International HIV/AIDS Alliance in India

Supporting Community Action on AIDS in India

Breaking New Ground Setting New Signposts

A Community-Based Care and Support Model for Injecting Drug Users Living with HIV

The SASO-Alliance Experience

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The SASO-Alliance Experience

The International HIV/AIDS Alliance is a global partnership of people, organisations and communities working towards a shared vision of supporting effective and sustainable community responses to reduce the spread of HIV and to meet the challenges of AIDS.

Our vision is of 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 and quality of life through access to comprehensive HIV prevention, care, support and treatment services, regardless of their gender, religion, class, race, ethnicity, sexual orientation, age, disability, drug use or sex work, backed up by an unbiased system of justice.

In fulfilling our vision, we are contributing towards achieving the Declaration of Commitment on HIV/AIDS of the United Nations General Assembly Special Session of June 2001 and the commitment in June 2006 by the UN General Assembly to the goal of Universal Access to HIV prevention, treatment, care, support by 2010 - in addition to the Millennium Development Goals on HIV and AIDS to halt and reverse the epidemic by 2015.

Established in 1999, the **India HIV/AIDS Alliance** comprises a country-based Alliance Secretariat in New Delhi, five lead partner organisations (also known as Linking Organisations within the global Alliance) and their networks of over 100 community-based non-governmental organisations and CBOs (community-based organisations) across five States – Andhra Pradesh, Tamil Nadu, Manipur, Maharashtra and Delhi.

In 2007, the Alliance 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 and AIDS, including reducing stigma and discrimination, particularly amongst the most vulnerable and marginalised communities key to the epidemic – such as sex workers, men who have sex with men, injecting drug users and adults and children living with HIV.

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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 virtual resource centre, Setu on www.aidsallianceindia.net or write to:

India HIV/AIDS Alliance
Kushal House, 39 Nehru Place
New Delhi 110 019
India
Telephone: +91 11 4163 3081, Fax: +91 11 4163 3085
Email: info@allianceindia.org

Design and Print:
New Concept Information Systems Pvt. Ltd.
Email: nc@newconceptinfo.com, nc.communication@gmail.com

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Abbreviations

AIDS	Acquired Immuno-deficiency Syndrome
ANC	Ante Natal Clinic
ANM	Auxiliary Nursing and Midwifery
ART	Anti-Retroviral Therapy
CBO	Community Based Organisation
DFID	Department for International Development
DIC	Drop-in Centre
GNM	General Nursing and Midwifery
GOI	Government of India
HCV	Hepatitis C Virus
HIV	Human Immuno-deficiency Virus
HR	Human Resource
HRG	High Risk Group
IDU	Injecting Drug User
IGP	Income Generation Programme
KFT	Kidney Function Test
KP	Key Population
LFT	Liver Function Test
MBBS	Bachelor of Medicine and Bachelor of Surgery
MHFW	Ministry of Health and Family Welfare
MNP+	Manipur Network of Positive People
MSACS	Manipur State AIDS Control Society
MSM	Men who have Sex with Men
NACO	National AIDS Control Organisation
NACP	National AIDS Control Programme
NGO	Non-Governmental Organisation
NSEP	Needle Syringe Exchange Programme
OD	Overdose
OI	Opportunistic Infection
OST	Oral Substitution Therapy
OVC	Orphans and Vulnerable Children
PCA	Participatory Community Assessment
PCR	Participatory Community Review
PLHIV	People Living with HIV
PPTCT	Prevention of Parent to Child Transmission
RIAC	Rapid Intervention and Care
RTI	Reproductive Tract Infection
SASO	Social Awareness Service Organisation
SHG	Self Help Group
SRH	Sexual and Reproductive Health
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection
TB	Tuberculosis
UN	United Nations
UNODC	United Nations Organisation for Drugs and Crimes
VCTC	Voluntary Counselling and Testing Centre
WLHIV	Women Living with HIV

Executive Summary

With a population of approximately 2.4 million which is about 0.2 per cent of India's population, Manipur ranks highest in HIV prevalence amongst the seven northeastern states of India. The adult HIV prevalence in Manipur (1.67 per cent) is even greater than the estimated national average (0.36 per cent)[1]. According to a recent report from the National AIDS Control Organisation (NACO)[2] – "…recent studies indicate that HIV prevalence has been stabilising, and states like Tamil Nadu, Andhra Pradesh, Karnataka, Maharashtra and Nagaland have started showing declining trends…" – it is to be noted here that Manipur does not figure among these states. Insurgency, high unemployment, poverty and easy availability of drugs leading to much other risky behaviour have all been contributing factors to high HIV prevalence.

The widespread use and sharing of heroin injections among drug users has been the major mode of HIV transmission in Manipur. HIV was first detected in Manipur in 1989 after testing a cluster of injecting drug users (IDUs). The HIV prevalence amongst IDUs rose dramatically from 0 per cent to almost 60 per cent by 1995, rapidly reaching a peak of almost 80 per cent by 1997[3]. Prevention initiatives by the State Government and a small number of non-government organisations (NGOs) helped to bring down the prevalence rate to about 21 per cent in 2004, with an upward turn in prevalence again in 2005 to an estimated rate of 24.1 per cent[4]. According to the sentinel surveillance data of 2006, the prevalence rate of HIV amongst IDUs is 20 per cent[5], which is still quite high.

Stigma and discrimination against IDUs has further exacerbated the HIV epidemic in Manipur. To feed their habit, many drug users become involved in petty crimes whilst many of their spouses/partners, often drug users themselves, resort to sex work. For both groups, their social marginalisation forces them underground, their vulnerability further accompanied by unsafe practices such as sharing of needles/syringes and non-usage of condoms. All these jointly contribute to the increase in sexually transmitted infections (STI), HIV and Hepatitis C Virus (HCV) in these groups. To add to the grim situation, lack of proper access to treatment further compounds the situation.

However, HIV is not limited to the IDU population in Manipur. Evidence from the field suggests that it has spread beyond the IDU population into the general population, primarily to their sexual partners and children. In a regression analysis of the factors associated with transmission of HIV from IDU husbands to their non-injecting wives, some interesting results have come up. Among 161 HIV-infected IDUs and their wives recruited from September 1996 to August 1997 inclusively, 72 wives (45 per cent) were HIV-positive[6]. In 2006, the prevalence rate among women visiting antenatal clinics (ANC) was 1.25 per cent and that among women visiting STD/STI clinics was as high as

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[1] National AIDS Control Organisation (NACO), Ministry of Health & Family Welfare (MHFW), Government of India (GOI): HIV Sentinel Surveillance and HIV Estimation, 2006
[2] NACO, MHFW, GOI: To halt and reverse the HIV epidemic in India, NACP-III, 2007
[3] Manipur State AIDS Control Society (MSACS): Manipur State PIP Report, NACP-III, January 2006
[4] NACO, MHFW, GOI: HIV/AIDS epidemiological surveillance & estimation report for the year 2005; April 2006
[5] NACO, MHFW, GOI: HIV Sentinel Surveillance and HIV Estimation, 2006
[6] Study on Transmission of HIV from injecting drug users to their wives in India by Panda S, Chatterjee A; Bhattacharya S. K; Manna B; Singh P. N; Sarkar S; Naik T. N; Chakrabarti S; Detels R.

4.8 per cent[7]. MSM (men who have sex with men) and sex workers are other two highly vulnerable population groups in Manipur; HIV prevalence rates of 10.4 per cent and 11.6 per cent (2006) respectively[8] are particularly high and continuing to increase.

Consequently, HIV infection, whether transmitted through injecting drug use or unsafe sex, is contributing to a serious public health emergency in Manipur. Although the state was one of the first in India to have adopted a preventive approach to drug use through harm reduction programming for IDUs, most projects and interventions have remained focused on harm reduction only with little emphasis on Behaviour Change Communication (BCC), care and support, and treatment adherence, considering the ever increasing number of people living with HIV (PLHIV) in the state. This situation points to the need for more comprehensive interventions with IDUs that place equal emphasis on addressing drug use and HIV prevention, care, support and treatment.

With this belief, the Alliance, with its long experience of home and community-based care and support programme, established partnership in Manipur with the Social Awareness Service Organisation (SASO), a pioneering NGO working for the rights of IDUs. The Alliance and SASO shared a similar approach of creating space for the community and ensuring the active and meaningful involvement of communities in response to HIV and AIDS.

