned at the end of the year 2008. (Please refer to Figure 2)

Technical Support (TS) Visits: Periodic as well as needs-based TS visits to the SRs (also SSRs), and by SR to SSRs is an integral function of the programme. TS needs are identified through review and re-planning meetings, cross-cluster meetings and quarterly programme reports. Skill building functions are also supplemented by expert consultants through state and national level workshops.

Cross-Cluster Teams: To ensure greater coordination, the Programme Officers of Alliance India are divided geographically on a cluster approach. Manipur and Maharashtra form one cluster while Andhra Pradesh and Tamil Nadu together form the other. Fortnightly cross-cluster team meetings are held to discuss programme related issues at the partner and community levels. This is a quality assurance mechanism for ensuring the pooling of skills for better programme management.

On Track Management System: Alliance India follows an internal management tool called the 'On Track Management System'. This system seeks to facilitate more systematic management

Figure 2



discussions between Programme and Finance teams, to monitor progress against plans, to give state update, identify any necessary actions/revision, and to highlight emerging risks. A quarterly consolidated report is then sent to the Alliance Secretariat in Brighton, UK.

Mutual Sharing and Learning Meeting (MSLM): MSLM is a mechanism for the horizontal exchange of information. The meetings are held bi-annually with all the state-wide SR and SSR representatives, to share their implementation experience, evaluate the success and impact of the adopted strategies to achieve targets/objectives and to facilitate coordination and eliminating duplication, replicating best practices, and promoting cross-learning.

Review and Replanning (R&R): R&R is a bi-annual exercise conducted with each SR, focussing on programme review, replanning, reporting and budgeting. The R&R discussion revolves around plans as recorded during the previous R&R outputs, operational issues related to programme management, achievements over the past six months, lessons learned, challenges, good practices, innovations, and future direction and plans. All of this then feeds into SR's and PR's MRS database and serves as the base for future planning.

Experiential Insights

- Close coordination with SACS results in better networking with other donors in the state, and serves to avoid duplication, in optimising the reach within the available resources and in enhancing the visibility of the project.
- The project staff plays an instrumental role in improving the access of families affected by HIV to government welfare schemes and programmes – through enhancing demand articulation by families, community and local citizen groups on the one hand and in improving the supply side response on the other.
- Myths and misconceptions about the HIV epidemic that presently abound at all levels accentuate the all-pervading climate of stigma and discrimination. Given the magnitude of myths and the level of stigma and discrimination, there is a need to work continuously hand-in-hand with community structures as also state and other civil society actors.
- Hands-on TS by the PR and SR in the field to project staff on a sustained basis supplements the efforts made through structured training programmes and workshops. The use of such methods and tools as the PCA and PCR enhances the understanding of ORW about the emerging and existing issues also leading to deeper familiarisation with the intervention areas.
- Local self governing institutions like the urban local bodies and three-tier Panchayati Raj Institutions offer many opportunities in dealing with issues of stigma and discrimination and in facilitating access to services and welfare schemes at their respective levels. However, building strong and sustained linkages with these institutions is a key area.
- In a large number of rural intervention sites that are far-flung and remote, HCBCS is perhaps the only viable option. ORWs face many daunting challenges in making an HCBCS programme work effectively and efficiently in such areas. Their task is further compounded in difficult terrains, conflict zones or places marked by insurgent activities.
- In order to ensure long-term sustainability of the project, it is imperative to look beyond the provision of direct services. An effective linkage with government agencies and local self-governing institutions at appropriate levels is a sine qua non in this regard. A need related to this aspect is the importance of local resource mobilisation. This will further help in ensuring sustainability and in meeting the gaps in the quantum of services.
- Children and AIDS policy is an important policy document that seeks to bring about changes at the appropriate levels and in creating a response from the concerned state actors in a manner that the basic support needs of children living with and affected by HIV are met. Alliance India and SRs are planning to take up the issue of implementation of the policy in letter and spirit at the state and district level as soon as the policy guidelines are in place.

