

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





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

A Report on Operations Research conducted in  
Maharashtra and Manipur

India HIV/AIDS Alliance, New Delhi

**December 2009**

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# About India HIV/AIDS Alliance

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

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

Established in 1999, **India HIV/AIDS Alliance (or, Alliance India)** comprises a Secretariat in New Delhi, five lead partner organisations (Linking Organisations within the global Alliance) and their networks of over 100 community-based Non-Government Organisations (NGOs) and Community-Based Organisations (CBOs) across Andhra Pradesh, Tamil Nadu, Maharashtra and Delhi, and a state partner in Manipur. Alliance India's project office in Hyderabad was formally launched in April, 2008 as the fifth lead partner (or, Linking Organisation) in India.

Alliance India has supported over 120 community-based projects through its NGO and CBO partners to prevent HIV infection; improve access to HIV treatment, care and support; and lessen the impact of HIV by reducing stigma and discrimination, particularly among the most vulnerable and marginalised communities which are key to the epidemic – sex workers, men who have sex with men (MSM), injecting drug users (IDUs) and adults and children living with and/or affected by HIV.

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# Acronyms

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<b>AIDS</b>	:	Acquired Immuno Deficiency Syndrome
<b>ANC</b>	:	Ante Natal Care
<b>ANM</b>	:	Auxillary Nurse Midwife
<b>ARV</b>	:	Antiretroviral
<b>ART</b>	:	Anti Retroviral Therapy
<b>ASHA</b>	:	Accredited Social Health Activist
<b>AWW</b>	:	Anganwadi Workers
<b>CAA</b>	:	Children Affected with AIDS
<b>CBO</b>	:	Community Based Organisation
<b>CCC</b>	:	Community Care Centre
<b>CCDT</b>	:	Committed Communities Development Trust
<b>CDMO</b>	:	Chief District Medical Officer
<b>CDPO</b>	:	Child Development Programme Officer
<b>CLHIV</b>	:	Children Living with HIV
<b>CHC</b>	:	Community Health Centre
<b>CMO</b>	:	Chief Medical Officer
<b>CSO</b>	:	Civil Society Organisation
<b>DED</b>	:	District Education Department
<b>DGO</b>	:	Diploma in Gynaecology and Obstetrics
<b>DIC</b>	:	Drop-in Centre
<b>DLHS</b>	:	District Level Household Survey
<b>DNA</b>	:	Deoxyribonucleic Acid
<b>DOTS</b>	:	Direct Observation Treatment Short Course
<b>DPT</b>	:	Diphtheria Tetanus whole cell Pertussis Vaccine
<b>EBC</b>	:	Exposed Baby Care
<b>EDI</b>	:	Entrepreneurship Development Institute
<b>ELISA</b>	:	Enzyme-Linked Immuno Sorbent Assay
<b>EID</b>	:	Early Infant Diagnosis
<b>FBO</b>	:	Faith Based Organisation
<b>FDC</b>	:	Fixed Dose Combination
<b>FGD</b>	:	Focus Group Discussion
<b>GFATM</b>	:	Global Fund to Fight against AIDS, Tuberculosis and Malaria
<b>HCBCS</b>	:	Home and Community Based Care and Support
<b>HCW</b>	:	Healthcare Workers
<b>HIV</b>	:	Human Immuno Deficiency Virus
<b>ICDS</b>	:	Integrated Child Development Scheme
<b>ICTC</b>	:	Integrated Counselling and Testing Centre
<b>IDI</b>	:	In-Depth Interview
<b>IDU</b>	:	Intravenous Drug Users

<b>IEC</b>	:	Information Education and Communication
<b>IGP</b>	:	Income Generation Programme
<b>INR</b>	:	Indian Rupee
<b>LAC</b>	:	Link ART Centre
<b>LFU</b>	:	Lost to Follow-up
<b>M&amp;E</b>	:	Monitoring and Evaluation
<b>MCH</b>	:	Maternal and Child Health
<b>MDACS</b>	:	Mumbai District AIDS Control Society
<b>MO</b>	:	Medical Officer
<b>MNP+</b>	:	Manipur Network of Positive People
<b>MSACS</b>	:	Maharashtra State AIDS Control Society
<b>MSM</b>	:	Men who have Sex with Men
<b>MTCT</b>	:	Mother to Child Transmission
<b>NACO</b>	:	National AIDS Control Organisation
<b>NACP</b>	:	National AIDS Control Programme
<b>NGO</b>	:	Non Government Organisation
<b>NRHM</b>	:	National Rural Health Mission
<b>OBG</b>	:	Obstetrics and Gynaecology
<b>OI</b>	:	Opportunistic Infection
<b>PCR</b>	:	Polymerase Chain Reaction
<b>PHC</b>	:	Primary Health Centre
<b>PLHIV</b>	:	People Living with HIV
<b>PNDT</b>	:	Prenatal Diagnostic Techniques
<b>PPTCT</b>	:	Prevention of Parent to Child Transmission
<b>PR</b>	:	Principal Recipient
<b>PRI</b>	:	Panchayati Raj Institution
<b>RCH</b>	:	Reproductive and Child Health
<b>RNTCP</b>	:	Revised National Tuberculosis Control Programme
<b>RTI</b>	:	Reproductive Tract Infection
<b>SACS</b>	:	State AIDS Control Society
<b>SAEP</b>	:	School AIDS Education Programme
<b>SASO</b>	:	Social Awareness Service Organisation
<b>SD</b>	:	Strategic Directions
<b>SHG</b>	:	Self Help Group
<b>SOP</b>	:	Standard Operating Procedures
<b>SR</b>	:	Sub-Recipient
<b>SSR</b>	:	Sub-Sub-Recipient
<b>STD</b>	:	Sexually Transmitted Disease
<b>STI</b>	:	Sexually Transmitted Infection
<b>TB</b>	:	Tuberculosis
<b>TBA</b>	:	Traditional Birth Attendants
<b>UNAIDS</b>	:	United Nations Programme on HIV and AIDS
<b>UNICEF</b>	:	United Nations Children's Fund
<b>VCTC</b>	:	Voluntary Counselling and Testing Centre
<b>VO</b>	:	Voluntary Organisation
<b>WHO</b>	:	World Health Organisation
<b>WLHIV</b>	:	Women Living with HIV

# Executive Summary

India has witnessed HIV and AIDS for nearly quarter of a century (first case of AIDS was reported in 1986), and it has become one of the most defining issues of our time. The progression of the epidemic in India has been a cause of major concern. According to HIV Sentinel Surveillance and HIV Estimation 2007 Report of National AIDS Control Organisation (NACO), it was estimated that there were 2.31 million People Living with HIV (PLHIV) in India by 2007, with estimated adult HIV prevalence of 0.34 percent (0.25 % - 0.43 %).

For PLHIV, free Anti Retroviral Therapy (ART) programme was launched by the Government of India on 1st April, 2004. It was scaled up in a phased manner to provide free ART to 2,00,000 PLHIV by 2011 in 250 centres across the country. However, the Programme largely remained confined to the adult PLHIV with very little paediatric focus. After having realised the disparity between the number of Children Living with HIV (CLHIV) and the number receiving ART, the Indian Paediatric AIDS Initiative was launched in November, 2006 with the objective to maximise the access of ART to the paediatric age group.

With a view to extend care and support to HIV positive children, CHAHA Programme was launched under the Global Fund Round 6 by India HIV/AIDS Alliance as a civil society Principal Recipient (PR).

Alliance India conducted a study on identifying barriers to accessing ART centres by CLHIV, both in urban and rural context, in two high prevalence states of Maharashtra and Manipur. The two states were selected to include a cross section of socio-cultural and economic diversity. In both states, one urban and one rural district was selected to collect data from diverse populations and arrive at conclusive results. Present report deals with the issues relating to the rural population.

Based on a wide range of subjects covered in the study, interviews from various stakeholders and service users were recorded and analysed to prepare evidence-based, strategic and child-focused interventions aimed at minimising the barriers that hamper access to paediatric ART services in rural areas.