Since 2005, SASO has been implementing its harm reduction project and providing a comprehensive package of services and support to IDUs and their partners through drop-in centres (DIC) and in the community. Some of these services include: one-to-one interactions, group sessions and focus group discussions with IDUs; STI treatment (including partner treatment); counselling and information on HIV prevention through counsellors and part-time doctors; referral and linkages with various public healthcare services; needle-syringe exchange programme (NSEP); training and capacity building for community members; and oral substitution therapy (OST). The DIC engages the IDUs in various recreational activities that help in diverting their minds from drugs, and provide additional opportunities for peer educators and/or SASO staff to promote further messages on harm reduction and HIV/AIDS. In effectively delivering many of these services, SASO has weaved its long experience gained through some of its earlier interventions e.g. the 'Bleach and Teach Programme' under which bleaches were being distributed to the IDUs way back in mid-90s. Similarly, SASO's experience gained through NSEP from late 90s also helped the cause.

To complement SASO's existing harm reduction interventions and further strengthen SASO and community responses to HIV and AIDS, the Alliance, in 2004, initiated the care and support programme for IDUs living with HIV and their families. In 2006, SASO was part of another Alliance programme, supported by the Department for International Development (DFID), whose objective was to address the growing 'feminisation' of HIV/AIDS across the country and the sexual and reproductive health (SRH) needs of female IDUs and/or spouses/partners of male IDUs and other vulnerable groups. This programme has been the first of its kind in Manipur and was instrumental in highlighting the impact of injecting drug use on women.

[7] NACO, MHFW, GOI: HIV Sentinel Surveillance and HIV Estimation, 2006
[8] Ibid; 2006

The SASO-Alliance programme approach of community participation and local leadership has led to increased community involvement and the acceptance of the IDU population and PLHIV by the community, which was a distant dream in Manipur. Focus on the families of IDUs has been brought through the programme as until recently most of the programmes in Manipur considered IDUs as an independent entity. The programme, for the first time, stressed on female IDUs because of their complex situation. There has been increase in outreach, reduction in vulnerability to HIV, prevention from harmful consequences of drug use, increased knowledge on HIV and AIDS, SRH and related issues, and improvement in health-seeking behaviour of the target population. In its partnership with the Alliance, SASO has emerged as a strong organisation supporting many other NGOs in Manipur and other Northeastern States of India, giving systematic and ongoing support to local organisations.

However, a few challenges need to be overcome to make the comprehensive approach of harm reduction and care and support even more impactful for the target population. Some of the recommendations are:

- Strengthening healthcare centres in Manipur, ensuring proper rehabilitation facility, up grading knowledge of medical practitioners, and establishing proper follow-up mechanism
- Scaling up hands-on-training for doctors and paramedics to equip the current medical practitioners in Manipur to deal with the emerging complexities of drug use, HIV/AIDS and HCV
- Advocating for prioritising HCV co-infection as one of the public health issues and making efforts to mainstream it for treatment facilities
- Scaling up the income generation component for economic enhancement and all round development of IDUs, PLHIV and their families
- Strengthening nutritional support from the government, and identifying and training more professionals specifically for the psycho-social counselling of children living with and affected by HIV
- Designing long-term initiatives for women (female IDUs, women living with HIV and other vulnerable groups) and addressing their issues at the state and policy level.

The NACP-III programme priorities and thrust areas offer a lot in terms of meeting a number of challenges and address the various needs of IDUs living with HIV, by giving significance to strengthening technical and financial support to meet challenges and filling in gap areas. While SASO – that has emerged as a major player in response to HIV and AIDS in Manipur – as a leading civil society organisation has demonstrated effective delivery of community-level programmes with high responsiveness and result-orientation, there is growing recognition of the fact that effective private-public partnership through involvement of various civil society organisations can indeed play a crucial role in prevention, care, support and treatment for IDUs living with HIV and their families.

Harm Reduction and HIV in Manipur

Due to the rapid growth of HIV infection in Manipur after its first identification in 1989, the Manipur State AIDS Control Society (MSACS), under the National AIDS Control Programme (NACP) Phase II, initiated a targeted prevention intervention called 'Rapid Intervention And Care (RIAC)' with harm reduction at its core. Two primary components of this programme, the Needle Syringe Exchange Programme (NSEP) and condom promotion, helped address the burgeoning HIV prevalence.

Harm reduction, central to the link between injecting drug use and HIV and AIDS, is directed at the reduction of the harmful consequences of drug use without necessarily focusing on abstinence. This is based on the realistic acknowledgement that complete elimination of drug use takes time, and that it is important to help drug users cope with the immediate harmful effects not only on their physical and psychological health, but also on their socio-economic and legal situation. This approach gives credence to the fact that the rapid transmission of HIV through unsafe injecting (and unsafe sexual practices) needs to be prevented first in order to achieve a longer-term objective of total abstention from drug use.

Harm reduction, central to the link between injecting drug use and HIV and AIDS, is directed at the reduction of the harmful consequences of drug use without necessarily focusing on abstinence.

As HIV prevalence and infection is primarily associated with the IDU population in Manipur, the Alliance believes that it is important to have a comprehensive intervention in which harm reduction can be interlinked and synchronised with HIV prevention, care and treatment programming for drug users, who may also be living with HIV. For example, while harm reduction services (e.g. NSEP, oral substitution therapy, condom promotion, and abscess management) are provided to IDUs as common practice, those who are also living with HIV require care, support and treatment services such as health check-ups, referrals to government hospitals/clinics for access to anti-retroviral treatment (ART) and treatment of opportunistic infections (OIs), counselling, nutritional and income generation support, and linkages with various welfare schemes and entitlements.

Care and support for IDUs living with HIV is as important as harm reduction and the components together add value to each other. It is the Alliance's belief that care and support can contribute to greater life expectancy, facilitate adherence to medicines, and improve income at home as well as providing support to family members and/or other caregivers. Providing care and support can also help to instill an attitude of positive living due to improved physical and psychological conditions. Providing counselling, treatment, care and support to IDUs living with HIV informs and changes behaviour on infection whilst NSEP provides an opportunity to undertake one-to-one interaction with IDUs that makes it easier to provide them with information about safer injecting and

sexual practices. Oral Substitution Therapy (OST) can contribute to improving ART adherence of an HIV-positive IDU who may otherwise give greater priority to drugs than medicines.

Governmental and non-governmental efforts have reduced societal stigma and discrimination against IDUs and PLHIV to a certain extent, and in Manipur, the general population appears to acknowledge the importance of harm reduction interventions. However, most of the programmes undertaken in the state during NACP-I and NACP-II have been targeted interventions focusing on prevention with limited components on care and support and minimal linkages with existing harm reduction interventions. The necessity of a comprehensive approach to HIV and AIDS has led MSACS to emphasise care and support programming under NACP-III.

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Although care and support interventions for PLHIV have attempted to encourage coordination and cross-referrals between government and NGOs in the state reaching out to PLHIV, affected families and vulnerable women in the community (and expanding support groups and self-help groups (SHGs); providing medical, nutritional and educational support; increasing the number of people going for voluntary counselling and testing, and encouraging PLHIV towards positive living), these efforts have been very limited in scope. HIV-related care, support and treatment facilities have been inadequate in quality and accessibility, and there has been a dearth of comprehensive approaches bringing together prevention and care and support in the state.

The Alliance - SASO Partnership

In 2000, the Alliance was the first organisation in India to pioneer and initiate an HIV home and community-based care and support programme to meet the needs of PLHIV and their affected families, doing so with NGO partners in Tamil Nadu, Andhra Pradesh and Delhi State. The involvement, active engagement and leadership of the community (especially PLHIV and key populations (KPs) such as sex workers and MSM) has always been adopted as an important approach by the Alliance for an effective community-driven response to the AIDS epidemic. Communities are involved right from the programme design stage to its evaluation through practices such as Participatory Community Assessments/Reviews (PCA/PCR), formation of support groups and working with PLHIV networks, and participatory methods for undertaking programme evaluation as well as training and capacity building of NGOs and CBOs at the grassroots level.

The involvement, active engagement and leadership of the community (especially PLHIV and key populations (KPs) such as sex workers and MSM) has always been adopted as an important approach by the Alliance for an effective community-driven response to the AIDS epidemic.

Taking forward the long experience of its care and support programming, and viewing injecting drug use as a primary trigger for HIV infection, the Alliance established its partnership in Manipur with a pioneering NGO working for the rights of IDUs – the Social Awareness Service Organisation (SASO). Registered in 1991, SASO was initially established as a CBO by a group of ex-drug users who wanted to collectively address issues related to injecting drug use, preventing drug users from relapse as well as HIV and AIDS, and more broadly doing so in a way that would help to change their community's perception about drug users. As former drug users themselves, they understood the problems and implications faced by drug users and the community much better.

