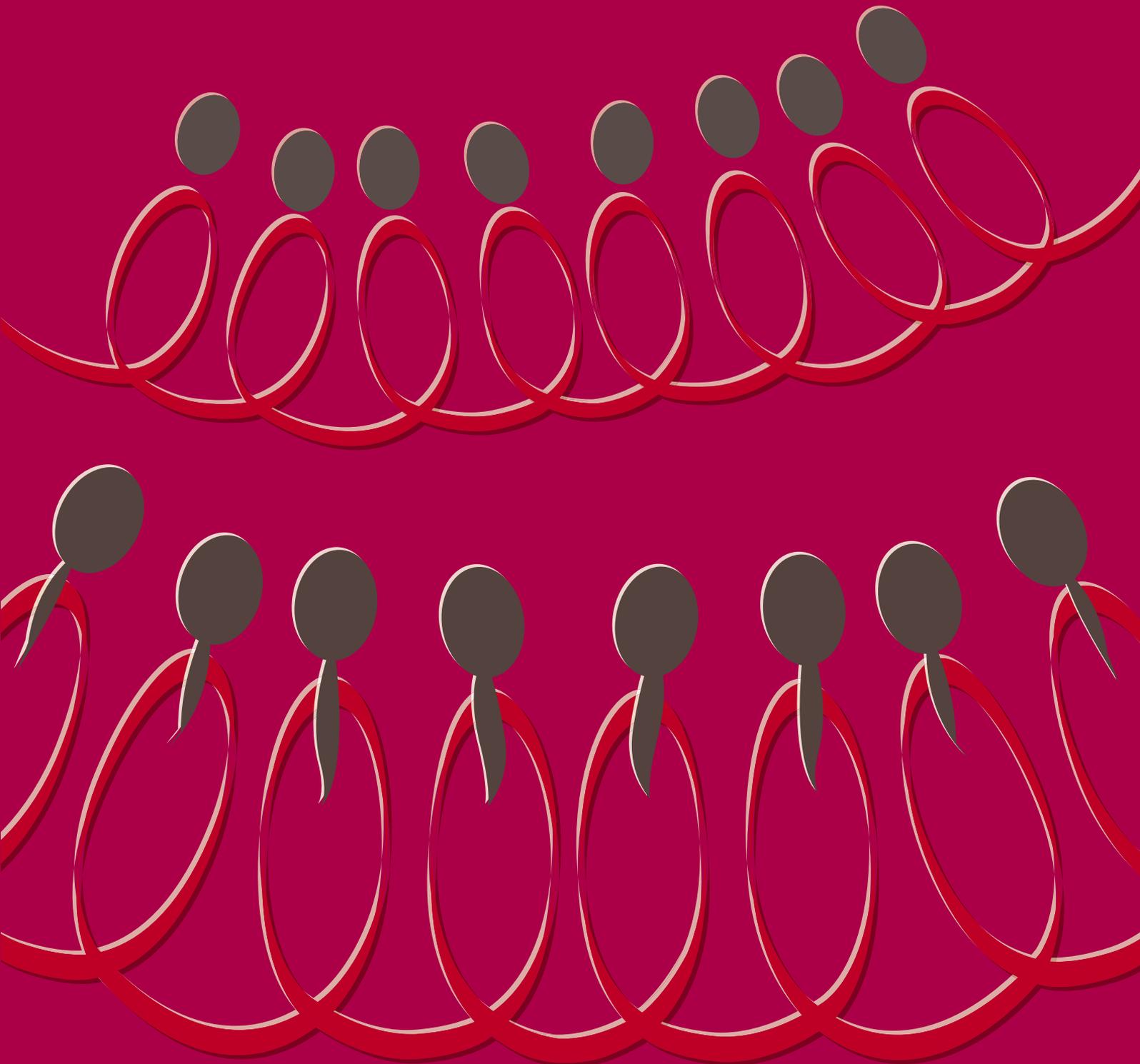


Common Cause, Collective Strength

Findings of an evaluation of support groups of women and children living with and/or affected by HIV/AIDS in three Indian States



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Report prepared by: India HIV/AIDS Alliance

The India HIV/AIDS Alliance (Alliance India) was established in 1999 to expand and intensify the International HIV/AIDS Alliance's global strategy of supporting community action to reduce the spread of HIV and mitigate the impact of AIDS. Since its inception, the Alliance has been committed to fostering and supporting the development of community-driven approaches to HIV/AIDS prevention, care and support and impact mitigation in India, with an emphasis on local leadership and responsibility.

Alliance India currently provides programmatic, technical, strategic, organisational development and financial support to a country-wide network of over 100 NGOs through a national Secretariat based in Delhi and six linking organisations (or, Lead Partners) and State partner organisations working in Delhi, Tamil Nadu, Andhra Pradesh, Manipur, Punjab and Orissa.

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For India-specific publications and documents from Alliance India and its partner organisations in addition to other related resources, please visit **SETU**, the virtual resource centre of Alliance India at www.aidsallianceindia.net

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Acronyms

AIDS	Acquired Immuno-deficiency Virus
AP	Andhra Pradesh
ART	Anti Retroviral Treatment
CAA	Children living with and/or affected by HIV/AIDS
CIA	Children living with HIV/AIDS
FAA	Family members affected by HIV/AIDS
FGD	Focus Group Discussion
FSW	Female Sex Worker
HCBCS	Home and Community-Based Care and Support Programme
HIV	Human Immunodeficiency Virus
iNGO	Implementing Non-Government Organisation
LP	Lead Partner
NACO	National AIDS Control Organisation
NACP	National AIDS Control Programme
OI	Opportunistic Infection
ORW	Outreach Worker
OVC	Orphans and Vulnerable Children
PCA	Participatory Community Assessment
PCR	Participatory Community Review
PD	Project Director
PE	Peer Educator
PLHA	People Living with HIV/AIDS
PPTCT	Prevention of Parent-to-Child Transmission
RTI	Reproductive Tract Infection
SACS	State AIDS Control Society
S & C	Saving and Credit
SHG	Self Help Group
SRH	Sexual and Reproductive Health
STI	Sexually Transmitted Infection
TN	Tamil Nadu
ToR	Terms of Reference
UN	United Nations
VCTC	Voluntary Testing and Counseling Centre
WLHA	Women Living with HIV/AIDS



Executive Summary

An assessment of the impact of support groups of women and children in the States of Tamil Nadu, Andhra Pradesh and Delhi was carried out by means of a *support group participatory evaluation* having the following objectives:

- Provide an overview of the programme process undertaken
- Evaluate the outcomes and impact of the support groups
- Explore the changes in support group capacity
- Identify and define reasons for change
- Provide recommendations

This report is a compilation of the expected outputs from the evaluation, i.e.:

- A methodology for enabling support groups and external stakeholders to monitor and evaluate support group capacity development
- A report of the outcomes of the evaluation, giving details on
 - Why and how the groups were formed
 - What helps and what hinders the start-up of support groups
 - What helps to keep support groups going
 - What hinders support groups

The underlying principle for the methodology developed for this evaluation emphasised the using of the process as an ‘empowering’ process and not as an ‘extractive’ tool. In a bid to make this a learning process for all the players, participatory tools were designed such that they helped to gather information against the set objectives, whilst enabling support groups to have a greater understanding of their achievements, strengths, weaknesses and capacity-building needs.

As part of the evaluation process, the children’s/adolescents groups (vulnerable, CAA/ CIA), WLHA groups and vulnerable women’s groups were met. Assessing the capacity and sustainability of the groups along with what is important to form a group and to keep it going was the main focus of this evaluation.

*A **support group** is a group where members provide each other with various types of non professional, non-material help for a particular shared burdensome characteristic. The help may take the form of providing relevant information, relating personal experiences, listening to others’ experiences, providing sympathetic understanding and establishing social networks. A support group may also provide ancillary support, such as serving as a voice for the public or engaging in advocacy.*

Findings indicate that support group formation is a robust and time-tested strategy to involve the community in bringing about awareness and knowledge transfer. Support group

formation can be seen to be an empowerment process of the individuals and the community within which they live as well as interact with. Lessons learnt can be summarised as follows:

- People not directly affected by HIV/AIDS can also take an active interest and help in promoting awareness, without necessarily getting or aspiring for material rewards.
- Support groups formed for different profiles of people help to address their individual needs, while also aiding the larger cause and impact sought by the project.
- Support groups find strength and confidence in the information that they get in these group meetings.
- Support groups cannot be promoted and advocated to function only for a project period. This will hamper the sustainability of the group.
- Smaller groups of 10-15 seem to function more cohesively. A larger group does not ensure participation and involvement of each member.
- Vulnerable groups use the information and knowledge they get as a source of power to increase one's status in community, to be heard, to bring about awareness, and also to promote prevention. They work towards acceptance and mainstreaming of positive people, giving them support and understanding. They take on the role of being socially responsible people.
- WLHA use the knowledge to empower oneself, to face oneself and know that this is not the end of the road for them. It gives them the confidence to face and challenge the stigma and discrimination that they face, and is a boost to their survival instinct. They work towards their own acceptance into the society and community
- Programme approaches differ for these two groups. WLHA give more importance to meeting and sharing and interacting with group members. The group plays the role of family for them. For the at-risk groups it is a means to make friends, socialise and create an identity for themselves within their homes and community.