The major issue brought out by the study related to an all-pervasive stigma and the resultant discrimination at all levels in rural areas not only within the family and community but also in school and even health care service facilities. The discriminatory attitude of service providers discourages both children and their parents, to access the ART centres. In many cases, this leads to non-disclosure of the HIV positive status of the child, thus keeping the child away from available services and interventions.

*The major issue brought out by the study related to an all-pervasive stigma and the resultant discrimination at all levels in rural areas not only within the family and community but also in schools and even health care service facilities.*

A focused effort is, therefore, needed to address issues like illiteracy, lack of awareness and limited access to Information, Education and Communication (IEC). The gross lack of awareness about paediatric ART services in the rural areas and

also the fact that these services are being provided free of charge by the government needs to be addressed by a rural and child-focused IEC strategy. In addition, media planning to bridge the information and knowledge gaps on the availability of paediatric ART is crucial.

The effort needs to be further supplemented and complemented by creating enabling conditions for wider participation of society at large – Panchayati Raj Institution (PRI) members, religious and spiritual leaders, local political leaders, teachers, even families and children themselves.

Access to ART centres gets constrained due to socio-economic factors as well. Despite the provision of free ART service, families have to incur substantial expenditure on travel, testing facilities and treatment of Opportunistic Infections (OI), which are not provided at ART centres. Innovative methods to bring ART to doorsteps through creation of Link ART Centres (LAC) or making ART and testing facilities available in Community Care Centres (CCC) can be the alternative for dealing with this situation. Linkages with rehabilitative services and some Income Generation Programme (IGP) activities especially designed for the rural population could be a big encouragement.

*Access to ART centres gets constrained due to socio-economic factors as well.*

The distance, location and timing of ART centres, besides the staffing pattern as well as patient-unfriendly procedures and facilities add up to difficulties in accessing ART services, which, in any case, are inadequate. The rural population, comprising mostly daily wage earners, not only lose their daily earnings to access these services but also incur a lot of expenses on travel for accessing ART centres. This leads to reluctance and avoidance in getting regular treatment.

The attitude of health care providers has a lot to do with the success of ART programme. They need to ensure an environment free from stigma or discrimination in health care settings. It has been observed that child focus is almost missing as the existing services are largely adult-centric. Training of doctors, paramedics and counsellors in paediatric orientation and counselling skills is, therefore, of paramount importance for providing meaningful ART.

The policy makers, too, need to ensure that there is an integration of all programmes and services which impact HIV and AIDS related activities. Thus, education, Integrated Child Development Schemes (ICDS), National Rural Health Mission (NRHM), Reproductive and Child Health (RCH) programme, Prevention of Parent to Child Transmission (PPTCT), Voluntary Counselling and Testing Centres (VCTC), Community Care Centres (CCC), Tuberculosis (TB) and ART centres need to function in close coordination to achieve the common objectives embedded in their programmes.

A formal involvement of the private sector, including NGOs, in the paediatric HIV programme will improve the coverage and delivery of standardised treatment which at present is inconsistent. It is, therefore, imperative that a practical and time-bound action plan is developed to address these issues at both programmatic and policy level.

# HIV and AIDS Scenario in India

HIV epidemic in India is heterogeneous in nature, both in terms of routes of transmission as well as geographic spread. Approximately 58 percent of PLHIV dwell in rural areas<sup>1</sup>; the HIV prevalence rate is 40 percent higher in urban areas than in rural areas (61% higher in urban areas than in rural areas for women and 28 percent higher for men).

According to HIV Sentinel Surveillance and HIV Estimation 2007 Report of NACO, it is estimated that in 2007, there were 2.31 million (1.8 – 2.9 million) PLHIV in India with an estimated adult HIV prevalence of 0.34 percent (0.25% – 0.43%). Females constituted around 39 percent, (0.9 million); children below 15 years around 3.5 percent while people older than 49 years constituted 7.8 percent of the estimated number of PLHIV<sup>2</sup>.

The survey also portrayed a concentrated epidemic in India with high prevalence amongst the high risk groups and low prevalence in antenatal attendees. In fact, except for Andhra Pradesh which recorded 1 percent prevalence rate, all other states recorded less than one percent prevalence in Antenatal Care (ANC) attendees.

## HIV Prevalence in Study States

In Manipur, the overall HIV prevalence rate among adults aged 15-49 years is 1.13 percent which is the highest of all states surveyed under the HIV Sentinel Surveillance and HIV Estimation conducted by NACO in 2007; among women aged 15-49 years, the prevalence is 0.76 percent and among men aged 15-49, the prevalence is twice as high at 1.59 percent. The HIV prevalence at antenatal clinics in Manipur has exceeded 1 percent in recent years<sup>2</sup>.

In Maharashtra, 0.62 percent of adults aged 15-49 years are living with HIV. HIV prevalence among women is 0.48 percent, compared to 0.77 percent among men. Prevalence among youth aged 15-24 years is 0.24 percent, which is lower than for the reproductive age population as a whole<sup>2</sup>.

Expanded surveillance among MSM has revealed more than 5 percent HIV prevalence in Manipur (16.4%) and Maharashtra (17.91%). Among Intravenous Drug Users (IDUs), Maharashtra records 24.4 percent, while Manipur stands at 17.9 percent. HIV prevalence among Female Sex Workers (FSWs) is very high in Maharashtra (17.91%), followed by Manipur (13.07%)<sup>2</sup>.

<sup>1</sup>WHO report, 2005.

<sup>2</sup>HIV Sentinel Surveillance and HIV Estimation Report NACO, 2007.

## Vulnerability of Children to HIV and AIDS

According to AIDS Epidemic Update, December 2009, released by UNAIDS, there were 33.4 million PLHIV including 2.1 million CLHIV globally by the end of 2008. Moreover, one third of HIV positive children die before the age of 1.5 years while half of them die by 2 years of age<sup>3</sup>.

Perinatal transmission is the most common cause of HIV in paediatric age group below 15 years. Most children under age 15 acquire HIV from their HIV positive mothers before or during birth or through breastfeeding. Besides Mother to Child Transmission (MTCT), children and adolescents are also extremely vulnerable to HIV through blood transmission, unsafe sex and injecting drug use. Overall progression of disease is more rapid in children because of their weak immune system<sup>4</sup>.

Paediatric AIDS results in death more quickly in developing countries, where there is widespread poverty, poor nutrition, low health awareness and other contributing factors that call for augmented efforts to provide free treatment to children and HIV positive mothers.

There are several factors that accentuate the vulnerability of children to HIV and AIDS. There is a lack of awareness about the existing care and support services. Children and families experience difficulty in accessing ART centres for a variety of reasons. The identification and follow up of children who are in difficult circumstances or those born to HIV positive mothers is grossly inadequate. In the case of infants, non-availability of mechanisms for early diagnosis adds to the vulnerability. There are other problems on the supply side too. It is widely felt that there is a lack of clear guidelines for treatment and that the overall capacity of service providers in clinical management of paediatric HIV/AIDS and nutrition in infants is weak. To add to the complexity, the surveillance and strategic information system for the paediatric age group (<15 years) leaves much to be desired.

<sup>3</sup>AIDS Epidemic Update, UNAIDS, December 2009.

<sup>4</sup>Manual for Management of HIV/AIDS in Children (UNICEF).

# Anti-Retroviral Therapy in India: An Overview

In September, 2003, WHO declared the lack of access to Antiretroviral (ARV) Treatment for HIV and AIDS a “global health emergency” and announced an emergency plan to scale up access to ARV treatment to cover at least three million people by the end of 2005. This announcement popularly came to be known as the “3 by 5” initiative. WHO guidelines for “Antiretroviral Use in Resource-constrained Settings” were revised in December, 2003 and again in August, 2006.

The Government of India launched free ART Programme on 1st April, 2004, starting with eight tertiary-level government hospitals in the six high-prevalence states of Andhra Pradesh, Karnataka, Maharashtra, Tamil Nadu, Manipur and Nagaland, as well as the National Capital Territory (NCT) of Delhi. In Phase 1 of this programme, subgroups of PLHIV who are targeted on a priority basis included: (i) sero-positive mothers who participated in PPTCT programme (ii) sero-positive children below the age of 15 years and (iii) PLHIV who seek treatment in government hospitals.