In the early days of its operations, the SASO team worked in an environment with considerable stigma and discrimination in which IDUs often had no family support and were isolated from the local community, making it very difficult to address the situation. To address this, SASO initially began without any support from other agencies with small-scale awareness building programmes as a means to creating more accepting attitudes towards drug users in various localities and communities across Imphal, the state capital. To do so, they used a combination of home-visits in the community, organised sports events and musical concerts and various traditional festivals. SASO also conducted detoxification camps for current drug users, using these to increase understanding of the harmful consequences of drug use, and referred these drug users to treatment centres if needed. Gradually, SASO was able to gain the confidence of the communities, especially families affected by drug use.

As HIV infection rapidly increased amongst the IDU community and had started to spread within the general population, HIV prevention for IDUs and care and

support for PLHIV became a necessity. To combat this, SASO members initiated a harm reduction intervention amongst practicing IDUs, mainly through promoting safer injecting practices and helping them reduce the risks and/or impact of HIV and other STIs, Hepatitis B and C, and related health problems. Some of the notable examples of its harm reduction interventions are 'Bleach and Teach', NSEP, OST, 'Operation G21' (syringe 2ml and 1ml), organising free detoxification camps etc. The discrimination against HIV-positive drugs users, particularly by healthcare providers, provided the impetus for developing SASO's home-based care programme and establishing self-help Positive People's group. The support of a few medical professionals became a significant step towards the provision of quality and non-discriminatory services to PLHIV.

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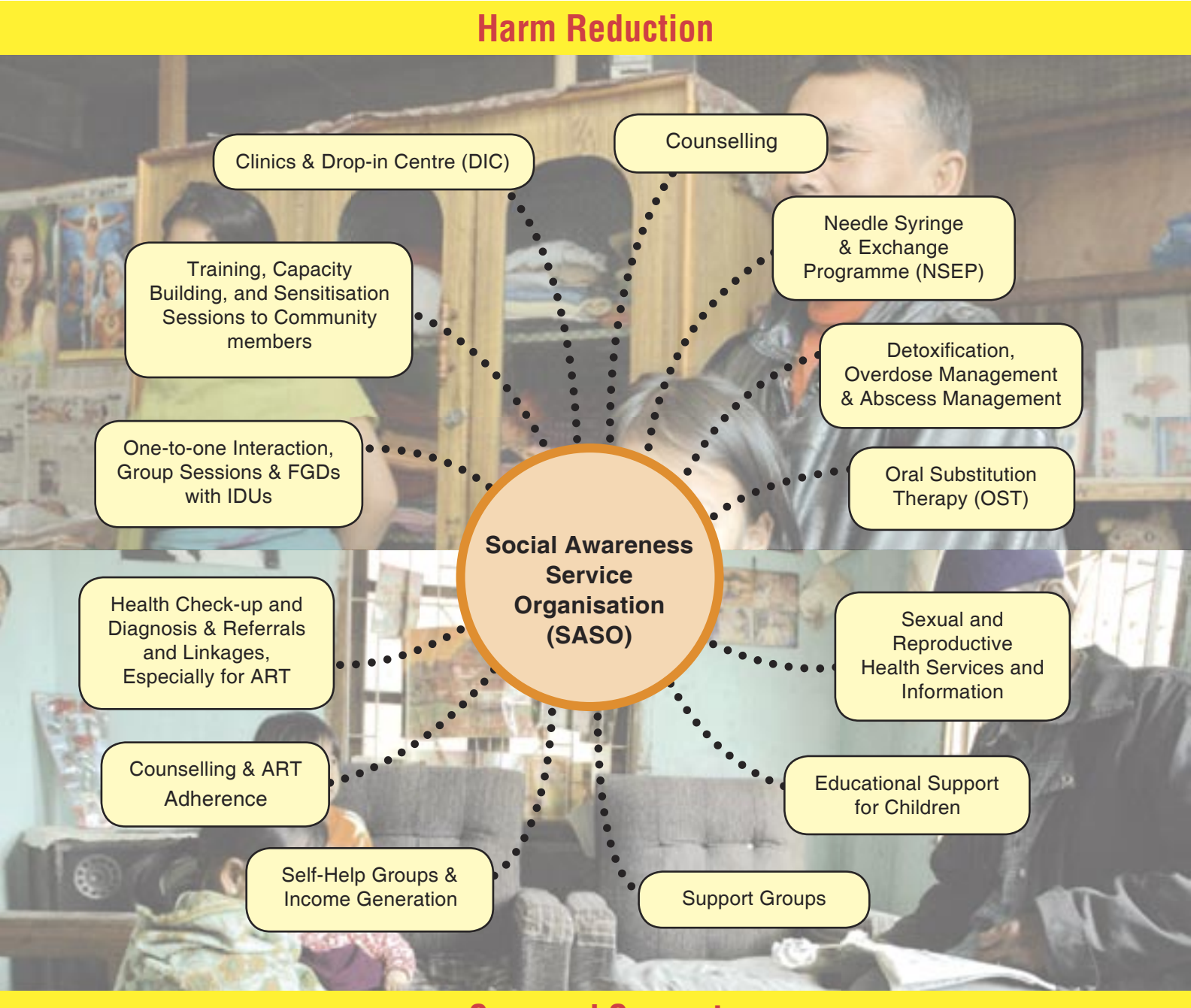
As the need for care, support and treatment for PLHIV continued to grow – but without a parallel growth in services and infrastructure to meet this demand – SASO members sought resources for scaling up their own HIV/AIDS interventions. Initially, with the support of the Department of Social Welfare of the Manipur State Government, SASO initiated its HIV/AIDS awareness programme and then combined this with some external aid to help start a medical clinic with a part-time doctor, providing free services to IDUs and PLHIV. Other support services included a telephone helpline, community outreach, counselling, home-based care, and harm reduction.

Thus, SASO and the Alliance shared a similar approach of creating space for the community and ensuring the active and meaningful involvement of communities in response to HIV and AIDS. The Alliance's experience of implementing programmes through building the programmatic and organisational capacity of intermediary NGOs and a belief that such interventions are most effective when implemented in partnership with grassroots organisations, especially the ones working with those most at risk or vulnerable to HIV, meant that working with SASO in Manipur was a logical step.

The Alliance and SASO:
A Continuum of Care

The inter-related issue of injecting drug use and HIV infection is a complicated one in Manipur. Primary anecdotal evidence on high risk behaviour suggests that a significant number of IDUs continue to share needles and syringes; many engage in sexual activity with multiple female partners, including both sex workers and their spouses/partners; many female IDUs engage in sex work to support their (and/or their male partners') drug habits; and inconsistent condom use has continued to fuel the spread of HIV and other STIs as well as other blood-borne viruses such as Hepatitis B and C among IDUs.

FIGURE 1



Since 2005, SASO has been implementing its **Harm Reduction Project** and providing a comprehensive package of services and support to IDUs and their partners through drop-in centres (DIC) and in the community. These include the following *(which are also summarised in Figure 1)*:

Since 2005, SASO has been implementing its Harm Reduction Project and providing a comprehensive package of services and support to IDUs and their partners through drop-in centres (DIC) and in the community.

- **Clinics and DIC:** Most services are provided through SASO's clinics and DICs. The clinics provide primary health care services and information through a host of well-trained healthcare providers such as doctors, health workers and counsellors. SASO has a separate DIC for women, with a female doctor and counsellor. Specifically to avoid relapse, unsafe injecting practices and to provide IDUs with an enabling environment, the DICs also provide a safe space where they can interact with those who have undergone similar experiences and problems. As part of this initiative, the DICs offer various recreational activities, which provide additional opportunities for peer educators and/or SASO staff to promote further messages on harm reduction and HIV and AIDS.

- **Needle and Syringe Exchange Programme (NSEP):** To promote safer injecting practices, all IDUs are encouraged to participate in the NSEP at the DIC or clinic, where they can obtain clean needles and syringes. SASO places central importance on waste management with regard to safe disposal and destroying of used syringes to prevent any reuse and/or environmental hazard. This was highlighted in a key campaign in 2003, Operation G21 under 'We Shall Overcome", led by SASO's various IDU support groups. It is now a key component of MSACS' NACP-III programme for the state.

