Building Linkages and Referrals- a step towards sustainability: Alliance India's Experience

Contents

Introduction

The International HIV/AIDS Alliance (or, Alliance) is a global partnership of nationally-based organisations working to support community action on AIDS in developing countries. **India HIV/AIDS Alliance (or, Alliance India)**, established in 1999, comprises a Secretariat in New Delhi, five Linking Organisations and their networks of over 100 community-based non-governmental organisations (NGOs) and community-based organisations (CBOs) across five states – Andhra Pradesh, Tamil Nadu, Manipur, Maharashtra and Delhi. In 2007, Alliance India supported over 120 community-based projects through its NGO and CBO partners to prevent HIV, improve access to HIV treatment, care and support; and lessen the impact of HIV by reducing stigma and discrimination, particularly among the most vulnerable and marginalised communities key to the epidemic – sex workers, men who have sex with men (MSM), injecting drug users (IDUs) and adults and children living with and affected by HIV.

Funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) was awarded to Alliance India in 2007, whereby the partnership in India has been broadened to include four external organisations and their networks of implementing NGO partners in project based partnerships. CHAHA is a care and support programme for children affected by AIDS (including those living with HIV) which works in four most affected states – Andhra Pradesh, Tamil Nadu, Manipur and Maharashtra. The programme, apart from providing a spectrum of direct services has a very strong focus on building linkages and a referral mechanism. There are many schemes and programmes of both central and state government in operation. CHAHA aspires to establish strong linkages with these government initiatives at the district and sub-district level for the sustainability of efforts beyond project duration.

Alliance India contact points:
Tanu Chhabra (tchhabra@allianceindia.org)**,** Programme Officer, or Pankaj Anand (panand@allianceindia.org), Programme Manager, Knowledge Management Team.

What are Linkages?

The connection facilitated by an NGO worker between a service provider and a client is defined as a linkage. The service provider could be a local, government or private hospital, another NGO, a network, a government department, a local business or even another project within the same NGO. The client here refers to the community of children, women and families affected/living with HIV.

Why are they needed?

A family affected by HIV is almost always pushed further towards the margins leading to decline in social status, income level and many other privileges they enjoyed earlier. Linkages are established for the purpose of survival, inclusion and entitlements of rights which lead to overall childhood development and prolongs the life of children and their families. CHAHA is a time-bound and target-based programme. While we may reach out to the most-in-need children there are many who may get left behind, owing to the fact that we are working in states most affected by the epidemic. This is where linkages lead

to inclusivity and an alternative to direct provision of services which only addresses the immediate needs and has a shelf-life.

'Linkages enable overall childhood development'

The term "childhood development" refers to the processes by which a child grows and thrives – physically, socially, emotionally and cognitively. A child's development requires an array of inputs and these inputs come in from a variety of formal and familial sources. Parents, relatives, friends, the environment, the community, the law, health and education services, are just a few of them. In a crisis situation when one or more of these inputs is withdrawn, like the death of a parent, sudden migration, loss of school friends caused by dropout from school, the child's development is affected, and can be jeopardised permanently. Linkages, reconnecting the same or an alternative input to replace one that was lost, helps in rebuilding the development of the child as is demonstrated through the following example:

Re-discovering lost childhood

Sagar, a 10 year old boy from Pune district of Maharashtra, moved to Thane district because his mother was thrown out after his father's death. Coping with the loss of his father, losing his set of friends after being withdrawn from the school and shifting base to a new area took its toll on the child's psyche. He stopped talking altogether and occasionally responded to his mother. CHAHA programme was running in both the districts and the case was transferred from one NGO to another. The Outreach Worker and the counsellor periodically met Sharad and invited him to a Child Support Group meeting. Here, he met, played games with and interacted with more children. He was also enrolled in a neighbourhood school and slowly Sagar became a usual 10 year old – happy, cheerful and at times, naughty!

'Linkages prolong life and improve health of parents and children'

Linking families to ART and ensuring adherence through continuous follow-up prolongs the lives and health of parents and children. Clubbed with the linkages established with Public Distribution Systems and other food and nutrition sources (like anganwadis, Mid-day meals) it becomes the best strategy for mitigating the emotional, economic and physical impact of HIV on children's lives.

'Linkages develop confidence to re-enter society'

Building and using linkages help the child and his/her family develop the confidence to re-enter society. For instance, linkages have taken Sujatha's life from sadness to hope. With a widow pension and a sewing machine she is able to get some income to manage the family and hold her head high within the community. Acceptance from people provides the psychological support to work through many hindrances that life may throw their way.

Renewing confidence, Reviving hope to Re-enter society!