ART centres were scaled up in a phased manner to provide free ART to 1,00,000 PLHIV by the end of 2007 and are expected to cater to 3,00,000 PLHIV by 2011 in 250 ART centres across the country. It implies a comprehensive prevention, care and treatment programme, with a standardised, simplified combination of ART regimens, a regular secure supply of good-quality ARV drugs, and a robust monitoring and evaluation system. However, the programme lacked focus on paediatric ART.

*Because of a paradigm shift in the National AIDS Control Programme of India, treatment, along with prevention, is now perceived as a significant part of a broad programme to combat HIV and AIDS with an added focus on the care and support of CLHIV.*

## Paediatric ART in India

Paediatric AIDS Initiative in India was launched in November, 2006, to combat the disparity between the number of CLHIV and the number of children receiving treatment. Because of a paradigm shift in the National AIDS Control Programme (NACP) of India, treatment, along with prevention, is now perceived as a significant part of a broad programme to combat HIV and AIDS with an added focus on the care and support of CLHIV. Although ART services are provided free to adults and children, access for children is often limited due to several socio-economic and institutional barriers.

After analysing the NACO data for projecting the existing gap in service provisioning, it is found that, as on September, 2008, only 12,116 paediatric cases were on ART out of a total 1,77,808 cases<sup>1</sup>. Cumulative number of paediatric cases ever started ART were 15,714 (6.17%) out of a total number of 2,45,515. With a total cumulative paediatric patients registered in HIV care being 42,106, only 37 percent could access ART in the country.

<sup>1</sup>CMIS Report on District ART Data - National AIDS Control Organisation- September 2008.

**Table 1:** Paediatric ART status in India

No. of Patients	Paediatric ART Status in India	Total	Males	Females
2,54,515	Cumulative number of paediatric patients ever started on ART	15,714 (6.17%)	9,144 (58.2%)	6,015 (41.8%)
1,77,808	Total number of patients alive and on ART as on September 2008	12,116 (15.57%)	7,294 (60.20%)	4,822 (39.80%)
1,07,592	Cumulative number of paediatric patients ever registered in HIV care	42,106 (39.20%)	23,508 (55.8%)	17,138 (34.4%)
26,744	Total paediatric patients who ever died	976	597	379
23,491	Total number of patients transferred out	1,558	916	642
2,206	Total number of patients who stopped treatment	76 (3.44%)	-	-
17,357	Lost to follow-up paediatric patients	625 (3.6%)	-	-

(Source: CMIS Report on ART Data - National AIDS Control Organisation - Sept 2008)

According to the report released jointly by WHO, UNICEF and UNAIDS in September, 2009, India is among the top 20 countries which recorded the highest percentage increase in the number of people receiving ART between 2007 and 2008 (from 1,58,000 to 2,34,000 i.e 48% increase). The number of facilities in India increased from 4,269 in 2007 to 4,817 in 2008. Yet, out of 80,000 pregnant Women Living with HIV (WLHIV), only 10,673 received the treatment till the end of 2008. Just about 22 percent children born to Indian women living with HIV were receiving ART for preventing mother to child transmission<sup>2</sup>. As of March, 2009, 47,784 CLHIV were registered for HIV care at ART centres and 14,303 CLHIV received free ART under the National Paediatric HIV and AIDS Initiative. By September 2009, out of 16,940 paediatric patients alive and on ART, 4,453 were from Maharashtra and 403 from Manipur, the two high prevalence states in India<sup>3</sup>.

## CHAHA: Facilitating Access to Paediatric ART

Alliance India initiated an expanded child-centred Home and Community Based Care and Support (HCBCS) Programme in the year 2007 called CHAHA (meaning 'a wish' in Hindi language). With funding from Round 6 of the Global Fund to Fight Against AIDS, Tuberculosis and Malaria (GFATM), Alliance India (as a civil society Principal Recipient), along with its consortium of nine Sub-Recipients (SR), is implementing CHAHA in line with the strategic priorities of the National AIDS Control Programme Phase III (NACP III).

<sup>2</sup>Times of India, 1st October 2009.

<sup>3</sup>Annual Report 2008-2009, Ministry of Health and Family Welfare, Government of India.

Alliance India is working closely with different stakeholders and the government to find ways to help keep orphans/CLHIV with their parents or extended families. It envisages extending care and support to 64,000 children living with and/or affected by HIV and their families (especially women-headed households) by January 2011.

Since improving access to health care and medical services is a prime objective of CHAHA, prevention, treatment, care and support continue to be the focus of entire intervention process under the programme. Ever since its inception, CHAHA has been instrumental in facilitating access to ART by CLHIV and their families. The programme strategy includes financial support to the families by taking care of the travel cost incurred in taking the child to ART centre, facilitating and monitoring treatment follow-up, providing paediatric counselling, nutrition and medicines (e.g., co-trimoxazole prophylaxis) to the affected children.

For long term sustainability and maintaining service availability to children living with and affected by HIV, Alliance India aims to work in close collaboration with various departments and government ministries e.g., Women & Child Development, Social Justice and Rural Development.

*Ever since its inception, CHAHA has been instrumental in facilitating access to ART by CLHIV and their families.*

## CHAPTER 3

# Study Rationale and Objectives

The reasons for lack of access to treatment of CLHIV include, among others, issues of late diagnosis of infants, absence of clear guidelines and lack of concerns amongst medical fraternity to follow the guidelines for treatment of children and lack of access to appropriate paediatric ART formulations. Inadequate capacity and knowledge of service providers in clinical management of paediatric HIV and AIDS, lack of surveillance and data in this age group (<15 years), poor nutrition for infants, inadequate follow-up of children born to HIV positive mothers, lack of convergence with Reproductive and Child Health (RCH) services and a dearth of minimum package for care and support of CLHIV are the other issues of concern.

*Barriers relating to health care system (including the programme level) and social barriers should be considered by policy makers and national HIV programme managers in ensuring sustainable access to ART centres by children.*

The paediatric formulation in ART was launched in 2006 but lack of access to ART needs to be addressed at various levels. Barriers relating to health care system (including the programme level) and social barriers should be considered by policy makers and national HIV programme managers in ensuring sustainable access to ART centres by children.

The Strategic Directions were envisaged under the CHAHA programme, with the following goals:

- To enhance access of HIV positive children to ART centres.
- To enhance the sustainability of access to ART centres for HIV positive children beyond project duration of Phase II under CHAHA.
- To tailor the strategies of programme implementation to improve upon the efforts of facilitating sustainable access of children and families to ART centres and to overcome barriers.

Keeping in view the above, a study for identifying barriers to sustainable access of children and families in rural India to ART centres and seeking solutions to address barriers was conducted by Alliance India with the following objectives:

## Objectives of the Study

- To highlight policy level issues on access of children and caregivers, take them up at appropriate forums and seek to build a wider and shared understanding of issues around barriers/bottlenecks. The research-based policy-advocacy initiatives will form the bedrock in addition to improving programme delivery wherever desirable and possible.
- To assess and highlight basic minimum level of standards in relation to access to ART centres in terms of adequacy, quality and timeliness of support needed, given the nature of resource-limited settings and gender differentials at the community level.
- To understand and highlight opportunities of linkages with state/district level departments and/or local self-governing institutions like *panchayats* etc.

## District Profile: Sangli and Ukhrul

The study was conducted in two high prevalence states of India - Maharashtra and Manipur. As the focus of this research was rural, one district each was selected for study from these states - Sangli in Maharashtra and Ukhrul in Manipur.

### General Indicators

According to United Nations (2005) report, approximately 72 percent of the population in India resides in the rural areas and approximately 58 percent of the PLHIV dwell in rural areas in India<sup>1</sup>.

Ukhrul district spreads over an area of 4,544 sq. kms with a population of 1,40,946. Decadal growth rate of district Ukhrul is 28.98 percent. Sangli district is located in the western part of Maharashtra. Spread over an area of 8,601 sq.kms., Sangli has a population of 2,583,524. Decadal growth rate of district Sangli is 16.85 percent. Literacy rate of Sangli is 73.12 percent and that of Ukhrul is 76.62 percent. In both the project districts, women are less literate than men.