- **Detoxification, Overdose Management and Abscess Management:** Support for detoxification, overdose (OD) management and abscess management for current IDUs is also provided through the SASO clinics/DICs. Specifically:

  - ***OD Management*** is a necessary component required for addressing emergency situations resulting from mixing or overdosing of drugs, and includes free-of-cost provision and injection of a life-saving drug. This is accompanied by ongoing provision of information about drug overdosing and its management to all IDUs and their family members through group-meetings, one-to-one interactions, counselling and with the help of IEC materials.

  - ***Detoxification***, undertaken for those who want to stop the use of drugs completely, is provided by SASO through two types of services: home-based and clinic-based. The clinic-based detoxification is for those IDUs who do not have family members or lack family support. On the other hand, home-based detoxification is for those whose families are ready to take on the care of their family member. The latter has been found to be a more effective approach by SASO because IDUs do not have to leave their homes, with less chance of relapse compared with the former where there is greater exposure to drug-using friends and peers. SASO staff meets the IDU (male or female) and it is compulsory for him/her to be accompanied by family member(s). A counselling process is then undertaken for both the IDU and the family member(s) during which the merits and demerits of detoxification are discussed. This is important to help the IDU make an informed

decision to undertake detoxification. Once initiated, the process requires the IDU to stop drugs immediately; this is accompanied by regular follow-up and interactions with the IDU as well as his/her family to avoid relapse and provide psychological support. However, the success rate of detoxification for female IDUs has been found to be far less than that for male IDUs, with their chances of relapsing much higher, primarily because of lack of family support (*see next section*). For those IDUs who relapse and return to drug use even after detoxification, are provided and encouraged to adopt safe injecting practices and condom use. Several IDUs have also been linked to rehabilitation centres managed through the Ministry of Health and Social Justice in Manipur.

- ***Abscess Management*** is the support/treatment provided by SASO to those IDUs who suffer with abscesses on their body due to injection of non-injectible drugs.

- **Oral Substitution Therapy (OST):** As an alternative method for reducing addiction and ultimately freeing users from drugs, SASO has piloted an OST programme since 1999/2000. OST is undertaken for 3-6 months and is based on the premise that IDUs switch to oral and safer modes of drug use through regular and fixed doses of medication that significantly reduce the desire for heroin and associated injecting which in turn also prevents HIV and other blood borne viruses, and helps in improving the quality of life by reducing stress and effects caused due to drug withdrawal symptoms. As a clinic-based treatment, OST also gives the opportunity for direct observation of the IDUs and so helps in bringing about a behavioural change in them, important in helping to prevent a relapse. As an integral part of the support to IDUs, SASO staff and peer educators are given training in relapse prevention, nutrition, and the health hazards of mixing of drugs with other chemicals. The impact of the OST programme is reflected in the response from users that their relationships with their families have improved, with many setting up their own small businesses or taking up other employment. Related to this, has been a reported improvement in ART adherence for IDUs living with HIV.

As an alternative method for reducing addiction and ultimately freeing users from drugs, SASO has piloted an OST programme since 1999/2000.

- **Regular one-to-one interactions, group sessions and focus group discussions with IDUs** conducted by the SASO staff in the DICs or in the community/household (often in the form of support groups) help to elicit information on their problems and needs, provide information on HIV and other STIs, safer injecting and sexual practices (including condom promotion), and address their expectations as community beneficiaries from the project. These sessions also assist SASO staff in monitoring levels of adoption of safer practices amongst IDUs.

- **STI treatment:** For men and women diagnosed with STIs, symptomatic and asymptomatic treatment with free diagnosis and medicine (including partner treatment) is given at a SASO clinic/DIC site together with appropriate counselling and information on HIV prevention. The counsellors and part-time doctors

also provide pre and post-test counselling for HIV and other tests, and have established systems of referral and linkages with various public healthcare services and facilities including that with government ART centres for those who require HIV treatment.

- **Training and capacity building:** Based on community feedback, various training sessions are regularly conducted by SASO to build the capacity of community members as peer educators on community sensitisation/mobilisation and advocacy; STIs, HIV/AIDS, methods of prevention, condom use and gender issues; and for support groups in leadership and team-building. In particular, these activities have encouraged women drug users and/or partners and family members of drug users to approach the DICs with less inhibition for information on HIV/STIs and treatment, and to obtain condoms.

- **Counselling:** In addition to the counselling for HIV testing and STI prevention, the counsellors at the DIC undertake most of the need-based counselling relating to care and support for an individual (e.g. family counselling, counselling for spouses/partners of IDUs, etc.). Other staff – outreach workers, peer educators and project officers from the programme – undertake counselling through one-to-one interactions and home-care visits, and motivate and link IDUs to various services. (Community-based care and support counselling relates to nutrition and diet, OI management and ART adherence as well as reinforcing messages on safer injecting and sexual practices).

The pilot project aimed to strengthen SASO's existing harm reduction and HIV prevention interventions whilst more specifically aiming to strengthen and extend the provision and facilitation of care, support and treatment not only to individuals but also to their families and communities.

During their early outreach work in the community, SASO staff and fieldworkers found many IDUs who were diagnosed HIV-positive, but lacking in any care and support services. Efforts were made to promote an attitude of positive living and to identify ways to reduce the often 'double' stigma and discrimination faced by them at multiple levels. SASO started its home-based care programme for the IDUs living with HIV and gradually scaled this up to include both clinic and home-based healthcare. In comparison with other healthcare providers in the public and private sectors, feedback from IDUs shows SASO's clinic-based services are considered user-friendly, its doctors and counsellors empathetic and non-discriminatory, and the services wide-ranging and attuned to their needs as current or ex-drug users living with HIV.

To further strengthen SASO and community responses to supporting IDUs living with HIV, the Alliance initiated support in developing a new partnership with SASO in 2004. The pilot project aimed to strengthen SASO's existing harm reduction and HIV prevention interventions whilst more specifically aiming to strengthen and extend the provision and facilitation of care, support and treatment not only to individuals but also to their families and communities. This was also influenced by a need to support an increasing number of widows/spouses and families of drug users, many of whom are also now HIV-positive (the result of infections from their partners or from having to resort to sex work as a means of financial support).

The package of **home and community-based care and support services** provided by SASO takes a holistic approach to supporting individual IDUs, their caregivers and/or families, incorporating services provided through the SASO clinic/DIC, the home and

the community, as well as conducting broader mobilisation activities in the community aimed at reducing stigma and discrimination against those most affected by drug use and/or HIV/AIDS:

- **Diagnostic support and health check-up facilities:** At the SASO clinic/DIC, diagnostic and medical support is provided to all those registering as IDUs or spouses/partners of IDUs. For IDUs, current or ex-users, living with HIV, diagnostic support is provided for those with a CD4 count below 200. This support also includes free health check ups with provision of basic healthcare medicines and treatment for OIs for those living with HIV.

- **Referrals and linkages:** Whilst the aforementioned support is provided at the clinic/DIC, these centres are unable to provide comprehensive services to IDUs living with HIV due to limited resources, so significant importance is attached to developing various referrals and linkages with governmental and other non-governmental organisations for appropriate services. Initiation of ART is preceded by other tests such as Hepatitis B and C, Liver Function Test (LFT), Kidney Function Test (KFT), ultrasound, chest x-ray, complete haemogram and blood sugar, for which they are linked to other healthcare centres. For widows with no support system and orphans and vulnerable children (OVC), these tests are facilitated by SASO either free of cost or at discounted price, with female IDUs being particularly encouraged to undertake diagnostic tests for free. All the tests for the target groups are accompanied by pre-test counselling. Additionally, HIV-positive IDUs frequently suffer various OIs such as, skin infection, tuberculosis (TB), diarrhoea, and cryptomaningitis (fungal infection of brain) for which they are referred for treatment to other healthcare centres. It should be noted that such referrals and linkages are two-way i.e. target groups are not only referred from SASO to other agencies but from other institutions (including drug rehabilitation centres, private or public healthcare providers, and NGOs/CBOs) to SASO. SASO staff has also advocated and been successful in obtaining monetary concessions/free services from these centres for female IDUs. The emphasis on referrals and linkages is very important for the sustainability of the services as well as preventing duplication. Referrals are made for those requiring HIV-related treatment that are free of cost, e.g. to government hospitals and HIV voluntary counselling and testing centre (VCTC), CD4 count, ART, and prevention of parent-to-child transmission (PPTCT).

While undergoing ART, one can become weak as a result of low CD4 count, making him/her more vulnerable to sickness and OIs.