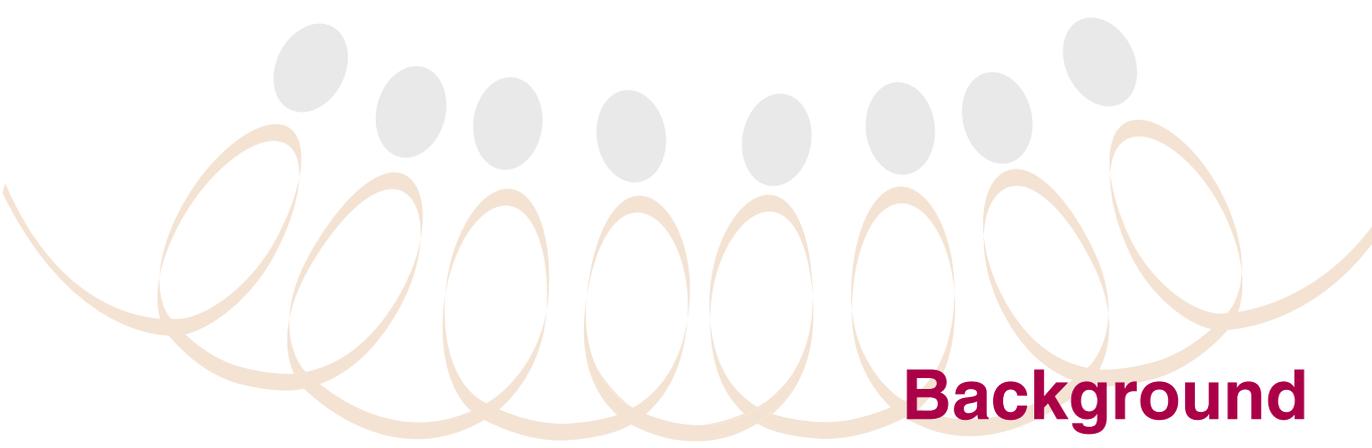
Dos and don'ts for establishing Support Groups:

- The existing presence of an iNGO in the community aids in group formations.
- Intensive interaction and participation of iNGO staff with the group members and the community is very important for establishing a functional group.
- People/persons with similar profiles should be part of one group.
- Fun times interspersed with training and information sessions helps ensure participation
- Issues that concern the members and can make a visible change in their lives immediately should be addressed first.
- Simultaneous awareness creation of the larger community is important to ensure that they support the group formation and participation by its members.
- It is important to tell the beneficiaries that even if the project period is small, all the activities are oriented towards making them self-reliant and making the group sustainable.
- Members should be made to realise and recognise their abilities and limitations.
- The income generation activities should not be given clear preference over other activities.
- Do not treat PLHAs as special. This only helps in increasing stigma and discrimination.
- Do not plan activities and group functioning as per project period only.
- Do not take up any activities that compromise on the confidentiality of the members.

The following are the broad areas of the capacity building of groups:

- Leadership skills, confidence building and self-reliance
- Team building, team spirit and group solidarity
- Networking and communication skills
- Resource mobilisation
- The value of a rights-based approach in community-led interventions
- Aspects of self-reliance and self-help as opposed to dependence on iNGO guidance and presence

Irrespective of the type of group, issues of sustainability and phasing out of the iNGO presence needs to be addressed. Some members were of the opinion that once the project period ended, the group would also stop functioning. Not because they feel that they cannot run the group themselves, they are simply unaware that the group can function without the presence of the iNGO. Participatory exercises will have to be conducted for groups to be able to comprehend their importance, the change it has brought into their lives and also the very fact that they themselves have been integral and instrumental in carrying out most of the activities. It is time now that the groups realised their potential in bringing about sustainable changes in their lives.



Background

Among the countless global problems today, none is as demanding, elusive or as complex as the HIV/AIDS epidemic. Difficult technical and ethical issues abound around HIV/AIDS. At the centre is the issue of priority: a calamity for the global community without rival, yet its treatment in many if not most global forums rarely reflects this urgency and centrality. Being a problem that cannot be solved quickly, it is a marathon battle that may last longer than most can anticipate. This calls for new kinds of partnerships that bring together leadership and institutions from different parts of society in new alliances and forms.

India has a population of one billion, around half of whom are adults in the sexually active age group. NACO (the National AIDS Control Organisation) has established an estimate of 5.2 million people, indicating that the number affected by the epidemic is huge.

Since its formal inception in 1999, the India HIV/AIDS Alliance (Alliance India) has worked to expand, adapt and intensify its strategic framework of supporting community action to reduce the spread of HIV and mitigate the impact of AIDS. Alliance India's approach to community-driven programmes focuses on working with key population groups who will have the most impact on the dynamics of the epidemic; women among key HIV-affected populations. The empowerment of women and building of social capital which results from their active engagement in the process is central to bringing about the changes needed.

Alliance India's Home and Community-Based Care Alliance and Support Programme (supported by the Abbott Fund) and the programme on Community-Driven Approaches to Address the Feminisation of HIV/AIDS (supported by DFID India Challenge Fund) come under the purview of this evaluation.

While the **Home and Community-Based Care and Support Programme (HCBCS)** aims to:

- Initiate and strengthen community-based care and support for people living with HIV/AIDS and/or affected by HIV/AIDS (adults, children and family members)
- Link, strengthen, and coordinate existing services for care and support
- Mobilise community towards care and support
- Initiate policy-related interventions towards promoting the integration of care and support and community based activities

The programme – **Community-Driven Approaches to Address the Feminisation of HIV/AIDS in India** aims to:

- Reduce the spread of HIV/AIDS and to mitigate its impact
- Develop and scale up innovative and sustainable community-driven responses to reduce HIV transmission amongst low-income women

Alliance India has developed and implemented the concept of supporting intermediary NGOs, known as Lead Partners (LP), for the mobilisation, facilitation, scaling up and long-term sustainability of innovative community responses to HIV/AIDS. The LPs provide similar support to implementing NGOs/CBOs (iNGOs) in their respective States.

The Methodology of Evaluation

2a. Aim of Evaluation

As part of the key activities of the sexual and reproductive health and HIV/AIDS integration programme and the home and community based care and support programme, support groups were promoted within the community. This has proved to be an effective mechanism for providing psychosocial and emotional support amongst members who are affected by and/or living with HIV/AIDS. Training and orientation sessions with women and children have been conducted on condom demonstration and negotiation skills; RTIs and STIs; basics of HIV/AIDS; ART, PPTCT and care; menstrual hygiene, contraception and pregnancy, and laws, policies, rights and entitlements.

The broad aim of this evaluation is to evaluate the impact of support groups of women and children in the states of Tamil Nadu, Andhra Pradesh and Delhi. Broadly the aims include:

- I. Providing an overview of the programme processes undertaken
- II. Evaluating the outcome and impact of the support groups of women and children
- III. Exploring the changes as per project indicators
- IV. Identifying and defining reasons for changes
- V. Suggesting recommendations for future programming

Expected outputs

1. A participatory methodology for enabling support groups and external stakeholders to monitor and evaluate support group capacity development
2. A report detailing the outcomes of the evaluation



2b. Methodology

The evaluation was carried out as a participatory exercise using participatory tools. The underlying principle for the methodology that was developed was that this evaluation is an empowering process vs. extractive evaluation'. The participatory tools developed were designed such that they helped to gather information against the set objectives, whilst also enabling support groups to have a greater understanding of their achievements, strengths, weaknesses and capacity-building needs through the discussions triggered during the exercises.

- (i) A semi-structured Focus Group Discussion (FGD) was designed to keep the methodology flexible and enable changes to be incorporated as and when required with the groups. This being a qualitative exercise, greater emphasis was laid on getting detailed information than on quantification.