### Demographic Indicators

**Table 2:** Comparative population of the study districts

Comparative Population	Maharashtra	Manipur
<b>Total Population</b>	9,67,52,247	22,94,000
	<b>Sangli Dist.</b>	<b>Ukhrul Dist.</b>
<b>Total</b>	25,83,524	1,40,946
Males	13,20,088	73,465
Females	12,63,436	67,313
Children (0-14 years)	6,90,620	49,302

(Source: Census of India 2001 online data)

Nearly 4.5 percent of the total population of Manipur dwells in Ukhrul district. The census figures depict that the population of Sangli is less than 3 percent of the total population of Maharashtra and nearly 25 times more than that of Ukhrul.

<sup>1</sup>WHO report, 2005.

## Economic Status

As for the economic status in study districts, per capita income of the people in Sangli is low, at Rs.14,476. Yet, it is nearly two times of that in Ukhrul (Rs. 7,758)<sup>2</sup>.

The Government of Manipur recognises that 52.3 percent or half the population of Ukhrul district is Below Poverty Line (BPL) even though the literacy rate is 76.62 percent. The BPL population is much higher in Ukhrul as compared to Sangli.

Factors like high BPL population, low literacy levels, low socio-economic status and a strong belief in superstitions account for low health awareness amongst the people, especially women, residing in rural areas.

## ART Status in Sangli and Ukhrul

As per NACO 2008 report on ART, number of patients registered and their treatment adherence in Sangli and Ukhrul districts is given in the following table:

**Table 3:** NACO report on ART in the study districts

ART Services	Sangli					Ukhrul				
	Adult	Paediatric (M)	Paediatric (F)	Paediatric (Total)	Total (Adult + Paediatric)	Adult	Paediatric (M)	Paediatric (F)	Paediatric (Total)	Total (Adult + Paediatric)
Number of persons registered during September 08	232	8	8	16	248	4	0	0	0	4
Cumulative number of persons ever registered in HIV care by end of September 08	8,731	591	448	1,039	9,770	84	0	0	0	84
Cumulative number of patients ever started on ART	4,516	288	197	490	5,006	53	0	0	0	53
Cumulative number of patients who ever died	699	15	9	24	723	2	0	0	0	2

Table contd...

<sup>2</sup>Report of Directorate of Economics & Statistics, Government of Manipur, Wikipedia and Census 2001

ART Services	Sangli					Ukhrul				
	Adult	Paediatric (M)	Paediatric (F)	Paediatric (Total)	Total (Adult + Paediatric)	Adult	Paediatric (M)	Paediatric (F)	Paediatric (Total)	Total (Adult + Paediatric)
Cumulative number of patients "transferred out"	681	46	29	75	756	0	0	0	0	0
Number of all patients whose treatment status is stopped treatment	24	3	2	5	29	2	0	0	0	2
Cumulative Number of patients who are lost to follow-up (LFU)	48	5	2	7	55	1	0	0	0	1
Total number of patients who are alive and are on ART	2,868	203	139	342	3210	47	0	0	0	47
Total number of patients who missed treatment	196	19	18	37	233	1	0	0	0	1

(Source: CMIS report on District ART Data - National AIDS Control Organisation - Sept 2008)

## CHAPTER 5

# Research Methodology

The approach of the research was participatory and mainly focused to capture a broad view of both the demand and supply issues from the perspective of community implementation and policy making. This was done by assessing the existing status of service provisioning, identification of existing gaps in access to ART services by children and assessing the knowledge, attitude, behaviour and practices of the general community, stakeholders, service users and service providers.

The Operations Research included both Qualitative and Quantitative methods and had the following components-

- Community Survey
- Stakeholders' Interviews
- Facility Survey

The data collection tools and techniques comprised of both primary and secondary sources. The primary data collection tools comprised of In-Depth Interviews, Focus Group Discussions, Case Studies and Direct Observations. The secondary data collection comprised of reports and documents from a number of sources including those from relevant government agencies.

## Sampling Framework

### Selection of Study Sites/Districts

Identification and selection of districts for the study was done as per the following criteria:

1. Districts falling in NACO's "A" category districts.<sup>1</sup>
2. Districts identified by CHAHA programme.
3. Availability of target groups as prescribed in the sample size as per NACO ART data 2008<sup>2</sup> and CHAHA monthly and quarterly reports<sup>3</sup>.
4. Availability of facilities catering to the target group in the identified states.

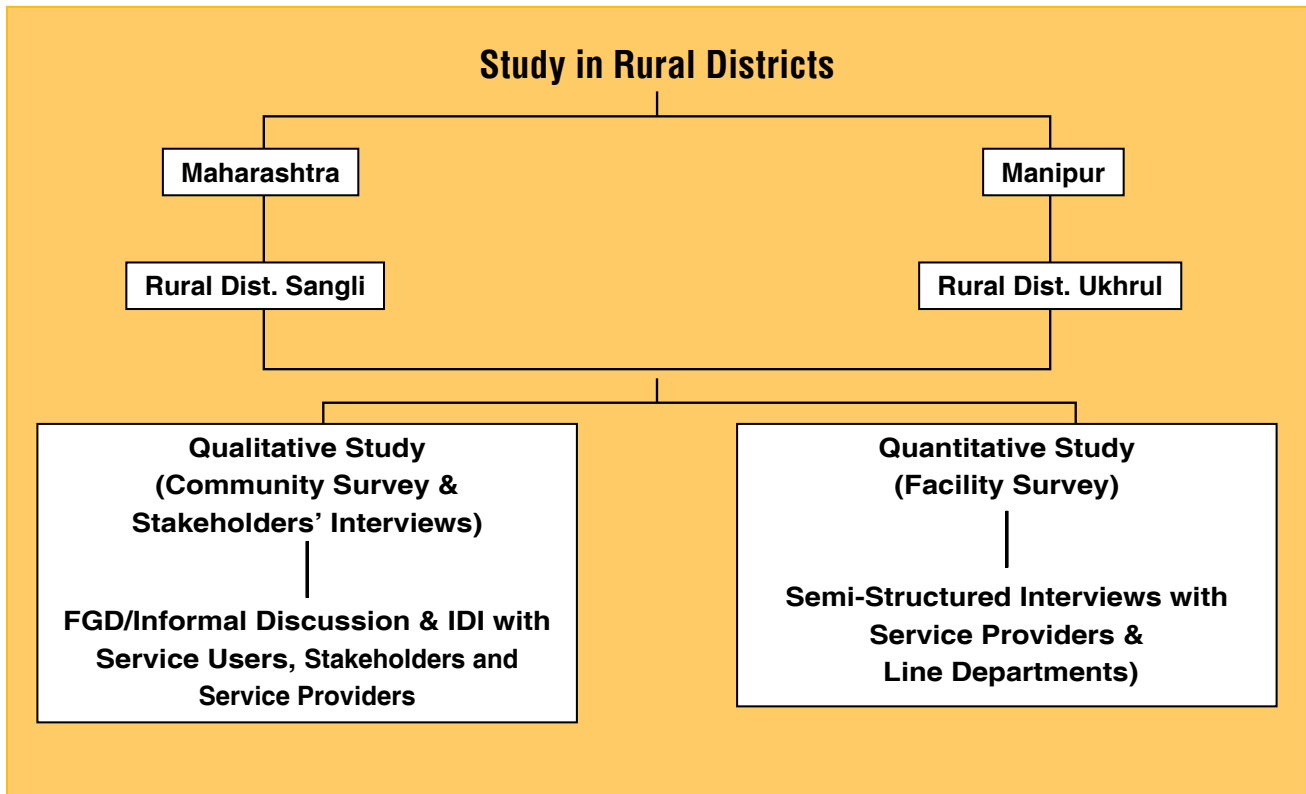
### Sampling Design

Keeping in view the specific focus of the study and its time line, Stratified Random Sampling Technique was used. Adequate rural sample size was planned in the designated districts that cater to a significant rural population in Sangli and Ukhrul, to capture the issues.