- **Counselling:** As already discussed above, counselling is provided at various levels, not only as a means to provide psycho-social support but also to provide accurate information about issues and services related to HIV/AIDS, and to encourage those infected with HIV to 'live positively' i.e. support in adjusting to new 'social identity' and to be careful with their health. Additionally, PLHIV are encouraged to join support groups and/or local positive networks. While undergoing ART, one can become weak as a result of low CD4 count, making him/her more vulnerable to sickness and OIs. However, if a PLHIV is current/active IDU, ART adherence is more challenging because of the greater importance attached to drugs over ART. Therefore, significant emphasis is placed on counselling of IDUs living with HIV and their families/caregivers on nutrition and ART adherence.

Positive living through care and support

My husband was a daily wage labourer, but after he started using drugs, he could not work and we became poorer. Later, he became hesitant to even meet people due to stigma.

I am 32 and we have 5 children. I approached SASO for my husband's detoxification. They gave me information about harmful effects of drugs, HIV/AIDS and ways to take care of my husband. However, he relapsed to drug use; then he underwent substitution therapy.

Later, he suffered TB, and on testing for HIV, he was found positive…Soon, I too faced health problems, contacted SASO, and was tested HIV positive. This resulted in our isolation from our family and community, depression and fear. But the SASO peer educator motivated me to join a support group, and I shared my problems and experience with other women who faced similar problems. Resultantly, I was instilled with a positive attitude.

Now I am receiving medical support from SASO clinic, information on HIV/STIs, and medicines for my family. On getting two of my children tested, the younger one has been found HIV positive, who is receiving education support from SASO. While I am currently under ART, SASO is facilitating for ART for my husband and child.

With a better health now, I am working as a food vendor and earning around INR 70-100 per day that supports my family. Although my husband is unable to work due to his health, I am ensuring his regular visit to SASO clinic and adherence to substitution therapy.

- **Income generation support:** At the community level, the formation of **self-help groups** for men (ex-IDUs) and women (spouses and widows of IDUs) has worked very well in mutual support between peers and for facilitating small income-generation support e.g. making pickles, detergents, writing pads, selling dry fish, catering, and supplying clothes. Strengthening the economic situation of IDUs by engaging them in such activities is seen as an essential approach for preventing them from relapsing to drug use and/or adherence to ART and other medical treatment.

- **Education support:** Basic education support to children affected by and/or living with HIV, especially children of widows, those orphaned as a result of losing one or both parents to injecting drug use and/or AIDS-related illnesses (and/or those judged to be living in the poorest conditions) is also provided as part of the care and support programme. This is need-based support in the form of payment for admission fees, school fees, uniforms and school books. Again, referrals and linkages have been very important in ensuring that those who most need support are linked with other NGOs providing support to children and women, especially widows, such as World Vision, Catholic Relief Services, Manipur Positive Network, Population Council of India and the Clinton Foundation.

Women and Injecting Drug Use

Working with IDUs, especially those living with HIV, and their families has consistently identified issues relating to female spouses or sexual partners, especially the increasing number of widows. Discussions in the community have highlighted issues of impoverishment and vulnerability amongst these women as a result of reduced (or, in many cases no) support from their deceased husbands'/partners' families – specifically, problems around property ownership and inheritance and support for their children. Additionally, many of these women have become IDUs and/or resort to sex work as a means of financial support, thus increasing their vulnerability to HIV.

More specifically, within the family, it is the spouse or partner of the IDU who is often the most affected by drug use and who bears an added burden in terms of the social, familial, economic, health and psychological consequences. For example, female spouses tend to be the breadwinners in the family and face the additional challenges of household income being diverted by their husbands or partners for buying drugs. In many cases, they also face domestic violence. Yet, a major burden faced by women is the extent to which they are often held responsible by the family for their partner or husband's drug use, thus having limited social support, resulting in feelings of guilt, embarrassment and depression with a consequent impact on their physical and emotional wellbeing. Above all, they have a huge risk of transmission of HIV/STIs.

Female drug users who are engaged in sex work face double vulnerability and risk of HIV infection as many of their clients force them to take alcohol and/or consume drugs.

Some spouses/partners of IDUs resort to drug use as a result of their own frustration and depression, habits which can be fuelled and sustained by the ease of access to drugs from their male partners and the broader drug environment, even amongst those who have undergone treatment. Female drug users who are engaged in sex work face double vulnerability and risk of HIV infection as many of their clients force them to take alcohol and/or consume drugs. Moreover, as with sex workers in other environments, the challenges of negotiating condom use with male sexual partners is an additional challenge to overcome. For female IDUs who have successfully become drug-free from time spent in rehabilitation centres but have no family support, the lack of a supportive home/family environment means that frequently they revert to sex work as their source of financial support, and, in many cases, relapse into drug use. Thus, levels of vulnerability and stigma are multiplied for female IDUs as compared with their male counterparts.

To respond to the significant evidence-based demand and needs of women within this environment, both users and/or spouses and partners of male IDUs, SASO became a key partner of an Alliance project in 2006, funded by the Department for International Development (DFID), with a focus on addressing the feminisation of HIV and AIDS in six states in India. This programme

was the first of its kind in Manipur and was instrumental in highlighting the impact and scale of injecting drug use on and amongst women. In the end of project evaluation, the Alliance/SASO programme was described as *"…ground-breaking, not only in terms of service provision for women, but specifically for bringing focus amongst the IDU NGOs on gender equity and gender-sensitive programming for the first time..*[9]*"*

The project focused on strengthening and developing community-centred approaches for enhancing awareness, information and knowledge on sexual and reproductive

My journey as a female drug user

I am 34 and have studied up to class tenth. After the birth of my second child, I found that my husband was an IDU, but he would quarrel if I would ask him to stop using drugs. He sold off most of the household items…Later, I too started injecting drugs along with him. Soon, my in-laws came to know and isolated me.

I contacted Sneha Bhawan, a rehabilitation centre, through a friend and stayed there for treatment. My husband often visited me there. As he refused to join me in the treatment despite my attempts to persuade him, we divorced. Then I was tested HIV positive. Gradually, after 3 years of my stay there, I left drugs. Later, I stayed with my sister and worked for nearly one year with an NGO working with sex workers, for which I frequently visited North AOC, a hub for sex work. During this time I had an affair with a man and planned to get married. Our families disapproved this. Depression got me back to drugs.

Drugs pushed me into drug-peddling and sex work at North AOC. I earned good money but at the same time felt guilty. I was harassed by clients who did not want to use condoms. Here, I came in touch with a SASO outreach worker who encouraged me to avail health services at SASO. Initially, reluctant to visit their DIC and health clinic, I started visiting it after a few interactions. I received needles and syringes, diagnosis, detoxification, medicines, and counselling. I also got involved in SHG activities and joined SASO as a peer educator after training. But I had to discontinue, as I got pregnant. Even then, they helped me register at a hospital for delivery, and later, arranged for my admission into a treatment centre, where I stayed with my newly born child. While I stopped using drugs, my baby died after six months.

Depression gripped me after I left the treatment centre and I was tempted to use alcohol and drugs. But on contacting, SASO staff encouraged me and employed me as an outreach worker. Here, I have made many friends who are facing similar problems. Although I know that I will not live long, yet I am conscious of my health and I motivate people like me to live positively.

[9] Department for International Development (2007), End of Project Evaluation, PMO, New Delhi,

health (SRH) and HIV/AIDS as well as increasing women's access to health, social and legal support services. Key to the approach – and recognising that female IDU issues remain complex and underground – has been the use of **small-group meetings** involving families and communities led by peer educators and outreach workers. The outreach workers, peer educators and volunteers gradually established contacts with the target population of women by making regular home and community visits and conducting small-group meetings. During such visits, relevant information about SRH, HIV/AIDS and other STIs as well as reproductive tract infections (RTIs), and harm reduction among IDUs in addition to available services at SASO and other institutions, was passed on to them. Women as well as adolescent girls found with symptoms of STI/RTI and other SRH problems were linked to service providers.

Recognising the special needs of female IDUs, the DFID programme helped to strengthen a **DIC** to be more women-friendly, in North AOC, a site in Imphal where the majority of the target beneficiaries were located. Many of them are sex workers and their clients, and male IDUs in search of drugs, resulting in this location being highly stigmatised by the general community. The DIC strategy has been particularly successful as an approach and resulted in an increased number of visitors and in the frequency of visits made by them.