Sujatha, her two children and mother stay in a tiny tenement in Chinnamanur block of Theni district in Andhra Pradesh. Sujatha was born in the adjacent state of Kerala and came to Theni after marriage. Her husband, a truck driver, died a year ago. It was during her husband's illness that Sujatha found out that she was HIV positive.

The outreach worker of MMSSS organisation found out about Sujatha in one of her visits to the ICTC counsellor. She decided to pay her a visit. Sujatha was passing through a near crisis. Money was fast diminishing, her husband had passed away and she had four mouths to feed and two children to send to school. She needed a shoulder to cry on. The ORW listened to her – a woman brought down by an illness that she had no idea about. The outreach worker registered her in the CHAHA programme. CHAHA provided educational support for the children and a small loan to her to start a business. This enabled her to regain some of her confidence and hope. With renewed energy, she went to the wholesale market and bought blouse materials. She began selling these in the local community, walking daily through the various lanes in her village.

The ORW continued to visit her and seeing her perseverance and energy accompanied her to the Social Welfare Board and helped her enroll in a free sewing machine programme of the State Government. Soon Sujatha was given a sewing machine and this allowed her to increase her income. In her next visit, the ORW took her to the mission hospital and registered her for special care where she got free OI treatment and occasionally some clothes. The ORW regularly monitored her health and then followed up by registering her with another state programme where widows were given a monthly pension. A few months later she began to get Rs.400 per month as pension.

Sujatha is now able to pay the rent and feed the children. What has been interesting is that she is now able to think of alternatives, beyond survival. She thinks of training girls in sewing and tailoring. She also thinks of stitching men's clothes. Though she needs some more equipment but more important is, she has begun to hope again.

How are Linkages facilitated within CHAHA?

The main thrust of the strategy of service provision within CHAHA is through referrals and linkages for several aspects of the service delivery, both medical and non-medical. The referrals are mainly for medical services like ART, registration in PPTCT programme, treatment for opportunistic infections. This practice works towards optimal utilisation of the existing services available and develops services only in those areas where the gaps are identified.

There are successful examples from the programme now where one registered family accompanies the newly enrolled families to health centres for their medical needs and also to government offices to access the schemes.

Alliance India's prior experience of working with communities demonstrates effectively that linkages can bring about important public health, socio-economic and individual benefits. Therefore, in the preparatory phase of CHAHA, all the Sub Sub-Recipients embarked on a task of mapping the essential services (health and education) and government schemes (social-security and livelihood related) and developed a directory for linking the communities they identify, with longer-term sustainable measures. The directory is periodically updated and the frontline force of over 350 outreach workers constantly works towards facilitating access to these services. CHAHA's programme framework involves multiple visits to all the families and children covered in the programme. The families' needs are periodically assessed and analysed against the existing package of services in CHAHA and government schemes and services. Though the easiest strategy would be to reach the quarterly targets by providing direct services as per need, Alliance India goes a step further because of its belief in nurturing sustainable community structures. The outreach workers accompany the family alongwith the child for any medical referrals to the ICTC, CD4 testing centre, ART centre or Primary Health Centre (PHC) for any other ailments and also for accessing Government's social security schemes till the time the family itself doesn't develop the confidence to do it on its own.

'Creating a conducive environment for medical referrals'

The first step is to create a conducive environment for medical referrals. The SSRs start by making initial visits to the ICTC centre, Anti Retroviral Therapy (ART) centre, Primary Health Centre and Government Hospitals. Led by the Project Coordinator at field level, the Outreach Workers meet with the Medical Superintendant or the doctor in-charge, explain the CHAHA programme, its objectives, the geographical coverage and expectations in detail in the initial phase. The CHAHA project team then requests for help in their programme both in identification and referral support. In most cases support is offered without hesitation. If not, advocacy with key stakeholders at district/state/national level is done by the implementing organisation/state level NGO or Alliance India respectively.

A second meeting is held with counsellors from ICTC centres. This meeting is managed by the Project Coordinator and the outreach workers. This meeting sets the stage for referral and identification methodologies, confidentiality procedures and in most cases, when the counsellor is convinced that confidentiality will be maintained, the contact list of people who are living with HIV is provided. A letter from the respective State AIDS Control Society (SACS) has also been procured in some states to facilitate this. Another enabler is that CHAHA is a national programme and National AIDS Control Organisation (NACO) and the respective SACS have been closely involved in the design and implementation of the programme. Orphan and Vulnerable Children and Care and Support data generated from the programme feeds into the overall CMIS of the country. All these factors have contributed to this exchange of information at the grassroots level where the ICTC counsellor can share information without fear of confidentiality being breached.