Challenges Faced

- There are several barriers to HIV testing and disclosure of status. Access to testing centres is many times hindered by lack of transport, travelling expenses, distance to testing centres, ICTC timings and also by shortage of testing kits. It is also reported in some places that some agencies provide cash incentives for referring children to ART or voluntary counselling and testing centre and therefore parents prefer to refer through these agencies. The prevailing stigma and discrimination acts as a deterrent for parents in disclosing the sero-positive status of children in a manner that service could be provided to affected children and families.
- Children support groups are constrained by several limiting factors, such as the need for safer spaces for conducting group meetings, a suitable time and duration of meetings as also their facilitation.
- Many parents are reluctant to put children on ART. This resistance by parents is primarily embedded in the fact that they themselves are facing problems of adherence to lifelong treatment. The resistance of parents further manifests itself in their refusal to accept home visits by project staff or in participating in community level sensitisation meetings.
- In certain instances, shortage of OI and prophylaxis at government health centres causes serious hardships and problems for children and families. To deal with these localised issues of shortage of key medicines, coordination with health authorities at the district or sub-district level is an ongoing effort that is made by the CHAHA programme officials at appropriate levels.
- The expectations of children and families regarding the quantum of direct services often surpass what can be optimally provided to children based on the needs assessment and principles of equity. This is against the backdrop of the fact that services such as nutrition support, IGP and household support are resource-intensive. In addition, the pressures of meeting certain demands during particular periods e.g., education support at the beginning of an academic year, requires adjustments within the planned provisions.
- Selection of beneficiaries on a needs-based criterion is a difficult aspect of planning services. In many areas, the number of children and families that required support exceeded the actual number planned.
- Outward-migration of affected families poses a serious challenge to follow-up on ART regimen and adherence.
- Foster care of orphan children is an area that continues to confound the project staff at the local level. Given the state of poverty and cultural factors, foster care at the community level has continued to receive indifferent response. The functioning of Child Welfare Committees (CWCs) at the district level also leaves much to be desired. CWCs are legally mandated to deal with issues of foster and institutional care of orphan children. It is a common observation that these committees are not responsive enough to mitigate the situation. This leads to serious issues of child neglect and distress in communities and families. The Alliance and its SRs are working out a coordinated plan of action to deal with the situation so that community response to foster care improves and that CWCs become more responsive institutions.
- While efforts towards improving access of children and families to entitlements and services from government schemes and programmes are being made, bureaucratic apathy and formalities proves to be a barrier in many instances. The challenge here is to coalesce as civil society and deepen effective linkages with government agencies.

Financial Summary

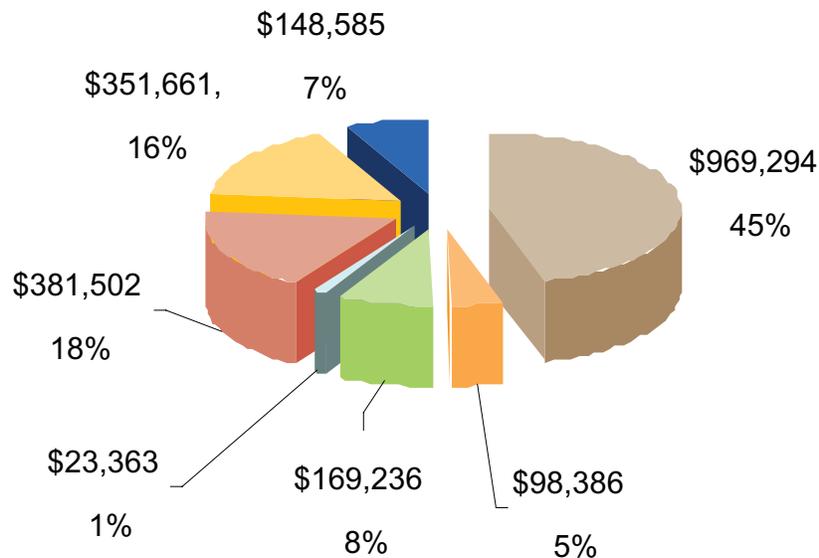
The Global Fund has signed an Agreement with the India HIV Alliance for a Phase 1 budget of US\$4.17 million. The income received during Year 1 of the project is US\$2.21 million. The funding from Global Fund contributes to 30 per cent of the total turnover for the period June 07-June 08.

Expenditure at the end of Year 1 has crossed US\$2.14 million, of which onward grants to

Sub-recipients constitute 70 per cent during the year.

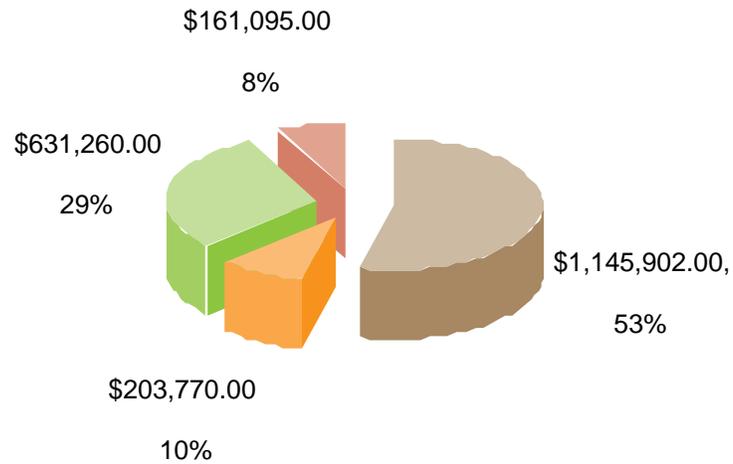
The funding has helped to expand programme coverage, build capacity and forge partnerships with NACO and SACS. We look forward to the coming year to strengthen the programme further.