At the DIC, the women receive a variety of support including needle/syringe exchange, free condoms, health check ups including medicines for basic healthcare, clinic based detoxification, OD management with free OD medicine, counselling and general information and advice on referrals to other institutions for reproductive health and HIV/AIDS-related care. The DIC also offers recreational opportunities including watching TV, reading newspapers and women's magazines, and space for chatting with friends and centre staff. Many women also use the centre to bathe and to use the make-up kits provided by the DIC, which also acts as a venue for meetings of the various self-help groups/support groups, as well as for conducting educational classes.

The DIC strategy has been particularly successful as an approach and resulted in an increased number of visitors and in the frequency of the visits made by them.

To ensure respect and confidentiality of its visitors, the DIC has encouraged mixed groups to use the facilities – including the general population who live in the locality around North AOC. This strategy has been adopted specifically to reduce stereotyping and branding of visitors to the DIC. This is the only such DIC in Manipur for female IDUs.

Till now most of the support has been extended to widows and spouses of IDUs and/or PLHIV. They have been helped with setting up of small businesses with the soft loans provided to them by SASO, e.g. tea stall, weaving, spinning of silk, and vegetable vendoring. Repayment of loans is made by them either monthly or weekly and the installment is decided by them. However, due to health problems, repayment becomes difficult for PLHIV and many of them are unable to continue with their business. To address this issue, lately, joint loans have been given to a group of five spouses of IDUs living with HIV. Income generation support to a group also leads to strengthening of the group and many other groups by experience-sharing and replication.

Support groups were formed with partners/spouses of male IDUs, widows, female IDUs, WLHIV, sex workers and adolescent girls, and were helped in building their institutional capacity. Through various activities, these support structures have not only helped in spreading awareness about HIV/AIDS, SRH and related issues such as ART and its adherence, STIs/RTIs, PPTCT, contraception, condom use, immunisation, but also provided information on legal rights and entitlements, health and social service schemes available and accessible in the community. The groups have also been instrumental in promoting psycho-social well-being and providing income generation support amongst members.

The target groups of women reached through the DFID programme were linked to various services through the DIC. Most of the women found the DIC 'friendly', chiefly because the majority of the staff, i.e. the health workers, counsellors, project staff, are women, and the majority of the co-visitors are also women. DIC visitors particularly liked the presence of a woman doctor. Some women have stated, "*We feel free to discuss anything confidential with SASO staff, even things we would not feel comfortable discussing with our family members and friends. We come here whenever we find some extra little time.*" The fact that the confidentiality of the status of the female IDUs, WLHIV, sex workers and other vulnerable groups, is maintained is appreciated by them.

Additionally, as part of its **referrals and linkages services**, apart from linkages with government institutions for services of ART and PPTCT and with few other NGOs for harm reduction and care and support services, SASO has been able to negotiate with two rehabilitation centres for female drug users, to exempt the treatment and rehabilitation costs for those referred by them.

To evaluate the impact of the programme, Alliance India utilised the participatory evaluation technique of 'Most Significant Change' to hear the voices of the communities.

Capacity building of NGO staff was another key element of this programme, as on one hand, it helped in enhancing the information and knowledge of the community on SRH and HIV/AIDS issues resulting in an increased demand for services from the community, and on the other hand, it would lead to increase in the access of health services and other benefits by the community. For this, various training and capacity building activities were undertaken on – participatory techniques for conducting PCAs with the community, SRH and related issues, Gender and Rights, Gender and Sexuality, Counselling, Resource Mobilisation, PPTCT, and Knowledge Management. As a result of trainings, SASO and NGO staff was able to develop a resource library, resource directory on various services available in the community, and IEC materials on OD management, home management of OIs, ANC and STI in local language. Such resources have provided support in spreading awareness and imparting information to the community on various issues related to SRH and HIV/AIDS.

To **evaluate** the impact of the programme, Alliance India utilised the participatory evaluation technique of 'Most Significant Change' to hear the voices of the communities. The impact of the programme was gauged in terms of changes brought about in the lives of people, capacity of NGOs' staff in implementing the programme and the emerging needs of women.

Strengthening Family Support

The SASO and Alliance have had a multi-pronged approach to enhance community acceptance and strengthen family support for IDUs living with HIV in Manipur, which was earlier quite difficult. Thus, for their increased participation and creation of an enabling environment, knowledge is imparted to family members through one-to-one interactions, counselling, care-givers' training and support group activities.

"My neighbours started supporting me. They are responsible for making my family understand my problem. They are concerned about my health all the time."
– a WLHIV, Manipur

One of the significant strategies to enhance families' ownership of responsibility towards their drug-using member is to involve them during the process of detoxification for IDUs. Family member(s) is invited and asked to accompany the IDU, and through various interactions, is made aware of the problems associated with drug use and the significance of the family's support for effective detoxification, treatment and prevention of relapse. Further, medicines are handed over to the family member(s) rather than the IDU, follow-up and home-visits are made to the families for maximum interaction and consistent counselling, besides continuous awareness on HIV/AIDS and available services. Similar approach is adopted for mobilising support, empathy, positive attitude and non-discriminatory practices from families and communities for the IDUs living with HIV to ensure their ART adherence and help them lead a normal life.

"People in the community supported by informing me to attend awareness programme. They look after my children when I go out for work. They support me to go out and meet people."
– a WLHIV, Manipur

Support Groups have also been an effective tool for garnering community-involvement and family support. The knowledge gained (on HIV and related issues and prevention) and support for income generation activities within support groups leads to empowerment of IDUs and/or those living with HIV, within the family as well as outside. As a spin off, the knowledge percolates down to the communities, which in turn get motivated to extend support to IDUs and/or PLHIV member in their families *(See more on support groups in the section below)*

Care-givers' training provided by SASO is yet another method for strengthening family support for IDUs living with HIV. Considering immediate family member(s) as primary care-giver(s) due to the emotional bonding, they are imparted training on home-based care that involves basic information on HIV/AIDS, nutrition, nursing care, OI management, universal precaution, ART management in special cases, and psycho-social support. The resource persons for this are usually doctors, specialists from other organisations, as well as SASO staff. The participatory method of training encourages wider sharing of experiences, issues and identifying ways to address them. Such trainings inculcate a sense of ownership for the problems of their family member who is an IDU living with HIV. SASO has ensured this training to almost every family having an IDU member, and to at least one family member within

such families; as a result 80 individuals have been provided care-givers' training till now.

Support Groups

Support groups help members in sharing relevant information, listening and learning from each others' experiences, and providing the much-needed psychosocial support to each other. Target population with similar backgrounds have been encouraged to be part of the same group so that they can address issues relevant to them. The support groups formed within the Alliance-SASO programmes have been those for spouses of IDUs, PLHIV widows, apart from those for male and female IDUs. Interestingly, in few districts of Manipur, there are several men's groups as well, formed at the request and

My support group is my strength

Anouba Mayol, meaning 'new bud' is the name the support group I belong to and all nine of us in this group are widows of PLHIV. I am 29 and also HIV positive.

Few years back, I had a love marriage. My husband was handsome, visited gym and had big biceps! He worked in a small family-owned studio. All was going well, until one day, after one year of our marriage, he started complaining of chest problem, and then disappeared with his brother and sister for five days. Later, I found that he had gone to Guwahati (Assam) for treatment. After much persuasion, one of his close friends told me that my husband was an IDU, and now HIV positive too. However, I did not disclose to my husband and his family that I had come to know about it. Eventually, he died; his family blamed me for this, tortured and threatened me, due to which I came back to my parents' house. Later, I claimed my share of my husband's property, but in vain. My husband's brother went to the extent of threatening me with a knife; I never went back again.

Later, I and my daughter were also found positive; depression gripped me, and fear of stigma and death made me lose sleep. At this time, a SASO peer educator approached me and assured me of all support. On her motivation, I joined the support group. We met once a month with a fixed agenda, maintained attendance register and a minute book, and took relevant decisions. The peer educator and outreach worker from SASO also attended our meetings and provided us with information on STI/RTI, PPTCT and HIV/AIDS, and the importance of 'positive living'. Gradually, we became competent to hold meetings on our own.

We also started some income generation activities, for which we were given support from SASO. I have been given INR1000 to make silk thread. Also, each member from the group contributes INR10 per month to the group-fund that is further used for loans on a rotational basis.

I have experienced immense change in my life due to the support group. I have realised that I need to live a healthy and longer life especially for my daughter. I am happy to receive nutritional and educational support for my daughter from SASO. While she is on ART, I will start soon…

initiative of women's groups, stating: "*If men do not change, our knowledge is often useless*". Truck drivers, traders, soldiers and policemen are included in these groups.