Over time, and with several visits, the linkage between the ORW and the counsellor and the doctor/counsellor at the ART strengthens. It is a mutually beneficial relationship where the on-site adherence and case identification is being provided by the ORW and new cases and support for CD4 tests and ART follow up is provided by the counsellors.

CHAHA has numerous examples of this relationship having survived NGO staff turnovers as well as staff movement at the government health centres. It is reflective of a systemic linkage that is moving beyond relationships.

'Creating systemic linkages with village level functionaries'

The second set of systemic linkage that is being created is with the grassroot level health workers, the Auxiliary Nurse Midwife (ANM) and the Anganwadi worker (AWW). These linkages are developed in a similar way as above. The NGO teams explain the project, the objectives and the outcomes and request for support both in identification and on-site child support. The Anganwadi worker is responsible for nutritional support, non-formal pre-school education of children under six years of age, children's enrolment in a formal school, health and nutrition of pregnant and lactating women. Many a times, informally, they also extend support to children who are living with and affected by HIV. Both these grassroots' health workers have proved instrumental in referring the outreach worker to families who may be HIV positive. These families are then linked to Prevention of Parent to Child Transmission (PPTCT) services, and weight monitoring and follow-up is done through the data generated by the Anganwadi Workers.

'Linking people with social security and income generation schemes of the national or state government'

Beyond health, the NGO builds linkages with agencies and line departments of the Government. Families get employment through National Rural Employment Guarantee Scheme (NREGS, a flagship rural employment guarantee programme of the Government of India); widows get pension under widow pension schemes; children are enrolled in primary schools under Sarv Shiksha Abhiyaan; sanitation and hygiene are ensured through the Total Sanitation Campaign of the Government; and some families who had lost their homes to the treatment expenses have also accessed the Indira Awas Yojana. Many grandparent-headed households have been linked with the old-age pension scheme of the government and ration at subsidised cost is being availed under the Antyodaya scheme. Though, linking to these schemes does not ensure a complete solution in dealing with depleting income resources and deteriorating health, but it offers a start. Some of the schemes require HIV status of the family member to be revealed

A place called Home, a feeling called Happiness

Purnima and Dev lost their father to HIV very early in their life. Coping with the loss of a parent is tough but Purnima and Dev also had to cope with their mother's illness. Purnima had to take over all the responsibilities of running their home as their mother got increasingly ill. Adding to all this their sources of income dried up and they had to move out of their rented house.

CHAHA programme registered the children and seeing the situation of the family, the team provided immediate support as well as counseling and psychosocial support. JVS Amravati, the NGO in the area, provided support to get the children readmitted to school and linked up Purnima's mother with the government scheme (Gharkul Yojna) for low cost housing. They were successful and now the family is building a new home for themselves with the loan that they got from the Social Welfare department. Linkages with the hospital and support for Income Generation through the programme has set the family back on their way to hope and given Dev and Purnima their childhood and a new place called 'Home'.

(e.g. widow pension) and this requires a lot of convincing by the outreach workers. The biggest barrier in linking families to government schemes is the lack of basic essential documents like ration card, birth and death certificate. Some families due to stigma move out or were thrown out of their parental homes and native villages, leaving all their belongings and documents behind. This also keeps arising as the single-most barrier to accessing such schemes.

To highlight the process of securing widow pension in Tamil Nadu, the Outreach Worker starts by facilitating procurement of death certificates and HIV positive status reports and fills up the necessary forms and gives it to the Project Coordinator. The Project Coordinator then files the papers with the District Programme Manager (DPM) appointed by Tamil Nadu State AIDS Control Society (TANSACS). The DPM forwards the applications with comments to the District Administration and ensures that the widow pension is approved. Similarly, the Outreach Worker collects proof of training and income certificate from single mothers for submitting applications under the sewing machine provision scheme of the Tamil Nadu Government. Once the papers are all complete the Outreach Worker ensures that they are submitted by the Project Coordinator to the Social Work Department. Advocacy by the positive networks in Tamil Nadu has ensured that at least 10% of the sewing machines are allocated to HIV positive women.

In some cases, the nature of support is also material like using local self-governing institutions' immovable and fixed assets for conducting sensitisation meetings and children support groups meetings.

'Special Linkages'

The other set of linkages is with local hospitals, other local NGOs, local businesses, private doctors, private schools, trade unions and the entire socio-economic milieu in which the family stays. The Outreach Workers have proved to be innovative in building linkages in this regard. In one instance, a local businessman was convinced to provide rent free accommodation while in another instance a community leader was convinced to provide a safe space for the children support group (CSG) meetings. Resource mobilisation is also done by tapping the local resources.