The FGDs helped to get information on:

- Understanding how the group was formed, why and what helped in the formation?
- What helps one to be a member, and what makes one want to be a member?
- What helps to keep the group going? What is unhelpful for keeping the group going?
- Lessons learnt on how to maintain a support group and how to grow or strengthen it by the group themselves.
- How this study would be of help to them and us? One would get to know the best ways to start and maintain groups; and what one should not do? The study would also give an idea to assess where the groups were placed initially and how much they have progressed and where they are headed now.

(ii) Sampling

Twenty-two support groups were selected, based on the profile of the groups.

Ten children's groups were selected. They were categorised as:

- Children's adolescent groups – 6 groups
- Groups of children affected by HIV/AIDS (CAA)/Children living with HIV/AIDS (CIA) – 4 groups

Twelve women's groups were selected. They were categorised as:

- WLHA groups - 6 groups
- Vulnerable women's groups - 6 groups. (These groups were again selected on the profile of the members based on their occupation or the occupation of the spouses, e.g. sex workers, wives of migrant spouses, women working in industries, women working as road construction workers and women who work as side artists in the film industry).

Matrix 1: List of Support Groups visited			
Lead Partner	NGO	Location	Group profile
Delhi (Khemkhurd village and New Delhi Railway Station)			
CSI	CSI	Metro Vihar slum, Holombi Khurd	Vulnerable adolescent girls
CSI	CSI	CSI office	PLHA from surrounding areas
SBT	SBT	New Delhi railway station	Vulnerable boys adolescent group; street children, some of whom are orphans or are living alone
SBT	SBT	New Delhi railway station	Vulnerable girls adolescent group
Andhra Pradesh (Hyderabad, Krishna, Prakasam and Guntur)			
Lepra	Lepra Society	Cheyutha office, Hyderabad	PLHA group; adolescent girls group
VMM	VMM	Kandrika slum	Mixed group (PLHA and HIV negative spouses); vulnerable adolescent girls group
VMM	AIRTDS	Tenali	Mixed group of women (mainly spouses of migrant workers); mixed vulnerable children's group
VMM	Mahila Mandali	Chirala urban slum	Women living with HIV/AIDS group (these women belong 4 close-by slums)
VMM	SHADOWS	Kettaveeram slum	Women living with HIV/AIDS group
Tamil Nadu (Tirunelveli, Madurai, Dindigul, Coimbatore)			
PWDS	AIRD- V	Vallaiampuram village	Vulnerable women's group; WLHA Group
PWDS	PACHE Trust	Boys hostel, Melur Thenkupatai village, Melur	CAA mixed group; vulnerable women's group
PWDS	SSH	Chinallapati village	Mixed women's group; CAA mixed group
PWDS	NMCT	Kasturipalyam, Coimbatore	FSW; CAA mixed group
PWDS	IMAYAM	Kempatty colony Selvapuram Slum	Women's side artists group (vulnerable); CAA mixed group



Support Groups: Results and Discussions

The two programmes under the purview of this evaluation were the Home and Community-Based Care and Support programme, and the SRH and HIV/AIDS integration programme. While the former is for a period of five years, the latter is only for the period of one year.

The Home and Community- Based Care and Support programme aims:

‘to work for an enabling sustainable, supportive environment towards community-based care and support for people living with HIV/AIDS, children affected by HIV/AIDS, and families affected by HIV/AIDS in Tamil Nadu, Andhra Pradesh and Delhi.’

The Sexual and Reproductive Health and HIV/AIDS Integration programme aims to:

- Strengthen and develop community-driven approaches to meet the sexual and reproductive health and HIV/AIDS needs of the women in a low-income setting
- Develop greater linkages/convergence between HIV/AIDS and SRH to address the needs of the women
- Ensure sustainability through building social capital in the broader community and the women to empower them to put their knowledge into practice to advocate for change at the community and district level

While one works towards a vision of capacity building of NGOs in providing low-cost community-based care and support for people living with HIV/AIDS, the other aims towards the convergence of HIV/AIDS and sexual and reproductive health issues to address the needs of women along with building the social capital by empowering the women in the community.

A key strategy in these projects has been the formation of support groups at different levels in the community. In this direction, the children’s groups as well as women’s groups were formed.

The expected outputs from the support groups are:

- **Increased informed demand:**
Increasing awareness and knowledge of HIV/AIDS and sexual and reproductive health to reduce stigma and discrimination and to create demand for accurate information and quality services (health, legal and social services)
- **Increased access to services and support:**
Increasing linkages between women target groups of the programme and HIV/AIDS and SRH service delivery and support mechanism at the community level.

- **Increased NGO and community capacity:**

Increasing skills and knowledge of partner NGOs, women target groups and their communities to undertake project activities and contribute to increasing informed demand and increased access to relevant services and support.

3.1 Strategies adopted by Alliance India's lead partners and implementing partners to promote group formation and ensure their regular functioning

- One-to-one and one-to-group community interactive sessions on HIV/AIDS, reproductive tract infections and sexually transmitted infections, anti retroviral therapy, prevention of parents-to-child transmission, menstrual hygiene, contraception and pregnancy, gender, laws, policies, rights, entitlements and government welfare schemes conducted regularly with the community. Condom demonstration was carried out in each group meeting.
- Capacity-building programmes on the above mentioned aspects were conducted regularly for community members and project staff by the iNGOs and the LPs.
- Information, Education and Communication (IEC) material distribution for Behaviour Change Communication (BCC) was an essential component of this programme. Apart from awareness generation, all the service providers on counselling, PPTCT, medical support, etc. are linked through referral service to the community.

Role of the LPs: The LPs were instrumental in carrying out strategic analyses to identify:

- Existing scenarios in terms of care and support for CAA, PLHA and their families
- Mechanisms and potential partners for collaboration in technical support provision and programme implementation
- The strength and organisational and technical capacity of partners (iNGOs and community)
- The gaps in participation and the extent of involvement of women in decision-making processes
- The state of discriminatory practices and attitudes towards WLHA

3.2 Stakeholder analysis

Matrix 2: Stakeholder analysis for Support Groups		
Stakeholders	Positive Impact (Opportunities/Potential Positive Outcomes)	Negative Impact (Risks/Potential Negative Outcomes)
Analysis		
Primary		
WLHA	<ul style="list-style-type: none"> ● Bound by a common factor (HIV) ● Emotional support ● Overcoming the fear of HIV/AIDS. Courage to face life and believe that they too have a right to live a life of dignity ● Overcoming or being able to handle stigma and discrimination ● Being able to talk and discuss their problems with people who are concerned about them ● Happiness and physical support in times of need ● Medical and nutritional support ● Education support for children ● Opportunities for employment with the iNGO ● Information and knowledge on various issues like health, hygiene, legal rights and women's rights ● Being part of a platform that will be able to voice their views and make the community respond to it 	<ul style="list-style-type: none"> ● People identifying that they are positive if they are still maintaining confidentiality ● Making time for meetings at the cost of losing a day's earning ● Losing their jobs with the iNGO if the iNGO withdraws its support (few support group members are currently working as volunteers with iNGOs and are paid an honorarium for travel) ● Neighbours taunting them for being members of a group
Vulnerable women	<ul style="list-style-type: none"> ● Uniting to help themselves ● Getting knowledge and information, which makes them more informed and able to negotiate for quality services ● Improved status at home vis-à-vis their spouses, in their families and also the community ● Information that helps them to improve their family life and health status ● Vocational training ● Getting over shyness in expressing themselves ● Opportunity to create awareness and interact with the larger community ● Information and knowledge on various issues like health, HIV/AIDS, hygiene, government schemes and how to avail them, legal rights and women's rights ● Being part of a platform that will be able to voice their views and make the community respond to it 	<ul style="list-style-type: none"> ● Group members may focus on savings and credit, which may change the purpose of the group formation ● Losing out members as there is no support being given for IGP ● Not being able to access any information or conduct group activities if the iNGO withdraws support. This may result in the group's becoming defunct