<sup>1</sup>Classification of districts is based on ANC/VCTC/STD/HRG data from NACO with A being highest prevalence & D being lowest prevalence/vulnerability factor - HIV Sentinel Surveillance 2003-2005).

<sup>2</sup>CMIS report on District ART Data - National AIDS Control Organization : Sep 2008.

<sup>3</sup>SR quarterly reporting July- Sept 2008 – No. of Children Support Groups formed, No. of CLHIV and CAA groups under 18 years of age benefiting from minimum package of care and support services.

**Figure 1:** Sampling design

It should be noted here that these centres are located in Municipal areas and therefore they understandably extend services to some urban population as well.

## Research Methods and Respondent Groups

**A Community Survey** using In-depth Interviews and Focus Group/Informal Discussions was conducted to gather qualitative information from the community, stakeholders and service providers under the following respondent groups:

### Community Level

- HIV positive children, HIV positive people, general community men, women and children.
- Community Care Centres and Drop-in Centres.

### Programme Implementers

- NGOs–Sub-Recipients (SR) and Sub-Sub Recipients (SSR).
- Health Care Workers (HCW)-Auxilliary Nurse Midwife (ANM), Anganwadi Workers (AWW), Link Workers and Outreach Workers.
- Self Help Groups (SHG) and Community Based Organisations (CBO)
- Private health care providers,

(Quantitative data was also collected under the community survey from a sample of HIV positive women/parents/caregivers and children.)

**A Facility Survey** using Semi Structured Interviews was held with line departments and service providers to collect quantitative data from the following sample respondents:

### Facility Level

- ART centres, PPTCT, VCTC/ICTC, CCC, Gynaecologists, Paediatricians, Counsellors, Private doctors, Lab Technicians.

### Line Departments

- Chief Medical Officer (CMO), Chief District Medical Officer (CDMO) Child Development Programme Officer (CDPO), Rehabilitation Programme Officer, TB Control Officer, Director Education, Teachers, Panchayati Raj Institution (PRI) members, IEC Personnel, District Nodal Officer/ District AIDS Coordination Officer.

### Sample Size

The sample size and respondents for Sangli and Ukhrul are given in the following table:

**Table 4 :** Sample size in selected districts

		Number of Groups		
		Sangli	Ukhrul	
Qualitative	FGDs / Informal Discussions & IDIs	<b>Respondent Groups</b>		
		<b>Community Voices</b>		
		PLHIV groups	4	4
		CLHIV groups	4	4
		General community (Men) groups	2	2
		General community (Women) groups	2	2
		General community (Children affected with AIDS/children in general groups	2	2
		SHGs/CBOs	2	2
		<b>TOTAL</b>	<b>16</b>	<b>16</b>
		<b>Service Providers</b>	<b>No. of Interviewees</b>	
		Health Staff (Auxilliary Nurse Midwife(ANM)/Accredited Social Health Activist (ASHA)/Anganwadi Worker (AWW)	20	20
		NGOs (SRs, SSRs)	2	2
		<b>TOTAL</b>	<b>22</b>	<b>22</b>
		<b>Community Voices</b>	<b>No. of Respondents</b>	
		HIV positive women, parents, care givers	18	18
		HIV positive children	18	18
		<b>TOTAL</b>	<b>36</b>	<b>36</b>

Table contd...

<b>Quantitative</b>	<b>Semi-Structured Interviews</b>	<b>Facility Survey (Service Providers and Line Departments)</b>	<b>Number Covered</b>	
		Chief District Medical Officers	1	0
		Chief Medical Officers	1	1
		Directors/Obstetrics and Gynaecology specialists (private hospitals)	5	3
		In-charge District TB control program	1	1
		Child Development Programme Officers	1	1
		Director Education/Zonal Officer	0	1
		Teachers preferably involved in School AIDS Education Programme	3	3
		District Nodal Officer	1	1
		In-charge Rehabilitation Programmes	0	1
		State IEC Bureau	1	1
		PRI Members	1	1
		<b>TOTAL</b>	<b>15</b>	<b>14</b>
		<b>ART centres</b> <b>2 for Sangli</b> <b>1 for Ukhrul</b>	<b>No. of Respondents</b>	
		Medical Officers ART	2	1
		Counsellors	2	1
		NGO members	1	0
		Pharmacists	2	1
		Paediatricians	0	0
		<b>TOTAL</b>	<b>7</b>	<b>3</b>
		<b>PPTCT centres</b> <b>1 for Sangli</b> <b>2 for Ukhrul (ICTC – 2)</b>	<b>No. of Respondents</b>	
		In-charge PPTCT	2	2
		Counsellors	1	2
		Lab Technicians	1	2
		Nurse Labour Room	2	1
		<b>TOTAL</b>	<b>6</b>	<b>7</b>

Table contd...

<b>Quantitative</b>	<b>Semi-Structured Interviews</b>	<b>PPTCT centres 1 for Sangli 2 for Ukhrul (ICTC – 2)</b>	<b>No. of Respondents</b>	
		In-charge PPTCT	2	2
		Counsellors	1	2
		Lab Technicians	1	2
		Nurse Labour Room	2	1
		<b>TOTAL</b>	<b>6</b>	<b>7</b>
		<b>VCTC 2 for Sangli 2 for Ukhrul ICTC</b>	<b>No. of Respondents</b>	
		Counsellors	1	0
		In-charge VCTC	2	0
		Lab Technicians	2	0
		<b>TOTAL</b>	<b>5</b>	<b>0</b>
		<b>CCC (2 for Sangli and 1 Ukhrul each) Drop-in Centre (DIC) (2 for Sangli and 1 Ukhrul each)</b>	<b>No. of Respondents</b>	
		In-charge CCC	4	2
		Doctor	4	2
		Counsellors	4	2
		<b>Total</b>	<b>12</b>	<b>6</b>
		Counsellors	5	0
		Gynaecologists	5	0 (ANM-4)
		Lab Technicians	5	3
		Paediatricians	5	1
<b>Total</b>	<b>20</b>	<b>8</b>		
<b>Total Rural Sample</b>	<b>139</b>	<b>112</b>		

It may, however, be noted that In Ukhrul, practically all the facilities were included in the study as the number of facilities to be covered to reach the sample size was less as compared to Sangli.

It was also decided that in case of shortfall in sample size, it will be covered from a rural area within the respective state where CHAHA is operational. As the adequate number of sample proposed in the study was not available in Ukhrul, the deficient sample was taken from Bishnupur.

## Ethical issues

At all times during the study, privacy of all CLHIV, their parents and care givers involved in the study was maintained. Care was taken to protect children dropping out of study due to any reason in terms of confidentiality and benefits. Due procedures were followed in obtaining informed consent of all category of respondents who participated in the study.

# Access to ART Centres: Key Findings

## HIV Diagnostic Testing: Global reviews on barriers to access paediatric ART

Barriers to testing infants and children for HIV infection lead to delay in diagnosis, and many infants and young children die before HIV is diagnosed or therapy can be given. Most paediatric HIV infections worldwide are attributable to mother-to-child transmission, with transmission occurring during pregnancy, around the time of birth, or through breast feeding. Special tests are needed to diagnose HIV infection in infants and young children. Psychological barriers to testing infants also lead to delays in diagnosis. The social stigma of the diagnosis for mother and child<sup>1</sup> and lack of treatment availability<sup>2</sup> may keep women from testing themselves to know about their own HIV status and testing their children for HIV. Community-wide fear of discussing HIV infection in children may compound the effect of this barrier.

*Source: <sup>1</sup>Varga CA, Sherman GG, Maphosa J, Jones SA. Psychosocial consequences of early diagnosis of HIV status in vertically exposed infants in Johannesburg, South Africa. Health Care Women Int. 2005;26 :387–397 [CrossRef] [Medline].*

*<sup>2</sup>Levy NC, Miksad RA, Fein OT. From treatment to prevention: the interplay between HIV and AIDS treatment availability and HIV and AIDS prevention Programmemeing in Khayelitsha, South Africa. J Urban Health. 2005;82 :498 –509.*

The barriers faced by rural population in accessing ART centres are significantly pronounced because of social, economic, infrastructure and community related factors. As a result, a large number of CLHIV and families are dissuaded or choose not to access the free ART services provided by NACO.