Sarada lives in Tiruppur district in Tamil Nadu and is a mother of four children, Rajan, Leela, Rani and Sree. They lived in a shack at the end of the village when the outreach worker from CEEMA (SSR) met them for the first time. A single mother, Sarada lost her husband to AIDS and she is also HIV positive. Sree and Rani are also living with HIV. The outreach worker registered the children and referred Sarada's case to a local businessman. He believed in community service and offered a small house (rent-free) to the family. Sarada works as a manual labourer and makes sure the children go to school. The family is stoic but the pain is palpable with Sree suffering from a painful stye and Sarada having to balance taking him to the hospital and going for work. Another linkage established by CEEMA fetches Sarada Rs 400 a month as widow pension. This provides some cushioning and Sarada is grateful for the help but there is a long way to go.

'Fostering Reverse Linkages'

The Tamil Nadu State AIDS Control Society (TANSACS) invited Alliance India to provide support to children affected and/or living with HIV in the 13 districts CHAHA is working in through two state-level NGOs – PWDS and TASOSS. This was to avoid duplication of services and overlap in numbers. A Memorandum of Understanding (MoU) has been signed in this regard with TANSACS and some children are also referred by them to be a part of the CHAHA programme.

Factors that promote effective linkages

'Mapping, documenting and creating community awareness around various services and schemes'

The first prerequisite towards beginning the process of linking is the presence of good quality services that are receptive and responsive to needs of communities. Continuously mapping these services, assessing their quality and matching it with community's need is an ongoing task for the outreach workers.

'Creating programme frameworks that look beyond service delivery'

The CHAHA programme applies a performance based system of management where each of the 54 SSR has set quarterly targets that they have to meet in terms of service delivery. At the same time, Alliance India puts great emphasis on building community structures and setting up systems. By keeping the targets for the first year really low, Alliance India enabled the SSRs to invest in building contact and relationship with ICTC counsellors, doctors at ART centres, positive networks, AWW, teachers, ANM at PHC and other local stakeholders. Gradually, as the targets escalate, the organisations are able to keep pace with them because of the relationship that was built in the initial phase. ICTC counsellors refer cases to the Outreach Workers, who then visit the families and register them in the programme. This cross-referral or two-way linkage is a sign of maturity of the programme.

'Highly motivated team with a positive attitude'

CHAHA's greatest strength is the 350 odd outreach workers who constantly strive to deliver their best in the interest of the children and families. Even if it requires multiple visits, the Outreach Workers accompanies the family for their ART, testing of children, procuring a ration card or other such documents. In the second year of implementation (2008-09), there are many examples from the field where communities are coming forward to support others like them in accessing services. This is also an indicator of empowerment that the previously stigmatised people are today confident enough to access services on their own and enabling other families to do the same.

'Ongoing capacity building of outreach workers and implementing NGOs'

It is important to continuously build capacities and skills of outreach workers and other project staff. Alliance India and their SRs constantly update the implementing

organisations and staff on the national and global policy environment, new government schemes, and new ways of working towards facilitating linkages.

'Creating institutional mechanisms locally to facilitate linkages'

Continued advocacy at national, state and district level ensures a greater systemic link with the government departments and it supplements the efforts by the outreach workers in meeting ground level officials. Through this, formal and informal mechanisms get created that facilitate the process of linking. Greater coordination amongst frontline workers and actors in these local settings leads to early identification of those in need and reaching out to them. Areas where services are found to be lacking or wanting in terms of quality get addressed through advocacy. In CHAHA, records of the families linked to various schemes and the process to access those services is maintained. This evidence also supports our advocacy efforts. We are also advocating for new schemes that are a felt need by the community.

Factors that inhibit effective linkages

Some factors that inhibit building effective linkage are absence of the abovementioned enabling factors, and also:

'Complex and time consuming'

The process of establishing a good working relationship with the local service providers may take weeks or months since it is a time-intensive process. Coupled with that is the problem of frequent transfers of government functionaries with whom a rapport and working relationship has been established. This can lead to frustration and in a performance based programme may also mean that one has less time available to extend support to the children.

'Stigma, discrimination and a lack of experience in public spaces''

Owing to the widespread stigma towards families affected by HIV/AIDS, many community members do not wish to come forward to access any services and prefer a life of isolation. Some government schemes such as widow pension scheme and free travel for ART require the status to be disclosed to village level authorities which instils fear amongst community members.

'Lack of essential documents'

The most common barrier and the most essential requirement to access any government scheme is a ration card, birth certificate, death certificate of the deceased husband. Most of the marginalised families in India do not have a ration card, and because of low awareness and low number of institutional deliveries, universal birth registration has not been achieved. In case they even have them, frequent and forced migration makes them leave these documents behind, fear of their status being disclosed through their HIV-test report, CD4 results or ART schedule makes them discard or burn these reports.