Stakeholders	Positive Impact (Opportunities/Potential Positive Outcomes)	Negative Impact (Risks/Potential Negative Outcomes)
CAA/CIA groups	<ul style="list-style-type: none"> ● Get emotional, physical and psychosocial support ● Get medical, nutritional and educational support for themselves as well as their family members ● Getting over shyness in expressing themselves ● Being able to continue with their education ● Acquiring friends and developing an increased sense of pride, self-esteem and confidence ● Information on various issues like health, hygiene, life-skills, child rights ● Being able to negotiate for the rights of the individual members as well as for the group as a whole with the community or extended friends and relatives as and when required ● Getting back their childhood and happiness 	<ul style="list-style-type: none"> ● Lack of support from community if the iNGO withdraws support, resulting in the group's not being able to function ● Parents not supporting their being part of a group ● Their being identified as CAA/CIA
Adolescent girls/children's group	<ul style="list-style-type: none"> ● Learning that unity and numbers bring strength ● Information on various issues like health, hygiene, life skills, child rights ● Being informed about various issues of concern to them individually, thus helping them in their life ahead ● Getting over shyness in expressing themselves ● Capacity building to give them the ability to decide, choose and negotiate for their rights ● Creating awareness in the community through various programmes ● A platform through which they can make their view and opinions be heard 	<ul style="list-style-type: none"> ● Parents not letting them remain members if the iNGO withdraws support ● Parents dissuading their wards from being part of these groups as they feel this information is not good for their daughters ● No access to information if iNGO withdraws support
iNGOs	<ul style="list-style-type: none"> ● Will add to the home-based care and support services that they provide within the community ● Get intense technical inputs and support on various issues from the LP ● Get access to the community and information on various aspects about them ● Increased presence within community ● Use this group as an effective phasing out and handing-over strategy ● Networking opportunities with the other iNGOs under the umbrella of the LP 	<ul style="list-style-type: none"> ● If phasing out not done properly they will have to take on the responsibility of the group for a period beyond the project period ● Waste of effort if the groups break down and the purpose is lost ● Staff turnover within short periods thus all the intensive training being given to staff is not put to use with the beneficiaries

Stakeholders	Positive Impact (Opportunities/Potential Positive Outcomes)	Negative Impact (Risks/Potential Negative Outcomes)
Lead Partners	<ul style="list-style-type: none"> ● Wider area of implementation of project ● Networking with many iNGOs, thus increasing their own presence in terms of area and community outreach ● Capacity-building inputs from Alliance India 	<ul style="list-style-type: none"> ● Not being able to monitor regularly due to spread of area
Alliance India	<ul style="list-style-type: none"> ● Funding stake in the project ● Identity for being able to make inroads into community on HIV/AIDS issue ● Networking with NGOs in different states ● Giving technical support and training to LPs and iNGOs 	<ul style="list-style-type: none"> ● Project not being implemented properly ● Inability to monitor the iNGOs independent of the LP presence
Secondary		
Family members affected by HIV/AIDS	<ul style="list-style-type: none"> ● Support to take care of the HIV positive person in the family ● Improved ability to manage the house due to nutritional, educational and medical support ● Information and awareness on various issues of concern to them and their families ● Breaking of myths and denial of HIV/AIDS ● Being able to handle stigma and discrimination that they face due to their family member(s) ● Learning to respect a positive person 	<ul style="list-style-type: none"> ● Not supporting their members for being part of the support groups ● Being identified as members of an infected family
Families of vulnerable groups	<ul style="list-style-type: none"> ● Access to information on various issues ● Change in attitude towards women in the household ● Ability to accept that women/girls can leave the house and play a role in ensuring a better life for themselves, their family as well as the community ● Improved knowledge of rights of women, their health and other needs 	<ul style="list-style-type: none"> ● Dissuading wives and daughters from being part of these groups ● Not liking the fact that the women are privy to information and knowledge ● Feeling neglected that they are not part of such a group ● Taunting and teasing from others when their wives and daughters break their social barriers ● Disharmony at home when they try and forcibly try to stop the women and daughters from attending meetings or workshops out of town

Stakeholders	Positive Impact (Opportunities/Potential Positive Outcomes)	Negative Impact (Risks/Potential Negative Outcomes)
Community	<ul style="list-style-type: none"> • Access to information and awareness on various issues • Breaking of myths, stigma and discrimination due to HIV/AIDS • Becoming a major support structure to these groups • Realising that the problems are not of the group members alone but social problems 	<ul style="list-style-type: none"> • Not being able to overcome stigma and discrimination • Refusal to support the support groups
Governmental agencies (hospitals, schools, employment, etc.)	<ul style="list-style-type: none"> • Change in attitude in quality of service to people coming to their institutions • Becoming more people-friendly institutions • Realising their importance in bringing about a positive impact in the community • Being part of the awareness-creating team 	<ul style="list-style-type: none"> • Failure to provide quality service due to lack of will and infrastructure
Community leaders/village panchayats	<ul style="list-style-type: none"> • Influence the community on various issues • Create awareness easily due to sphere of influence • Being able to influence officials on policy issues at a higher level • Can play the role of being the voice of the community 	<ul style="list-style-type: none"> • Discourage the community from taking a positive stand • Refuse to give the support of community structures to the groups when required • Look for monetary benefit • Look for fame to use as voter bank when required
Tertiary		
Neighbouring areas (villages/slums, etc.)	<ul style="list-style-type: none"> • Awareness of various issues by being witness and hearing of the activities of the groups • Interest generated on wanting to be part of similar activities 	<ul style="list-style-type: none"> • Lack of curiosity and interest in such activities, which may discourage the groups involved in such activities

3.3 Findings

Support group formation is an empowerment process of individuals and the community within which they live and interact.

Formation of a support group was one of the main activities of the project. The following is an assessment of the profiles of the groups and what plays an important role in group formation and continuance.

Support Groups: Issues of size, activity, membership and maturity

Size: Most children's groups maintain a size of less than 20 while women's groups have members ranging from 10 – 16. In the case of vulnerable children's groups, it was seen that there may be even 40 members in the group. However, for adolescent girls' groups and CAA/CIA groups the numbers were below 20. Interestingly, discussions revealed that smaller groups of 10-15 women seem to function more cohesively. A larger group does not ensure

the participation and involvement of each member. Size seems to be determined by the local iNGO and number willing to be members.

Maturity: There are some children's groups which are more than four years old while there are some which are just four months old. Maturity of the group does not seem to have played much role in the progress of a group. Regular activities and constant inputs into the group that has kept it going, and time is not a factor here. In as much as women groups are concerned, years of being in a group do not seem to have played a role in making the groups more independent, self-reliant or progressive. If they are old groups, members have come and have been a part and moved on due to relocation or other reasons, while others have joined the group recently.

Activities: The type of activity and its importance to a group are determined by the frequency of group meetings and the profile of the group. For example, the CAA group of Imayam (an NGO based at Coimbatore) meets once in three months. It was evident from the discussions with the group that meeting their friends and playing and having a fun-filled time to overcome their problems at home was their main agenda. They clearly stated that they wanted friends with whom they could share their problems. In contrast, the groups promoted by Salaam Baalak Trust, an iNGO in Delhi, meet every day. Hence studying, classes, etc. are regular activities for them. Psychosocial support, referral and medical support are the most important activities for the WLHA whereas for the vulnerable group activities that give them information on issues they are ignorant about, the increase in status due to being more informed, and knowing that one can do something constructive for the community is important. However, in some cases the types of expectations that the vulnerable groups had of the group were similar to those of the WLHA. They too felt that they should get support for their children.

While the common activity for all groups is:

- training on leadership, confidence building, communication skills
- classes on various issues like health, legal rights, child rights, etc.
- information on how to avail and make use of facilities
- exposure trips, picnics
- learning dance, singing and acting as per the group's preferences
- participating in functions as per group's abilities
- playing together, competitions
- taking part in programmes to create awareness and knowledge transfer
- celebrating festivals and occasions together

As part of their activities or inputs, CAA/CIA groups also get:

- medical, nutritional and educational support
- some of their families have been able to get employment opportunities within the project as volunteers
- clothes

Women's groups additionally have activities that support information on health-related issues, contraception and condom usage, legal rights, gender, women's rights, SRH/STI/STDs, government schemes and how to avail them. WLHA groups also get as inputs;

- support for their children in the form of food, education and clothes
- nutritional and medical support for self
- employment support within the iNGO as a volunteer
- vocational training

Membership: Increase in membership is mostly due to the efforts of the iNGO staff. In some cases there has been an increase in membership due to children influencing children. Parents often decide whether their wards will be part of such groups. In some cases, as in the girls' group promoted by SBT, Delhi, they clearly stated that they were being allowed to come since the parents knew of the activities of the iNGO and also know that they are getting benefits materially by being part of the group. Where there has been a decrease in membership because of children leaving due to peer pressure or parents disallowing them, no extra effort has been made by the iNGOs or the children to get the member to make a comeback.