An attempt was made by this study to identify the main barriers that adversely affect access to ART by children and families in rural India. Some of the apparent barriers that emerged as a result of the study are described below:

## Stigma and Discrimination

Stigma and the resultant discrimination are seen as major barriers by the community, care givers, health care providers, children living with and affected by HIV and their parents that bar access to ART services.

This is more pronounced in rural areas due to low literacy and awareness levels, myths and misconceptions about HIV, coupled with lack of exposure to communication media. Limited reach of the programme to rural hinterland further worsens the situation. As mentioned by general community women during FGD-

*“Log unse baat nahi karte...”* (People do not talk to them) *“Log unke mame par nahi jaate”* - (community does not attend cremation of positive people).

In rural India which has a significant face-to-face relationships and close inter-personal ties, stigma and discrimination are much more discernible.

*Stigma and the resultant discrimination are seen as major barriers by the community, care givers, health care providers, children living with and affected by HIV and their parents that bar access to ART services.*

CLHIV are many a time barred from community level events, activities or groupings. Denial of access to schools or community interactions are also commonplace. Also, there are innumerable instances where CLHIV or their parents have been denied right to ancestral property and even turned out of the villages once their HIV positive status was disclosed.

*“HIV badith bachchoe ko negative/dusre bachchon ke sath nahi khelne diya jata.....”* (HIV positive children are not allowed to play with other children) - as informed by PLHIV and CLHIV groups.

The situation becomes a major concern in schools in relation to children or parents whose HIV status is known. These children are subjected to ridicule, ostracism, isolation and other subtle forms of discrimination by peers and teachers. Consequently, the parents do not take their children to ART centre in the hope that the status of the children is not disclosed.

*“If my friends are having food and I go to them, I am pushed back and taunted that I am a disease carrier and I should not even look at their tiffins”* - a significant reason of non-disclosure of status as pointed out by an HIV positive child.

A child mentioned *“...school mein teacher aur bachche bhi bhedbhav karte hain aur kabhi kabhi to school se nikal bhi dete hain”* (In the school, teacher and children discriminate and sometimes ask me to leave the school).

*“Kai log humare maa – baap se theek se baat nahi karte kyunki hume HIV hai, aur humare bhai behen ko bhi achcha nahi samajhte jinhe HIV nahi hai (Some people do not talk with our parents nicely due to our HIV positive status. They also do not even like our brothers and sisters who are not HIV positive).”*

-CLHIV group, Sangli

Lack of psycho-social support for CLHIV and their families tends to aggravate this situation. In an atmosphere surcharged with an all-pervading stigma, parents of CLHIV are cut off from the social groups reducing the level of daily interactions to the extent that even other children in the family have to bear the brunt of stigma in the form of ostracism and social isolation.

As mentioned by a CAA in Ukhrul that - *“...karigumba eikhoigi schoolgi eemanabasingna makhoi HIV positive hoi haiba khangba taradi, makhoina classta accept touroi.....”* (If their school friends come to know about the status of their HIV positive siblings, they would not accept them in the class).

Also children in the CLHIV group opined that - *“kai log humare maa – baap se theek se baat nahi karte kyunki hume HIV hai, aur humare bhai behen ko bhi achcha nahi samajhte jinhe HIV nahi hai”* (Some people do not talk with our parents nicely due to our HIV positive status. They also do not even like our brothers and sisters who are not HIV positive).

In a state of voluntary non-disclosure or concealment of status, it is apparent that parents or caregivers choose not to seek the support of ‘significant others’ even in conditions of their own poor health or lack of resources. Concealment and non-disclosure is resorted to by parents and caregivers so that their status does not result in discrimination at the level of extended family, neighbourhood or the wider village community.

Apart from a general climate of social stigma, the study identified self generated stigma among adolescents. This is accompanied by biological and psychological changes experienced by children in the age group of 11 to 18 years as a part of their growing up process. Remarked a child during a discussion with CAAs that -

*“aspatal mein lambi line mein main aur meri behen ART lene ke liye khade the... to hamarey school ke ladke ne dekh liya aur fir sabko bata diya ki meri behen ko HIV hai. Tab se koi bhi ladka humse baat nahi karta (My sister and I were standing in the long queue in the hospital for ART when a boy from our school saw us and then told everyone that my sister is HIV positive. Since then no boy talks to us).*

*“I am afraid of my friend, she might see me in the ART centre, and then the doubt will come in her/ his mind that what I was doing there?” - as brought out by an HIV positive girl.*

These children have a desire to be a part of their peers and experiment with adolescent behaviours. It is felt by adolescents that disclosure of HIV status will take away their social space among the peer group members leading to difficulties in sustaining their relationship with their friends and the ‘we-feeling’ of their close-knit peer groups. Therefore, the self-inflicted pressure of maintaining confidentiality remains an important feature agenda in the lives of adolescents.

The study findings reveal that a majority of CLHIV (more than 80%) in the 11-15 years age group preferred not to disclose their sero-status to their friends. While a few (about 15%) mentioned having revealed their positive status to their larger circle of friends, only 1 percent revealed it to close friends in the peer group. As a result of strong self-stigma experienced by adolescents in the family, parents more often dissuade children from disclosing their status due to the fear of consequential discrimination.

Discrimination and stigma are also faced by CLHIV and their families at the health care facility especially at the hands of lower level staff and this is more pronounced in rural and small urban centres as compared to urban areas or big towns. A PLHIV woman remarked during FGD - *“...chaprasi humse dus rupiya leta hai aur tab hume aage line mein ART lene ke liye laga deta hai....”* (Peon takes a bribe of Rs. 10/- to put us ahead in the queue).

CLHIV are often denied adequate medical care, refused admission, subjected to disdain and sub-humane behaviour. Wearing of masks, avoidance of touch and use of pens or pencils to examine them are examples of such behaviour by the health caregivers at the government facilities. On raising their voice, they often face open and brazen non-cooperation sometimes in full public view. Complained an HIV positive child - *“Doctors do not examine HIV positive people properly; they do not touch us. Sometimes they examine us with a pen only.”*

*“Aspatal mein lambi line mein main aur meri behen ART lene ke liye khade the... to hamarey school ke ladke ne dekh liya aur fir sabko bata diya ki meri behen ko HIV hai. Tab se koi bhi ladka humse baat nahi karta (My sister and I were standing in the long queue in the hospital for ART when a boy from our school saw us and then told everyone that my sister is HIV positive. Since then no boy talks to us).”*

- a CAA, Sangli

## Economic Constraints

Inadequate availability of financial resources is a major hurdle for the children and families in accessing ART services. The literacy rate in rural areas is low and the opportunities to remain gainfully employed are significantly less. These situations mean that the family finds it difficult to rebuild the resources that are depleted on account of treatment expenses incurred even before a person is tested positive. A woman added during a case study session - *“Peisakheidi eikhoi nupana drug charambanina mahakna puraga loina chatkhre laireibakta, adunani eikhoina houjik*

*sen thumgi awaba mayoknaribasi. Sarkarna eikhoi HIV positive ki oiba sen thumgi mateng khara pamgbiradi fani...* (As he was a drug user, all money has been carried away by my husband to the heaven. That is why we are facing financial problem. It will be nice, if government provides some financial support to we PLHIV).

*“Eikhoidi nungtigi thabak suraga peisa tanba kangbuni Hospital chatpa numitudi thabak karamna chatkani. Thabak chatpagi mahutta, peisa oina tingi. Aduna eikhoidadi ani thokna mangjei (We are daily wagers. How can we go to work on the day we go to the hospital? It is double loss for us).”*

- a PLHIV, Ukhrul

The study focused on districts with a predominantly rural population where the mainstay of family income is agriculture. The agricultural income in these rural hinterlands is low and subject to vagaries of nature. It further gets accentuated in hilly terrain and locally disturbing factors like long standing insurgency as in Manipur. In addition, depleted capacity of one or both parent or caregivers due to sickness or old age causes the income to reach abysmally low and unsustainable levels. Those who manage to get some work, frequently lose their jobs because of stigma attached to this disease if their status is disclosed. It was mentioned by an HIV positive man that - *“Mere maalik ko pata chala ki mujhe AIDS hai.... mujhe nikaal diya gaya.....kuch kamane ke liye nahi tha aur.....kuch bhi khane ke liye nahi tha.....”* (My boss came to know about my HIV status, fired me from the job... there was no way to earn ..there was nothing to eat).