The support groups' capacity has been built by SASO staff on organising various activities in the groups (including agenda-setting and minuting of meetings), accounts-keeping, besides providing them with information on drug use, HIV/AIDS, SRH and related services and welfare schemes. Group-savings and income generation activities are also facilitated through support groups.

The adolescent girls' support group has been quite active, and as reported by them, they feel quite happy to be a part of such forum where they are able to freely discuss about their health, sexuality and HIV/AIDS. They have been actively transferring to their peers in the community, schools and colleges, information related to HIV/AIDS, STI/RTI, gender and rights, safe sex and negotiating condom use with partners.

The Alliance and SASO have also facilitated the linkage of many women from various support groups to government health centres, special social welfare schemes, legal aid organisations, and vocational training centres, based on their needs.

The Alliance and SASO have also facilitated the linkage of many women from various support groups to government health centres, special social welfare schemes, legal aid organisations, and vocational training centres, based on their needs.

The empowered members of various support groups have been helping other IDUs in refraining from drugs and preventing themselves from either contracting or transmitting HIV. They have been also instrumental in motivating the communities and families to strengthen their much-needed support for the IDUs and those living with HIV.

Hands-on-Training for Doctors and Paramedics

In Manipur, four main issues related to the healthcare needs of PLHIV are – insufficient health care facilities for increasing number of PLHIV; inaccessibility of most existing healthcare centres; discrimination and avoidance on the part of many healthcare professionals to attend to PLHIV for fear of infection; and absence of training opportunities for medical practitioners who are interested in HIV/AIDS work.

To address these needs, a hands-on-training for doctors and paramedics in Manipur was initiated by SASO. Preceded by assessment/service mapping through consultations with SASO staff, MNP+, care workers, NGOs providing treatment and care, and doctors involved in HIV/AIDS work, the training was designed on the basis of the current services available as well as the gaps identified through this assessment process.

Since 2004, four such trainings have been completed for 11 doctors and 12 paramedics. Trainees have been selected from among those already working with SASO, other NGOs working with PLHIV, and private and government medical practitioners. Besides an eligibility criteria of MBBS degree for doctors and ANM/GNM degree for paramedics, selection is based on an assessment (undertaken through one-to-one interaction) of their commitment levels.

Till now all such trainings have hinged upon both the updated theoretical aspects on HIV/AIDS and related issues, besides practical experiences of dealing with positive persons. Rapport and relationship building with the PLHIV, considering their anxieties,

depression levels and psychological trauma, has been pivotal to these trainings. Hands-on treatment and interaction with the PLHIV, practical dealings with their problems such as OIs, co-infections, ART, and maintaining confidentiality have been the key components too. A short exposure visit to government hospitals is included for first-hand experience of treatment and management in residential setting, especially for cases of more severe complications who normally do not turn up in an outpatient or clinic setting. Home visits help them in understanding the socio-economic and psychological problems faced by PLHIV. This understanding supports them in times when counselling is required for PLHIV who visit them for treatment.

Hands-on-training for doctors and paramedics has proved to be an effective model. This has not only been instrumental in updating and enhancing the technical knowledge of medical practitioners with regard to HIV/AIDS, but has also been successful in transforming their attitude towards PLHIV. The participant doctors and paramedics, after the completion of the training, have committed to further voluntary service at SASO and other organisations working for PLHIV. This approach is deemed significant, as it not only indicates the commitment of the trained medical practitioners, but also allows them to practice what they have learnt during the training in a real field situation.

Ignorance of a doctor, humiliation of an IDU

An unmarried IDU and 30 years of age, Meena, along with a SASO staff, visited the Dental OPD at a nearby hospital for tooth extraction. During an informal conversation, the doctor, after hearing that she was accompanied by a SASO staff, probed more and asked details about her personal life, including drug use and HIV status. She told him specifically that she was not HIV positive. Subsequently, the doctor tried to frighten her about tooth extraction, saying it might lead to complications.

After waiting outside for long, the SASO staff entered the room, and the doctor tried to re-confirm from him if Meena was HIV positive. Despite being told again that she was not positive, the doctor continued to hesitate and referred her to another OPD for a check-up on her heart rate and blood pressure. These tests were obviously unnecessary; the doctor was simply avoiding Meena. Due to the resultant argument between the doctor and the SASO staff, the doctor made him sign a written statement stating that he would own the responsibility for any harm caused to the doctor or patient while extracting the tooth. Eventually, the doctor still refused to attend to Meena and discharged her with false diagnosis and medicines.

Meena then at SASO office, broke down into tears for the humiliation and swore not to visit any hospital again. However, after counselling by the SASO staff, she finally visited another hospital linked with SASO, where her tooth was extracted and treated. Subsequently, the SASO Secretary submitted a written complaint about the incident to the Superintendent of the former hospital, but in vain.

- There has been marked increase in community involvement and acceptance for the IDUs and PLHIV that was extremely difficult before. SASO's peer educators and outreach workers, initially condemned by the community, are now being welcomed and supported for organising various meetings and awareness-building activities. The target groups are increasingly supporting and participating in programme implementation, and voluntarily approaching the DIC for obtaining care, support and treatment and prevention services.

- Focus has been brought on families, unlike recently when most of the programmes for IDUs in Manipur considered them as a separate entity. Resultantly, a holistic approach with comprehensive services for IDUs and those living with HIV, has brought about considerable reduction in stigma and discrimination within the families and communities. As reported, majority of male IDUs are being now accompanied by their mothers and/or wives for services, which directly indicates the increased significance of the role of women in HIV prevention and care and support.

- The income generation support has been of immense value, especially to women. Earning a skill and stable income has resulted in their financial independence and enhanced their self-confidence and self-esteem.

- Emphasis on female IDUs for the first time in Manipur has been brought through the SASO-Alliance programme. Creating a separate and user-friendly DIC for female IDUs and other female target groups has been an important step towards protecting them from police harassment, teasing by male counterparts, and for understanding their problems more comprehensively. This is the first ever DIC in Manipur for female IDUs.

- Addressing the SRH issues of women including the female IDUs, has not only improved their knowledge on – STI/RTI, menstrual hygiene, contraception including condom use and its negotiation with partners, importance of family planning and birth spacing – but has also given a smooth entry into HIV/AIDS issues. There has been a perceptible increase in access to services like STI treatment, VCTC, ART and PPTCT, and safer injecting and sexual practices.

- Through support groups and other networks, greater access to wider target population has been reached and better understanding of their problems has been acquired, with appropriate responses provided. Many women (spouses/partners of IDUs, sex workers, female IDUs and other vulnerable women) have acquired the skills of negotiating with their partners for condom use through the awareness and knowledge gained. Many of them have reported to have greater awareness on their rights and entitlements and laws; greater negotiating power even within the families and community; and living positively despite facing multiple problems. Some of their statements are: "*Now we have a place to go to in times of trouble*"; "*I do not feel alone*"; "*Now I have more confidence in life. I will get over the problem some*

"Through IGP, I am able to earn and maintain my family. This financial independence is important for me as I am no longer dependent on my in-laws. I can now voice my feelings openly… I am not afraid of facing anyone now…"

– Pramo Devi, 34, Imphal

"I am now ready to fight for anything. Now even the HIV is scared of me; it is inside my body only because it does not have an outlet!"

– Spouse of an IDU, Imphal

"Men cannot take undue advantage from us now!"
– Adolescent girls' support group

"The training period was extensive…We could 'touch' the patients ourselves. This is very important in medical training… We learned how to deal with the PLHIV with utmost sensitivity. I feel much more confident and skilled..."
– Dr. Indira, part-time doctor, DIC, SASO

day"; "*I feel motivated to work for others like me*"; "*My health is far better now than before*"; "*We help our friends during times of crisis*".

- The hands-on-training for doctors and paramedics has been able to enhance their knowledge and awareness on HIV/AIDS, sensitise them towards those living with and affected by HIV, and thus reducing stigma and discrimination at their end. The comprehensive, updated, intensive and locally contextualised training modality developed and used amidst acute resource constraints has been inspiring. Post training, all the trainees are now working with the community in Manipur – with SASO, MNP+ and other NGOs engaged in the field of HIV/AIDS, and in health projects providing services to the PLHIV in rural Manipur. There is now a greater demand for the training, especially from the younger doctors and paramedics in Manipur. This is a significant change if looked at the hindsight when the health professionals used to avoid treating PLHIV and discriminated them.