Support Group formation: Factors that facilitate formation and membership retention

CAA, Imayam, Coimbatore, Tamil Nadu

“We thought that if we form a group we can find friends with whom we can discuss our feelings and problems in confidence. We cannot discuss everything freely with friends that we have where we stay since we are not sure if they will keep things in confidence or talk about it with others. We want to feel free and get peace of mind”

Children / adolescent's groups:

Group formation has been promoted solely by the iNGOs. Only in the case of the adolescent girls groups promoted by the Lepira Society was there a demand from the girls of the slum that a group be formed for them. In all cases a common factor that influenced them into being members of such a group, was the fact that they had been told by the NGO that they would benefit, and the trust they had in the iNGO due to its existing activities in the area. Even if there were apprehensions at first, they thought they would give it a try; some wanted to be a part of the iNGO's activities. Hence the existing reputation of the iNGO, and wanting to gain something from the iNGO's inputs in that community were primary reasons for agreeing to form a group.

In the case of CAA/CIA, the hope that it would improve their life materially and emotionally was a major factor of influence. The CAA/CIA are children of families who are under the existing community-based care and support services.

Women's groups

Women's groups formed can be categorised based on whether they are the at-risk population or carriers of HIV. This seems to make a difference in the reasons for being in a group and the type of inputs required by a group.

WLHA groups: The initial stages or early members in a group were influenced by the iNGOs. Members who joined later were also convinced by the iNGO worker based on the feedback by the existing members. A common reason for wanting to be part of groups by WLHA is the

dire need to reach out to people who are in similar situations as them. Members have attributed overcoming of depression and suicidal tendencies in themselves to the group. They also realise that through these groups they can access many benefits meant for them and gain access to information on various issues, which will help them and their families.

Mancharivali, young widows PLHA group, Tirunelveli, Tamil Nadu

“After my husband died I fell into great depression for 6 months. I am also positive and I felt lonely and lost. The ORW came and convinced me to leave the house and take a bus and travel this distance to attend a meeting. That itself was a big step for me”

Vulnerable groups: Vulnerability or at-risk groups are defined as the population that may be at risk due to the occupation that they or their spouses are in. The members of these groups may also be a part of some self-help group or savings and credit groups. It was curiosity and the hope that they may get some help financially that made them become members of the group. Though most of them still hope for a financial component in the group activity, they also admit that the information and exposure to the world outside is what is that holds them together. Improved status and self-esteem at home and at the community level, being actively involved in knowledge transfer at their level is a big change for them.

Support Group formation: Factors that hinder growth and accentuate dropouts

Children’s / adolescent groups

The sole reason for hindrance in the group formation is children being dissuaded by their parents from becoming members. Lack of awareness on the part of parents and the elders in the community is the biggest stumbling block.

The timing of meetings is another influencing factor. This determines attendance/participation as well as the type of activities a group would focus on. It has been seen that groups that meet once in fifteen days or once a week are actively involved in various activities. In groups where the members keep contact regularly, the bonding is very high, even if they meet once a month. This is true for most CAA/CIA groups.

Women’s Groups

WLHA: Self-stigma, fear of possible discrimination by neighbours and hesitation to come

Girls adolescent group, Holombi Khurd, CSI, Delhi

A mother of one of the members attended one of the meetings and then stopped her daughter from being part of this group. She also tried to influence other girls but was not able to stop them from joining the group. The girls too haven’t been able to convince her to allow her child to rejoin the group

Young widows WLHA group, Chirala, Mahila Mandali, Andhra Pradesh

“There are some women who fear attending meetings and become members of the group. They feel that their status will be discovered by the neighbours and they may discriminate against them. We are not able to convince them”

out and discuss their problems are major reasons for their not being part of a group. Another influencing factor is they are hard-pressed for time since they have to go out and work to manage their homes.

Vulnerable Groups: Spouses and in-laws stopping them from leaving their houses to attend meetings is a big hindering factor. The fear in spouses that their women are

getting more informed and hence more assertive is a major hindrance. Expectation of some financial gain from the group and the lack of this activity in the group can also be a factor for members leaving the group after a period of time. This hasn't happened yet, but the groups are still very new for the members to be able to make up their mind.

Lack of awareness is the main hindrance for people forming groups.

Support Group: Important reasons for people continuing to be members and what they benefit

The reason for remaining a member is determined by the need of the group and its individual members.

Children/adolescent's groups

Discussions with children revealed that there is a difference between what is the most important thing that the group gives them vis-à-vis what gives them happiness. All the groups expressed that being in a group has given them new friends, love and affection, a place to play and also the chance to go on picnics and exposure trips. They also acknowledged that while the above gave them happiness, the information and training that they get from the groups has given them courage, made them more informed, which has helped them feel more confident and capable of fighting for what is their right. The ability to choose and decide what is right has helped them to make their lives more organised.

The CAA/CIA groups depend on the group like on their family. The emotional support and the outlet that they get to discuss their problems is an important factor. All groups mentioned that they were able to relieve themselves of stress and get peace of mind after they joined the groups. The support that they get for education, nutrition and medical is also an important reason for their being part of the group.

Adolescent boys group, SBT, Delhi

“After becoming members here, we have learnt and understood the importance of education, of helping others and how to manage money. Some of us were IDUs. But some have learnt to choose and decide that it is not right and with support from the group we have overcome this”

A common refrain in all WLHA groups:

“We felt that the world has come to an end and we were constantly suffering from depression. The desire to commit suicide was very great. We have now learnt to face the situation and also realised that we too have a right to live life fully,”

“We realised after being part of this group that our own personal problem was so small compared to the sufferings of others”

Women’s Groups: As mentioned before, reasons for being in groups vary according to the group profile.

WLHA: The major benefit that they get from being in these groups is psychosocial and physical support. The ability to reach out, get over suicidal tendencies and be able to talk is what helps them.

The information and training that they get has helped them to improve their lives. They have become more aware and vocal about their rights, be it medical, social or even legal. Young widows have been able to get access to government schemes wherein they are given a pension every month in Tamil Nadu as well as Andhra Pradesh.

The support that they get for their children’s upkeep is a big relief for them. Given their financial constraints and poor health, they feel that as of now this is one burden less to shoulder while they also get help to plan and strategise for their own future as well as that of the children.

WLHA use knowledge to empower and face themselves, and know that this is not the end of the road for them. **It gives them the confidence to face and challenge the stigma and discrimination that they are confronted with, giving a boost to their survival instinct. They work towards their own acceptance into the society and community.**

Vulnerable groups: Information, training and the scope to participate in exposure trips and picnics as a team is the driving force for these groups. The pride that they feel about being informed and being able to negotiate with their families and community is topmost in their list of achievements. Being in a group has given them an identity and this identity also helps them in getting various benefits.

Side artists group, Imayam, Tamil Nadu

“We had no idea of governmental schemes available for us. Once when we went as individuals, we were told that the application form would cost us Rs.120/-. But when we went as part of a group they were willing to explain the procedures to us and we got the form for Rs.4/-”

The realisation that strength lies in unity and that now they are important agents of knowledge transfer in the community has made a big difference to their level of confidence and self-esteem.

The vulnerable group members use the information that they get in the group as power to increase one's status in community, to be heard, to bring about awareness, and prevention. They work towards acceptance and mainstreaming of positive people. They give them support and understanding. These groups act as agents in helping the members become socially responsible individuals.

Women's group, Dindigul, Tamil Nadu

“We work in the nearby industries. We have always been exposed to sexual overtures by the bosses. Previously we didn't know how to handle it or were too shy to talk about it. Now we talk to them firmly and refuse to come under pressure”

Devina, the secretary of the group promoted by VMM, Andhra Pradesh, is negative while her husband, a member of the same group, is positive. When she initially got to know about her husband's status, she was very hurt and depressed. Her parents wanted her to divorce him. But after meeting others she decided to stay with him and support him. She felt that she cannot let him down in this hour of crisis

Support Groups: What keeps it going...?

A major cause for ensuring the regular functioning of the groups is the 'feel good' factor that it has brought into the lives of the members. Discussions reveal that the feel-good factor for the members is not necessarily the inputs put into the group to increase their access to information and knowledge levels. It may just stem from factors like recognition, appreciation or the fact that they have met a group with whom they can talk, share and just enjoy themselves.

The responses from groups on how they visualise their group, is an indication of how important the group is to them and how they would like to see it function and grow. All of them, irrespective of age and profile, attributed strength, shelter, support, and fame as the mainstay of their groups.