For working parents, going to the hospital consumes one whole day, which means they have to lose their daily earning while having to spend additional money on the transport and other logistics. It, therefore, becomes difficult for these families to access free ART services at distant government centres despite the fact that ARV drugs are provided free-of-charge.

*“Eikhoidi nungtigi thabak suraga peisa tanba kangbuni Hospital chatpa numitudi thabak karamna chatkani. Thabak chatpagi mahutta, peisa oina tingi. Aduna eikhoidadi ani thokna mangjei”* (We are daily wagers. How can we go to work on the day we go to the hospital? It is double loss for us) - as explained by a PLHIV in Ukhrul.

*“...Eikhoigi khundadi mee loinamak laireiye, hospitalsu yam lapi, buski bhara piningai leitabasu yao-ee...”* (In our village, people are poor, hospital is very far, and sometime they do not have money for bus fare) - as mentioned by general community women.

All the above factors combined lead to financial hardships in meeting the basic necessities like nutrition, shelter and clothing. Inadequate nutrition to CLHIV can directly impact the CD4 count and the prognosis.

Expenses are required to be made to get pre-ART investigations done and to provide for treatment for Opportunistic Infections (OI) as some of the drugs for OI are sometimes not available in the hospital and have to be purchased from the market. In addition, a sum of Rupees five has to be spent on stamping the registration card on every visit. These expenses, for many families, are not within their means on a regular basis. As clearly mentioned by a CLHIV in Sangli - *“Hume har bar paanch rupaiya dene padte hai aur phir jaanch hoti hai ...”* (Every time we have to pay Rs. five for registration to get ART).

*“...Garibi ke karan bahut sare log swasth sewao tak pahuch nahi sakte aur acha khan pan bhi nahi rakh sakte....”* (Due to poverty, people can't access health facilities or take proper nutrition) - as voiced by general community men.

The economic constraints are even more pronounced in the case of child-headed families. In such cases, there is a near-total dependence of the family on the child or an old caregiver leading to treatment taking a back seat. The parents and grandparents who are already financially drained having spent enough money on the treatment of their son/daughter also feel the treatment to be an additional burden. The psychological condition due to earlier bereavements in the family adds to their woes. Children, whose parents are or were Intravenous Drug User (IDU), have to commonly face financial stress as most of the cash and material resources are already used up on drug use, care and treatment.

## Infrastructural Issues

The study findings clearly highlight the issues of infrastructure which adversely affect access to ART centres. The geographical area of the districts under survey, location of ART centres, existing number of centres, availability of transport and travel time, climatic conditions *et al* are some of the important factors which have a major impact on the access of children to ART centres.

The ART centres are mainly located in district centres. Most of these centres, barring those located in urban metropolitan cities and large towns, cater to a large population which lives in far-off villages. The CLHIV and caregivers have to cover long distances to reach the centre. The situation is compounded by the fact that there is lack of adequate transport connectivity from villages to the ART centre coupled with poor condition of the roads. As general community expressed - “...hospital thapagi awbane, bus masing yamdabagi awane, hospitalda toina chatpasi makhoidadi yamna waba jatnida...” (Long distance to the hospital, very few buses to the town, going regularly to the hospital is a big challenge).

“Aushadhi kewal civil aspatal mein hi milti hai aur logon ko bahut dur se aana padta hai....” (People have to travel long distances to reach the ART centres, since ART is available only in the Civil Hospital) - as brought out by a health care worker in Sangli.

A CLHIV group in Bishnupur also added- “Bishnupuradadi ART leite, aduna layengnabagimak Imphal tana chatli...” (There is no ART centre in Bishnupur, so we have to go to Imphal for treatment).

In certain instances people in far-flung villages have to walk as far as 3-5 Kms to catch the first available transport from a nearby village or town with an additional travel time of usually of 3 to 4 hours, sometimes even without seat to reach the district headquarters. For reaching the district headquarters, the parents and children have to further walk down or take another conveyance from the bus stand to reach the ART centre. A CLHIV group mentioned-

“Humein paanch se saat Km. paidal chalna padta hai aur phir bus pakadni padti hai...” (We have to walk down 5 to 7 Kms to catch the bus and reach the ART centre).

“Eikhoi sidagi Imphal youba bus leitabanina, main road faoba khongna natraga autoda chatlaga main road tagi bus farga Imphal faoba chatlaba matungda, Imphalgi Bus kamfamdagi, auto natraga rivkshaw tonglaga RIMS faoba chatli, yamnasu wai” (There are no direct buses from our village to Imphal. We have to walk or go by auto to the main road to catch a bus. After reaching bus stand/stop in Imphal, we have to catch a rickshaw or another auto to reach RIMS. Doing all this we really get tired).

“...hospital thapagi awbane, bus masing yamdabagi awane, hospitalda toina chatpasi makhoidadi yamna waba jatnida....

(Long distance to the hospital, very few buses to the town, going regularly to the hospital is a big challenge).

- general community group, Sangli

In district Ukhul, for people living in the villages in interior of the district like Namrei, Kasom Khulele, it takes nearly 7 to 8 hours to reach RT centres. In some places like Kasom Khulele, as the buses are available on alternate days, only two buses are operational from Ukhul town to Kasom and Khulele sub divisions. As private service dominates the transport map in the state of Manipur, charges are prohibitive on longer routes. The movement is further restricted due to bad condition of the roads in the hilly terrain. The cumbersome, erratic and bothersome transport services result in missing or postponing the pre-fixed appointments for testing and receiving their monthly quota of ARV. The centres are open for fixed durations of time which results in additional expenditure to be incurred on food and lodging. The CLHIV and caregivers have to stay overnight when transport is unavailable to take them back.

*“Busna hospital faoba chatpada pung ahum natraga mari change, lambisu yam fate, karigumbada kok ngaodana obasu yao-ee, aduna lambi saangna chatpase yamna wai.....(It takes 3-4 hours to reach hospital by bus. Road is also not good, and we have headache and vomiting; therefore, traveling long distance is tiresome for us).”*

- a CLHIV, Ukhul

Similarly in district Sangli, the travelling time from some villages to Sangli Civil Hospital is nearly 3 to 5 hours with or without a seat in an overcrowded public transport. These long distances coupled with lack of adequate monetary resources, physical condition of the parents and ailing children, non availability of time to cover the long distances and weather conditions especially in Ukhul pose a big challenge for children as well as care givers to manage their appointment with the ART centre. Another barrier highlighted by the CLHIV is that after travelling long distances to the ART centre, there is no provision of a resting area or room for them.

*“Busna hospital faoba chatpada pung ahum natraga mari change, lambisu yam fate, karigumbada kok ngaodana obasu yao-ee, aduna lambi saangna chatpase yamna wai.....”* (It takes 3-4 hours to reach hospital by bus. Road is also not good, and we have headache and vomiting; therefore, traveling long distance is tiresome for us)- as strongly shared by a CLHIV.

Women living with HIV (WLHIV) who are in the last trimester of pregnancy face difficulty in accessing antenatal care and PPTCT services. These facilities are conspicuously low in number and are far away from rural areas. This situation is sometimes heightened due to lack of support from families and certain age-old beliefs and practices. In such conditions, pregnant WLHIV prefer to deliver at home with the help from untrained *dais* (midwife). This then serves the purpose of keeping the status of child undisclosed even if the child may be a fit candidate for ART.

## Lack of Support from Caregivers

The study findings have underlined several micro level factors that have a bearing on access of CLHIV to the ART centres. Owing to several procedural difficulties and formalities at the ART centres, the CLHIV need parents or other adult caregivers to accompany them to the ART centre for availing the services.