- SASO has gradually emerged as a role model community-based organisation, and is one of the very few organisations in Manipur that involves the families and communities of IDUs and focuses on female IDUs for a comprehensive development and greater impact. As part of organisational development of SASO, the Alliance supported them in analysing their own capacities, identifying the gaps for capacity building, as well as strengths for enhancing them, as a result of which:
  - SASO's management system was strengthened, its vision and strategies were reformulated, and a governance system including human resource (HR), financial system, procurement policy, and staff selection process, was developed. An Operational System Manual including policies and guidelines for the aforementioned aspects was also prepared.
  - Having emerged as a strong organisation and supporting many other NGOs, SASO has been able to give systematic and ongoing support to local organisations in Manipur and other Northeastern States of India. SASO staff have extended their learning from capacity building trainings received from Alliance to these organisations – mainly in programmatic areas, such as, SRH, immunisation, child care, STI, adolescent health, gender and sexuality, PPTCT, information on schemes and legal issues, resource mobilisation and advocacy.
  - It has gained wide scale recognition for its programmes in Manipur. In fact, the SASO-Alliance model of home and community-based care and support to IDUs living with HIV and their families, has been acknowledged by UNAIDS and UNODC as a best practice model for Asian countries. It is being replicated by NGOs in many states of India, particularly the Northeast; and its home-based detoxification method has been included in the Government's RIAC project. As a result of its best practices, experiences and knowledge, SASO has been considered an important organisation for providing inputs in formulation of various policies and programmes by MSACS, and had been given responsibility for HIV test counselling in two testing centres. These are now directly managed by MSACS.
  - Currently a State Partner to the Alliance, SASO is being envisioned as its Linking Organisation.

Addressing the Challenges and Moving Forward

- IDUs and PLHIV continue to give low priority to their health and changing their behaviour, which is further fuelling the HIV/AIDS epidemic and the increasing infection rates amongst the general population in Manipur. Frequent follow-up by service providers and peer educators is necessary for determining their health condition, encouraging safer injecting and sexual practices, and health-seeking behaviour. Due to limited resources, however, it is difficult for SASO to cope with the increasing demand for medical and counselling services. Therefore, there is a need to strengthen other healthcare centres by ensuring proper rehabilitation and support facilities, upgrading of knowledge of medical practitioners, and effective follow-up mechanisms, especially at the community level.

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- The SASO trained paramedics and doctors are high in demand but are too few as compared to the magnitude of the problem in Manipur. With newer complications among PLHIV, more resources are required to undertake systematic research to understand and deal with them, as currently, the trainers, trainees, as well as other medical practitioners in Manipur find themselves ill-equipped to deal with these emerging complexities. Although, the hands-on-training for doctors and paramedics is replicable, resource constraints prevent scaling up of such training.

- Prevalence rate of Hepatitis C co-infection among the PLHIV is on a rise in Manipur and what is more worrying is that most of them are ignorant about it. Unfortunately, those who are aware are unable to access the treatment as they lack resources and information about services. Besides, there is little local expertise to deal with the issue and limited systematic research undertaken for the same. HepC is a blood borne virus that affects the liver immensely, and since the chances for the damage of the liver of the PLHIV under ART is quite high, HCV co-infection makes it all the more difficult. It is noteworthy that the efforts made for curbing the HIV/AIDS epidemic would be a sheer waste if newer complications like HCV are overlooked. There is a need to advocate for a comprehensive package that includes a provision for adequate care for HCV, integrated with HIV/AIDS treatment and services. At the policy level, the government at the national and state levels, along with other stakeholders should make concerted efforts to prioritise HCV as one of the public health issues and make efforts to mainstream it for treatment facilities.

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- To address the deteriorated economic condition of IDUs and PLHIV, though the Alliance provides income generation support, yet the support is mostly provided for their spouses and/or widows because women have been seen to be taking up family responsibility, and men usually expect money for large-scale business. Funds allocated in the programme fall short for such demands and private banks do not offer loans to PLHIV, and even if they do, with high interest rates. Also, for women who have been given loans, repayment becomes difficult owing to their falling health. To address this issue, the Alliance and SASO have recently given loan to a group of women so that if one falls sick, others could continue the business. Interaction with women from such a group has revealed that they lack certain basic

skills that are necessary for undertaking a business, such as, accounts-keeping, and tracking of profit/loss.

Considering the numerous challenges faced with regard to income generation support for PLHIV, it is recommended that there be a systematic approach for large scale benefit of target population. Instead of involving IGP as only one of the components of a programme, it should be implemented as a separate programme altogether. This approach would have many advantages – first, all the funds by a particular donor organisation would be directed towards income generation activities, which will not only facilitate giving seed money to many people, but also larger amount for initiating sustainable businesses; secondly, such single-agenda programme would lead to comprehensive services including monitoring, capacity building, advocacy and linkages with others institutions that would help in promoting and sustaining their businesses; thirdly, the target groups will be able to easily repay the loans and on time. Economic enhancement through comprehensive income generation support would definitely lead to all round development of IDUs, PLHIV and their families.

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- In Manipur, not many programmes have addressed the issues with children of IDUs and PLHIV holistically. The two major challenges faced in Manipur are related to nutritional and psycho-social support for children. While nutritional support is inadequate, children's counselling is difficult as in most circumstances they either do not know about their own positive status, or their parents', or both, but are on ART. There is a need to have strengthened advocacy for nutritional support from the government and more professionals should be identified and trained specifically for the psycho-social counselling of children living with and affected by HIV.

- For the female IDUs and sex workers, it is difficult to undertake a regular follow-up as they are a highly mobile population, either within or outside Imphal, in search of work. In many cases, their families, due to fear of isolation from the rest of the community, dissociate with them. This is also one of the reasons for the weakening of the support group for female IDUs. Apart from this, the provision of information about laws and entitlements under the SRH and HIV/AIDS integration programme, though led to growth of information level amongst the women groups, however, it rarely got translated into access of these services, mainly because many of them were apprehensive about the long judicial process and lack of shelter homes for female drug users, and therefore preferred to negotiate with their families and settle the issues amicably. Therefore, there is a need to design long-term initiatives for women (female IDUs, WLHIV and other vulnerable groups), incorporate the SRH and HIV/AIDS integration approach into other care and support services, and look at their issues at the state and policy level.

A number of challenges have been identified in the preceding paragraphs. NACP-III offers a guide to the commitment of Government of India in halting and reversing the epidemic in India through a multi-pronged strategy that includes prevention of new infections in high risk groups (HRGs) and general population through saturation of HRGs with targeted interventions and scaled-up interventions in the general population, providing greater care, support and treatment to larger number

of PLHIV and strengthening the infrastructure, systems and human resources in the programmes. NACP-III is informed by a set of guiding principles, one of which states that strategic and programme interventions will be attuned to reflect specific local contexts. This is particularly of great importance in the context of Manipur because NACP-III recognises that IDU-driven HIV can quickly spiral from a core group to the general population, necessitating a comprehensive response based on robust epidemiological networks. Clearly, innovative IDU surveillance and IDU responses need higher attention than has so far been the case.

The NACP-III programme priorities and thrust areas offer a lot in terms of meeting a number of challenges mentioned earlier. Of particular significance is the need to leverage technical and financial resources for optimum results keeping in mind the existing challenges and systemic gaps. It is important to recognise that some of the existing challenges can only be met through effective partnerships and multi-sectoral response. Civil society organisations can indeed play a crucial role in prevention, care, support, treatment and service delivery. SASO has emerged as a major player in response to HIV and AIDS in Manipur. While SASO, as a leading civil society organisation, has demonstrated on how community-led programmes are delivered with high responsiveness and result-orientation, there is also a growing recognition that much more needs to be done to consolidate the gains made thus far. Indeed the road is long and winding and it would require persistent efforts rooted in community perspectives and experience.

Civil society organisations can indeed play a crucial role in prevention, care, support, treatment and service delivery.

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

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

India HIV/AIDS Alliance
Third Floor, Kushal House
39 Nehru Place, New Delhi - 110019
Phone: +91-11-41633081
Fax: +91-11-41633085
Website: www.aidsalliance.org;
Setu Virtual Resource Centre:
www.aidsallianceindia.net

Social Awareness Service Organisation (SASO)
Khwai Lalambung Makhong, RIMS Road (S)
Imphal - 795001
Manipur
Phone: +91- 385-2411408, 2414011
Fax: +91 -385- 2411409
Email: saso.imp@gmail.com