Children's/adolescent groups

Love, affection, courage and happiness are the main reasons for continuity of CAA/CIA groups. Information, guidance, and exposure to new things are the mainstay for vulnerable children's groups. Both take pride in being well informed as well as in being able to transfer knowledge to the community at large. They feel that being in the group has not only increased their knowledge, made them confident but also helped them discover their talents. In the case of street children and girls who do not have access to education due to various physical factors, the group allows them an escape from their homes and household chores.

Diagram 1: Organogram giving detailed representation of what keeps children's groups going (CAA group, NMCT, Coimbatore)

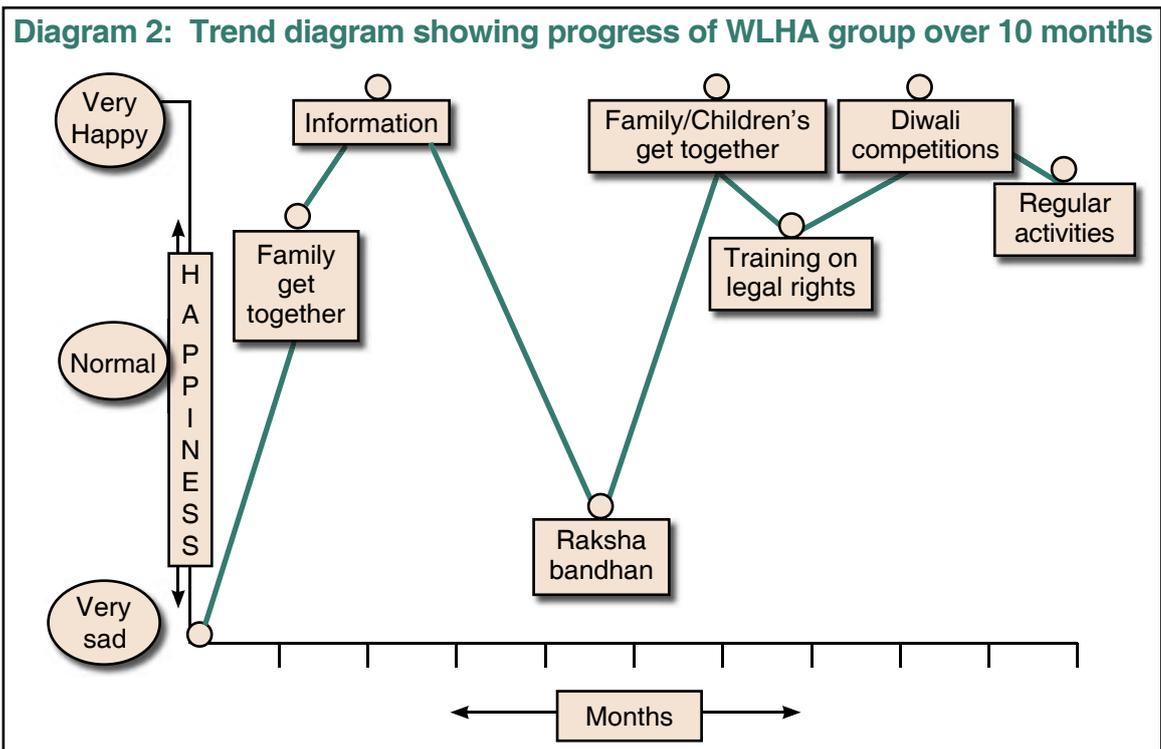


* Thickness of lines indicates importance

Women's group

WLHA: Regular activities like family get-togethers, couple get-togethers, training and classes keep a group functioning. For the young widows' groups, it's a great incentive to be able to participate in all functions. Below is a graph of showing the progress of a ten month-old group of WLHA, some of whom are widows. The highs and lows, which have had an impact on their sustained progress, are mapped.

Vulnerable groups: Increased status and self-esteem, encouragement due to increased membership, and the information that they get is what keeps the group going. The fact that now they are well informed to create awareness amongst the larger community gives them a sense of pride, and a feeling that they are doing their bit for the community.



- WLHA group, Cheyutha, Hyderabad

* Rakshabandhan was a low for them since it received media attention and they were scared that they would be recognised.

Given below is a step-by-step growth of a nine month-old FSW group in Coimbatore

1. NMCT held meetings and sowed the seed of forming a group in their mind
2. The group was formed
3. Sharing and bonding amongst members
4. Information received helped us learn new things. Plan to start S&C activity
5. Training given / exposure visit
6. New members joined and members felt happy
7. Participation of members enhanced
8. Feeling of confidence in members. We feel more knowledgeable
9. Increase in self-esteem. Unity as a group. Plan to open a bank account for S&C activity



Support Groups: What hinders their functioning...?

Children's/adolescent groups

The timing of meeting, parental opposition and lack of communication can be a hindrance in the normal functioning of a group. In some groups it was seen that the meetings were held on a week-day, during late afternoons or mornings. Hence, the attendance in the adolescent groups was of girls who did not study. If all the members do not participate in the activities, the purpose of a group and group activities is lost. Some groups stated examples of parents stopping children from attending group sessions.

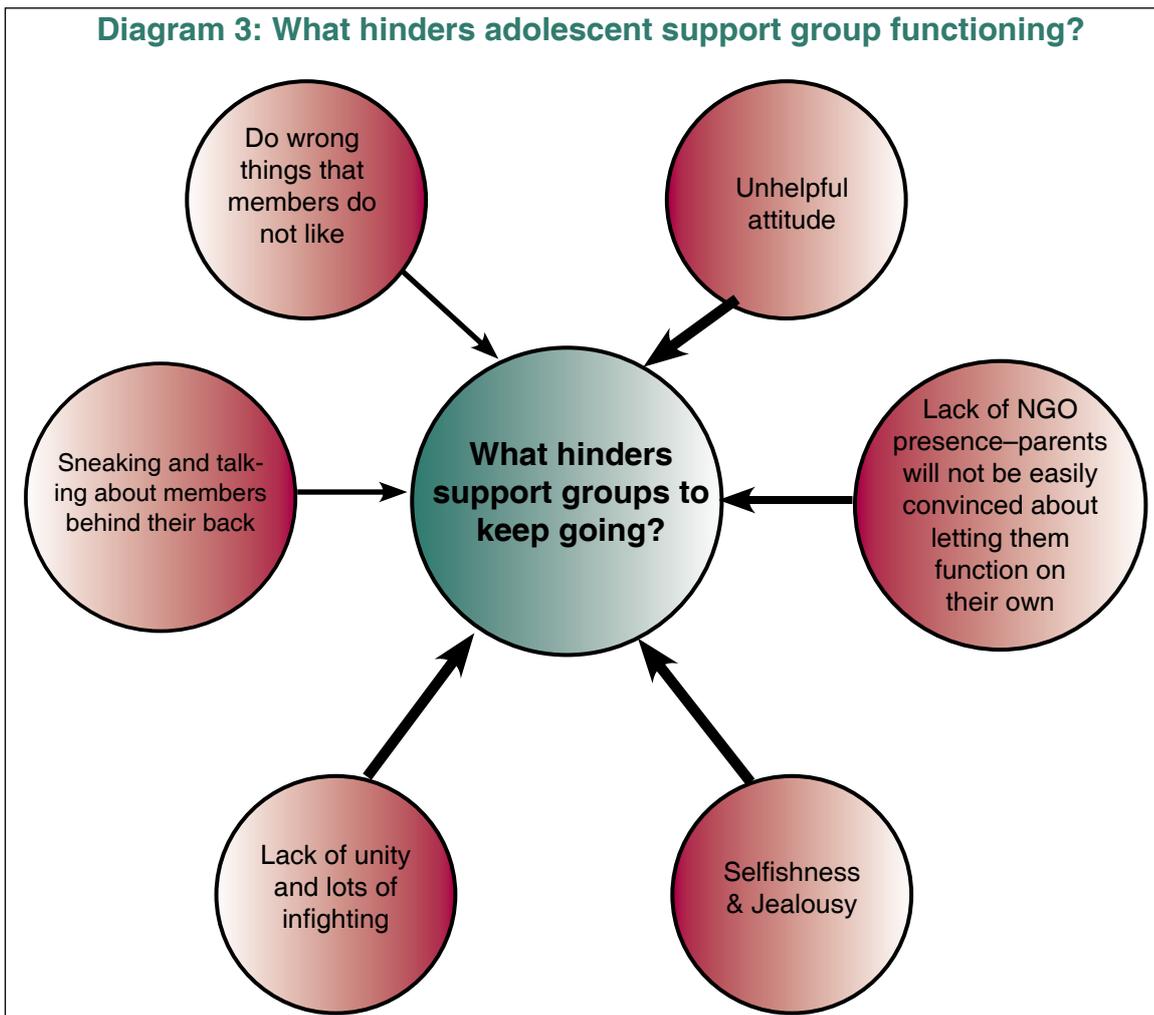
The girls group in Holombi Khurd attended a three day workshop. Some members were unaware of this and could not participate. When they heard about it, they were very disappointed.