Expenditure by Cost Category



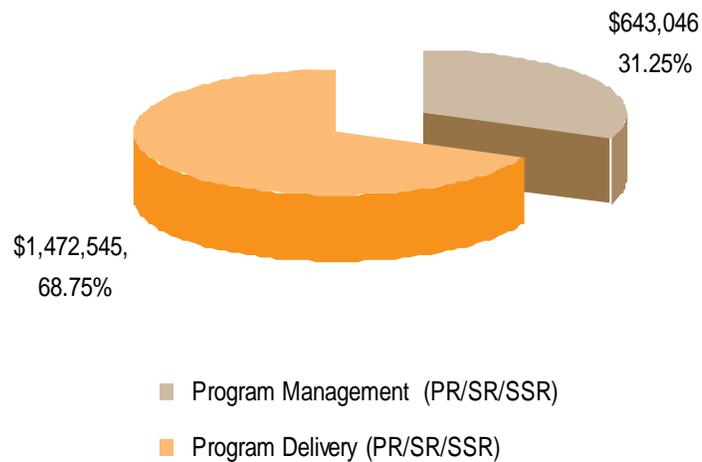
- Human Resources
- Infrastructure and Other Equipment
- Living Support to Clients/ Target Population
- Overheads
- Training
- Monitoring and Evaluation
- Planning and Administration

Expenditure by Service Delivery Area



- Care and Support: Support for orphans and vulnerable children
- Supportive Environment: Stigma reduction and respect of confidentiality
- Supportive Environment: Strengthening of Civil Society
- Supportive Environment: Monitoring and evaluation and operations research

Program Implementation & Management



Alliance India's CHAHA Partners

Sub Recipients

Alliance for AIDS Action, Andhra Pradesh
Catholic Relief Services (CRS), Tamil Nadu and Maharashtra
LEPRA Society, Andhra Pradesh
MAMTA-Health Institute for Mother and Child, Maharashtra
Plan India, Andhra Pradesh & Maharashtra
Palmyrah Workers Development Society (PWDS), Tamil Nadu
Social Awareness Service Organisation (SASO), Manipur
Vasavya Mahila Mandali (VMM), Andhra Pradesh

Sub Sub Recipients

Palmyrah Workers Development Society (PWDS)

Anbalayam
 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)

CRS-Tamilnadu Social Service Society (TASOSS)

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)

Social Awareness Service Organisation (SASO)

Manipur Network of Positive People (MNP+)
 Dedicated People's Union (DPU)
 Social Awareness Service Organisation (SASO) as an iNGO
 Sneha Bhavan- Imphal East
 Sneha Bhavan-Chandel
 Sneha Bhavan – Thoubal

LEPRA Society

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

Vasavya Mahila Mandali (VMM)

Annamma School for the Hearing and Physically Handicapped & Baby Care Center
 Deepthi Socio Educational Society
 Gramasiri Rural Activities in National Development Society
 Youth Club of Bejjipuram
 Swarajya Abudaya Seva Samithi
 ARDAR (Association for Rural Development and Action Research)

MAMTA-HIMC

Network of Maharashtra by people living with HIV/AIDS (NMP+)
 Bharatiya Adim Jati Sevak Sangh
 RTM SAP Mandal
 Janhitay Mandal

Plan India

Committed Communities Development Trust
 Community Aid & Sponsorship Programme (CASP)
 Arthik Samata Mandal
 Janakalyan Welfare Society
 Rural Energy for Environment Development Society (REEDS)
 GUIDE
 Society for Help Entire Lower & Rural People (HELP)
 Social Activities for Rural Development Society
 Chaitany Jyothi Welfare Society

Alliance for AIDS Action

Rural Education and Community Health (REACH)
 Lodi Multipurpose Social Service Society (LMSSS)
 Jagruthi

Catholic Relief Services (CRS)

Tamilnadu Social Service Society (TASOSS)

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)

CRS-Santhome Trust of Kalyan

Santhome Charitable Trust of Kalyan
 Kripa Foundation
 Jeevan Vikas Sanstha, Amravati
 Sangli Mission Society- Miraj
 Sangli Mission Society- Kolhapur
 Nagpur Multipurpose Social Service Society
 Sarva Seva Sangh- Pune
 Paramprasad Charitable Society, Satara
 Paramprasad Charitable Society, Satara



A global partnership:
International HIV/AIDS Alliance
Supporting community action on AIDS in developing countries



Alliance for AIDS Action
www.allianceforaidsaction.org



Lepra India
www.lepraIndia.org



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



Palmyrah Workers
Development Society
www.pwds.org



Vasavya Mahila Mandali
www.vasavya.com



CATHOLIC RELIEF SERVICES



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