Other reasons are discrimination and taunts that the children sometimes face from neighbours when they become members of such support groups, of which other children from the community are not a part. When some children can't take part in trips and workshops out of town because their parents don't allow them, it disheartens them and they feel that they are not getting as much out of the group as the others. There is a lack of trust amongst members if and when there is jealousy and selfishness in the group.

Women's group

WLHA: Discrimination faced by the group may dishearten them affecting the functioning of a group. In the initial days acute depression and suicidal tendencies, self-stigma and fear of discrimination are hindrances which may not let a group continue or even begin functioning. The timing of meetings and the time required for activities puts a constraint.

Vulnerable group: Husbands and in-laws dissuading them. Fear that the information they get is making the women too independent. Neighbours taunting and questioning reasons for group formation. Repetition of information given can make them bored and lose interest in activities. Irregular participation by members is very discouraging.



(-Girls' adolescent group, SBT, New Delhi) * Thickness of lines indicates importance

Support Groups: Future needs and the step forward

The groups were asked to suggest what they felt they would need in the future to ensure the sustainability of their group. It is important to mention here, that in none of the groups the need to make themselves self-reliant and independent of the iNGO in the near future has been addressed.

Irrespective of the profile of group, be it adult or children/adolescent, everyone was of the view that they needed the group to continue. The initial response was that they needed to have the NGO to help them and guide them. They do not seem to have the confidence in themselves to function on their own since they haven't as yet been able to recognise their ability.

Children/adolescent's groups

There was a unanimous demand for more training to improve their leadership, communication and confidence. They felt that they need more information on various issues of concern to them. More exposure visits, participation in cultural activities were important, they said, to help them overcome their shyness and to encourage them. As per individual group needs, there were demands for literacy classes for groups of adolescent girls who do not have access to educational facilities.

The CAA/CIA groups stated that they would need constant nutritional, medicinal and educational support.

Future activities that they would like to take up:

- All the groups stated that they want to take part actively in awareness creation in the community through various means, be it rallies, public speaking, acting, dance or street plays
- Increased membership or attempts to bring in more people within the fold of their group activities
- Increased awareness of parents and elders so that they do not stop them or dissuade them from organising more activities within the community so as to be able to create an identity within the community

Women's group

There was a unanimous demand for more training to improve their leadership, communication and confidence. They too felt that exposure visits and picnics as a group helped in binding them together.

The needs of the WLHA groups are distinctly different from that of the vulnerable population.

WLHA

- They expressed the need for some livelihood opportunities within the group, as that would give them a stable form of income. They don't want to work under anyone as they feel that employers don't understand their problems of ill health and having to take frequent leave from work.
- Most of the WLHA felt the need for a crèche for their children and also a hostel for the women and children, to avoid harassment from house-owners and the family they stay with.

- They feel the need to be independent in every way so that they are not a burden on anyone and others don't have to suffer from stigma and discrimination because of them.
- Continued support for the education of their children
- Continued nutritional and medical support

As part of their future activities, they would like to:

- Take up activities for creating awareness
- Network with similar groups
- Work on reducing stigma and discrimination
- Advocate testing for HIV before marriage
- Advocate for widow remarriage, even for women who are HIV positive
- Work on reducing sexual violence against widows.

Group leader, PLHA group CSI, Delhi

She is positive and is married for a second time to a person who is negative. But they have had to leave their families and he finds it difficult to get a regular job as he has married a positive person. Finding a house to stay is also a big problem for them

Matrix 3: Future activities charted out By PLHA group promoted by Cheyutha, Hyderabad

1 year	5 years	10 years
<ul style="list-style-type: none"> • Ensure through awareness that no child is born HIV positive • Children's care and support centre • Lobby with government to get full support for education and nutrition of children affected by HIV/AIDS • Promote widow remarriage • Start a savings and credit group • Ensure that widows get pension 	<ul style="list-style-type: none"> • Advocate for compulsory testing for HIV before marriage • Lobby for loans from government so that they can make their own houses • Start more such groups 	<ul style="list-style-type: none"> • No discrimination shall exist • This group can then take up activities like gender and other such social issues

Vulnerable groups: The vulnerable groups expressed a need for:

- Increased training inputs in communication, leadership and confidence building
- More information on various issues
- IGP training and support
- Help to access loans
- More exposure visits and picnics
- NGO support and guidance

As part of their future activities, they would like to:

- Start an S&C activity
- Carry out programmes for awareness creation in the community
- Play an important role in knowledge transfer
- Work on developmental issues for their village or slum

Groups, which felt that they need the iNGO support for some time stated that they would need more inputs to develop their capacity to become self-reliant. They felt that the iNGO presence

for another six months at the least would help to stabilise the group and help them sustain the activities without iNGO help.

3.4 Observations

The inputs into support group formation activity have helped in achieving the following with respect to the expected outputs:

Matrix 4: Achievements		
Expected output	Achievement	Comments
Increased informed demand: Increasing awareness and knowledge of HIV/AIDS and sexual and reproductive health to reduce stigma and discrimination and to create demand for accurate information and quality services (health, legal and social services)	Children's / adolescent groups: <ul style="list-style-type: none"> Increased awareness of HIV/AIDS. Children who were not aware of what is AIDS or had the wrong picture about it are now informed and know how to live with it and face it. The fear of HIV/AIDS has reduced Ability to handle stigma and discrimination. They don't get perturbed or depressed by their status Knowledge of their rights as children Increased ability to help themselves as a group and also others in times of need Increased confidence, courage and strength as a group Happiness and unity as a group 	<ul style="list-style-type: none"> Dependent on the iNGO for guidance and support They feel that they can carry the activity forward but there may be some activities which they would not be able to mobilise resources for (like nutrition, education and medical support) Need for community support is very important to ensure sustainability
Increased access to services and support : Increasing linkages between women target groups and HIV/AIDS and SRH service delivery and support mechanism at the community level	<ul style="list-style-type: none"> Improved information and increased access to services and support More number of people living with HIV/AIDS has been brought under treatment after the start of these programmes Target groups have access to nutrition/ educational/medical support Vulnerable population have access to facilities to ensure prevention and check ups Confidence to ask for quality services and talk openly about their health problems 	<ul style="list-style-type: none"> Phasing-out period has not been discussed so as to help the groups plan for the future

Expected output	Achievement	Comments
<p>Increased NGO and community capacity: Increasing skills and knowledge of partner NGOs, women target groups and their communities to undertake project activities and contribute to increasing informed demand and increased access to relevant services and support</p>	<ul style="list-style-type: none"> ● Intensive training and inputs on various issues has increased the capacity of the community as well as the staff at the iNGO and LP levels ● Ability to promote awareness on issues of importance within the community ● Thus resulting in increased demand and access to relevant services and support by the community at large ● Improved status of women and increased participation in decision making on important issues like contraception, children's lives, etc 	<ul style="list-style-type: none"> ● Intense monitoring of activities by iNGOs has helped in the groups' progress



Recommendations

Support Group: A group where members provide each other with various types of non-professional, non-material help for a particular shared burdensome characteristic. The help may take the form of providing relevant information, relating personal experiences, listening to others' experiences, providing sympathetic understanding and establishing social networks. A support group may also provide ancillary support, such as serving as a voice for the public or engaging in advocacy.

Support groups maintain interpersonal contact among their members in a variety of ways. Most groups follow the traditionally face-to-face mode, in group sizes that allow conversational interaction. Support groups may also maintain contact through printed newsletters, telephone chains, internet forums, and mailing lists.

4.1 Lessons learnt

Support group formation is a very good strategy to involve the community in bringing about awareness and knowledge transfer. Support group formation can be seen to be an empowerment process of the individual and the community within which they live and interact.

Group formation is generally identified with the self-help groups and S&C groups. In these groups the main activity is the financial component and the other activities like social welfare, access to information, training, awareness are secondary factors.

The salient features of groups formed under this programme are:

- Groups have been formed at different levels with people of differing profiles, and also with not only infected but vulnerable populations too
- This programme proves that people not directly affected can also take an active interest and help in promoting awareness, without gaining anything tangible in return
- Intensive inputs given to group members and iNGO staff can help the group make very good progress in a short period. Therefore, time is not a factor for success but continuous and constant support in the form of information and training is important
- Support groups formed for different profiles of people help to address their need as per the individual needs, while at the same time aiding the larger cause and impact sought for by the project
- Support groups find strength and confidence in the information that they get in these group meetings; they realise that information is power
- Support groups cannot be promoted and advocated to function only for a project period. This will hamper the sustainability of the group

- Volunteering and knowledge transfer adds to the self-value of members. They feel they too have something to tell others about
- Smaller groups of 10 to 15 seem to function more cohesively. A larger group does not ensure participation and involvement of each member
- Vulnerable groups use the information they get as power to increase one's status in the community, to be heard, to bring about awareness, and also prevention. They work towards acceptance and mainstreaming of positive people. They give them support and understanding. They are geared more towards being socially responsible people
- PLHA use the knowledge to empower themselves, be able to face oneself, and know that this is not the end of the road for them. It gives them the confidence to face and challenge the stigma and discrimination that they are confronted with. It gives a boost to their survival instinct. They work towards their own acceptance into the society and community
- Programme approaches differ for these two groups. PLHA give more importance to meeting and sharing and interacting with group members. The group plays the role of family for them. For the at-risk groups it is a way to make friends and socialise and get an identity
- At-risk groups are more oriented towards doing welfare activities for their village, SHG activities.

4.2 Lessons learnt: Dos and don'ts for Support Group formation

Dos

Role of iNGO

- iNGO staff are key persons in aiding group formation
- Intensive interaction and participation of iNGO staff with the group members and the community is very important
- They are responsible for intensive inputs in the form of training and information to the target groups
- Very important to simultaneously build the capacity of the iNGO staff through training and orientation
- Existing presence of iNGO in the community, aids in group formations.

Group formation

- People/persons with similar profiles should be part of one group. This helps in bonding between members as there is a common understanding of each others' situation and problems
- The time of meeting and frequency of meetings have a bearing on the progress and activities undertaken by the group. Convenient timings, which do not interfere with commitments of individual members should be chosen to ensure maximum participation. Long gaps between two meetings do not help to build the bonding between members and it takes longer for members to know each other
- Smaller groups of 10 to 15 members seem to function more cohesively. Larger groups do not ensure the participation and involvement of each member
- It is imperative to keep the interest alive of groups by involving them in activities that increase their interest and give them a feeling that they are benefiting out of being part of the group
- Fun elements and activities play a major role in establishing groups
- Fun times interspersed with training and information sessions help to ensure participation
- Issues that concern the members and can make a visible change in their lives should be addressed immediately.

- Efforts have to be made to organise the way the meeting is held. It helps new members feel important
- Simultaneous awareness creation of the community at large is important to ensure that they support the group formation and participation by its members.

Don'ts

Role of iNGO

- Irregular visits, participation and interaction by staff will result in meetings not being conducted regularly by the group.
- Don't make false promises of material benefits when convincing people to join the group.
- Don't dictate terms and the functioning of the group.
- Don't fix meetings and activities as per iNGO mandate and time only.

Group formation

- Ensure that if a leader is chosen that person isn't given full attention and responsibility for decision making of group activities
- Ensure that members who are being taunted or dissuaded are given enough support to be able to continue participation in meetings

4.3 Lessons learnt: Dos and don'ts for keeping Support Groups going and strengthening their capacity

Dos

- Activities should be planned such that they address the needs of the group.
- Support and help that members get from each other is the mainstay of the group.
- Members have to share and discuss their problems with each other freely.
- Programme approaches differ for PLHA and vulnerable groups.
- PLHA give prime importance to meeting and sharing and interacting with group members. The group plays the role of a family for them.
- For the at-risk groups, being part of a group is a means to make friends, socialise and do some work to help the community and themselves. Identity, appreciation and recognition in the community are important for them.
- At-risk groups are more oriented towards doing welfare activities for their village, and SHG activities. They can be encouraged to take them up on their own initiative.
- The size and number of years do not matter where progress of the group is concerned.
- It is very important to tell the target groups that even if the project period is small, all the activities are oriented towards making them self-reliant and to make the group sustainable.
- Members should be made to realise and recognise their ability and limitations.
- Repetitive information bores groups.
- Ensure that communication amongst members in group activities and decisions is clear and transparent.
- Information has to be tailor-made to suit the requirements of the group as per age and profile.
- Members above the age of eighteen may also become part of the adolescent group as their unmarried status makes it uncomfortable for them to be part of the adult women's group
- Livelihood opportunities through the group is an expectation that PLHA have. They should

be encouraged to take up such activities on their own initiative, with some support being mobilised for this purpose.

- Exposure as a group is very important for building their sense of pride vis-à-vis the group.
- Encourage members to help in increasing membership.
- Make members party to decisions on the functioning of the group.
- Ensure that every member gets a turn to take part in exposure activities.

Don'ts

- Do not allow economic disparities between members to play a role in the group.
- Don't allow economic enhancement activities take priority in the group.
- Don't let expectations of vulnerable groups develop such that they also expect the same type of material benefits from the groups like the PLHA.
- Don't allow discrimination based on the profession of the members in the group.
- In mixed groups ensure that members do not hurt the sentiments of the infected or affected person.
- Do not treat PLHA as special as that only helps in increasing stigma and discrimination.
- Don't plan activities and group functioning as per project period only.
- Don't take up any activities that compromise on the confidentiality of the members.

4.4 Capacity-Building requirements of the different types of Support Groups

Irrespective of the type of group, issues of sustainability and phasing-out of iNGO presence will have to be addressed. While some groups were aware that the project was only for a year, they hadn't discussed or given any thought to what would be the future of the group. Some were of the opinion that once the programme period ended, the group would also stop. Not because they feel that they can't run the group themselves, but they are simply unaware that the group can function without the presence of the iNGO. All the groups have to be made aware of their capabilities and this evaluation methodology tried to give them a picture of how much they have got from being a part of the group and how it has changed their lives. More such participatory exercises will have to be conducted for the groups to be able to comprehend their importance, the change it has brought into their lives and also the very fact that they themselves have been integral and instrumental in carrying out most of the activities. Recognising their own capabilities today is very important.

Detailed discussions and probing on how they would like to see their group evolve resulted in the groups listing the following:

Children/adolescent's groups

- Training to inculcate leadership, confidence and self-reliance
- Activities that will help increase team spirit as well as enhance the unity of the group
- Networking and communication skills
- How to mobilise resources
- Information gathering and dissemination
- Sensitise community and elders to support the group
- How to adapt a rights-based approach in their activities
- To handle a few issues at a time
- To plan and prioritise what is most important to the group
- Reduce the dependence on iNGO guidance and presence

CAA/CIA groups

- Not to become overtly dependent on the material and physical support received
- Training in self-confidence and self-reliance is very important
- Vocational and skill training (for children to work part time to support their families who are ill)
- More information on low-cost nutrition/OIs/health care

Women's groups

- Training to inculcate leadership, confidence and self-reliance
- Activities that will help increase team spirit as well as enhance the unity of the group
- Networking and communication skills
- How to mobilise resources
- Information gathering and dissemination
- How to adapt a rights-based approach in their activities
- To handle a few issues at a time
- To plan and prioritise what is most important to the group
- Understand the importance of what the group has gained till date through information and training and its value
- Reduce the dependence on iNGO guidance and presence
- Using of directory service started to help them contact the right people in times of need

WLHA

- How to source information on issues that are of concern to them
- Ability to network and negotiate with various agencies for their needs and rights
- Vocational training and support for IGP as a group
- Help in gaining economic independence
- Ability to handle discrimination and stigma. Don't let the group develop a feeling that they are at the mercy of others. Ability to handle sexual violence that young widows face, as the very people who discriminate against them are also willing to sexually exploit them.
- Find a place for them to be able to meet regularly
- Positive speaking and attitude building to overcome depression when they think of their own and their children's future

Vulnerable groups

- More information on their rights as women.
- Courage and confidence building to handle abuse that they face at their workplace
- Increase the knowledge of sex workers on use of preventive methods like condoms and build their capacity in negotiating with their clients for the same.

Member, FSW Group, CSI, Delhi

“I won't take up any IGP promoted by the group. I know that it will never match with what I earn now. I am illiterate and no matter how much skill training you give me it cannot match up to what I earn today”

The India HIV/AIDS Alliance

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