It is known that low literacy levels in villages along with prevalent myths, beliefs and practices relating to health issues lead to low health-seeking behaviour. They instead take recourse to quacks and traditional faith healers rather than seeking referral to a proper health care facility leading to grave prognosis. In some cases, the apprehension of side effects of treatment also inhibits the parents to initiate ART for the children. In many instances, the fatalistic attitude of the parents is illustrated by their affirmation that ‘death is a certainty, sooner or later, so why access treatment with so much trouble’. In such situations, the attitude of the parents itself becomes a barrier in accessing ART centres.

While the state of parents or caregivers on account of health, age and/or financial means leading to lack of support to CLHIV in accessing ART centres for care and treatment is one prominent reason, another facet is evident in case of estranged families, broken families and orphans. As expressed by a general community group man -

*“Jin bachchon ke maa baap nahi hote un bachchon ko aspatal le jaane wala koi nahi hota”* (Those children who don't have parents, have no one to take them to the hospital).

A general community woman expressed her feeling towards orphaned HIV positive children - *“bin maa baap ke bachchon ka koi bhi sahara nahi hota ki unhe ART centre tak le ke jaya jaye...”* (orphans do not have any support mechanism so that they can be taken to the ART centre).

Extreme gender biases coupled with stigma continues to play its role in adversely affecting the health seeking behaviour of women living with HIV. Destitute WLHIV are thrown out of their houses along with their HIV positive children with little or no means to support the treatment for these CLHIV - *“...Babasu kuire sikhiba, mahakna drug chabada imungi peisakhei loinamak loisinli hai, natlamdrabadi eikhoi lairaramloibadani haina imana hai. Imana keithel chtlaga potlaka ensang napi yolaga imung manung yengsiilibani...”* (Father had expired long time ago. Mother shared that father used to take drugs, and he utilised all money/property on that. Otherwise, we would not have been poor like we are today. Mother sells vegetables in the market, and run the family) - as brought out by a child affected with AIDS (CAA) during FGD.

The same causative factors are also largely true for WLHIV who are widowed. A gender reality that affects access to ART is that WLHIV or widows are not comfortable in engaging in public spaces. It is common knowledge that due to acute poverty and lack of gainful employment opportunities in rural areas, individuals and families migrate to urban areas in search of livelihood. Some of these migrated families return to the villages after the parents and children have undergone treatment in their town or city of residence. Some of these parents display apathy in adherence to ART for themselves and their children. These parents do not make efforts to find the nearest ART centre and re-register the child much for the same reasons outlined above. Some parents of CLHIV opined -

*“Peisa paidabagi awabadi eikhoi khaktagi natana khungi mi khudingmakini. Tha kudingi hospital chatpa haibase peisa tingbanina, eikhoi HIV positive oiba kangbugidi laibak thibanine”* (Problem of not having money is not only for us, but for all of us in the village. Going every month to the hospital consumes money; therefore, it becomes extremely difficult for us).

**“ Peisa**  
*paidabagi awabadi*  
*eikhoi khaktagi*  
*natana khungi mi*  
*khudingmakini. Tha*  
*kudingi hospital*  
*chatpa haibase peisa*  
*tingbanina, eikhoi*  
*HIV positive oiba*  
*kangbugidi laibak*  
*thibanine* (Problem  
of not having money  
is not only for us, but  
for all of us in the  
village. Going every  
month to the hospital  
consumes money;  
therefore, it becomes  
extremely difficult for  
us).”

- Parents of CLHIV, Ukhrul

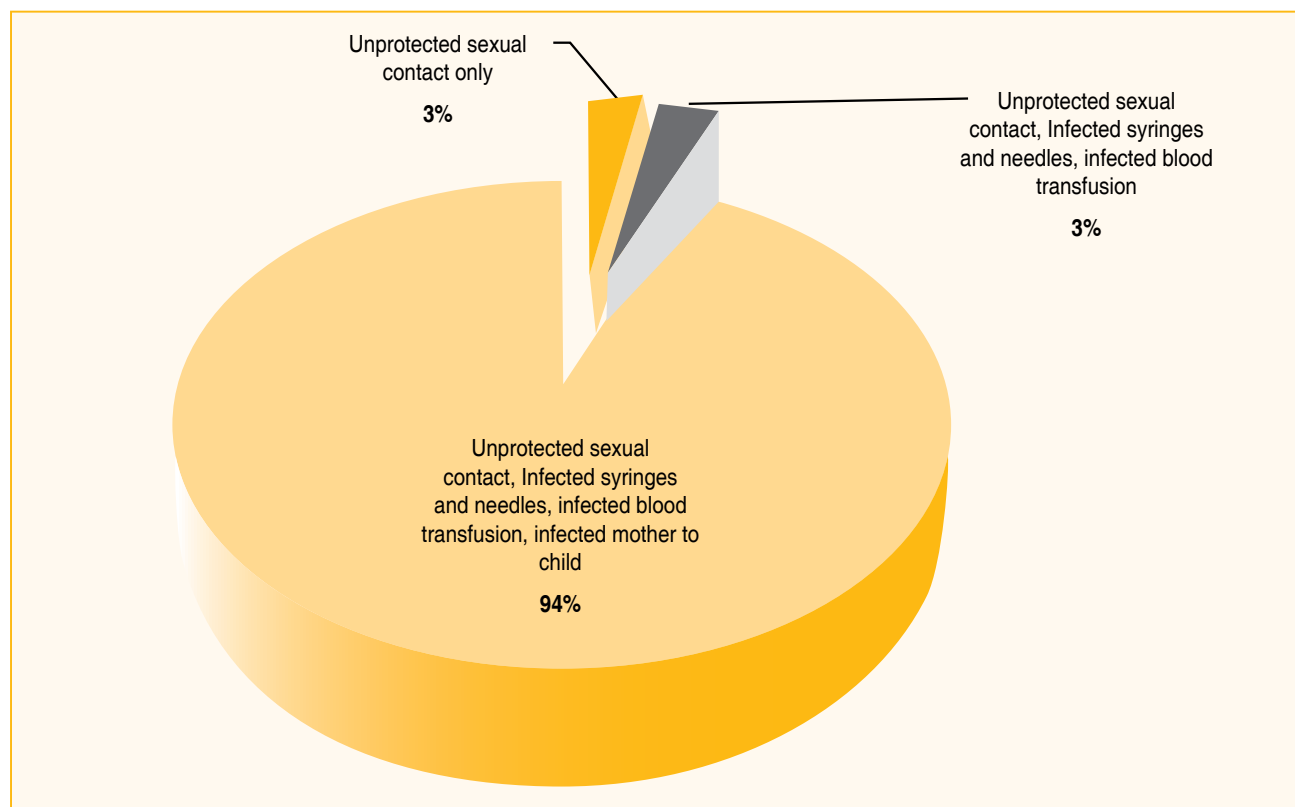
## Lack of Awareness about Paediatric HIV/AIDS and ART Services

There is a lack of awareness in the rural community about paediatric HIV/AIDS and availability of paediatric ART services. This is so because the initial focus of the policy makers has been mainly on adult-centric treatment as evidenced by the fact that ART was first rolled out for adults followed over two years later by paediatric ART. The study sought to find out the knowledge of respondents (HIV positive

women) on routes of transmission and the right age for testing of HIV status of a child as described below:

**Knowledge of HIV positive women on modes of transmission:** The research sought to understand the knowledge of WLHIV on modes of transmission of HIV. Significantly, more than 90 percent of the women were aware of all the modes of transmission of HIV including mother-to-child transmission. The knowledge of routes of transmission among WLHIV is high thereby creating optimism about enhancing PPTCT services in rural areas. However, the knowledge of women about the right age for testing of children was found to be relatively low.

**Graph 1:** Knowledge of HIV positive women (respondents) on modes of transmission



**Knowledge about the right age for HIV testing of children:** Nearly 40 percent of the women interviewed were aware about the correct age of testing i.e., 18 months as per existing facilities. The remaining 60 percent of the women either had incorrect knowledge of the right age at which a child can be tested or did not know at all about the age for HIV testing as per existing facilities. The knowledge of women about the age for HIV testing of a child (18 months) is deemed correct because their knowledge is based on presently used Enzyme-Linked Immuno Sorbent Assay (ELISA) method. These rural women are completely ignorant about another possible methods of testing i.e.; Polymerase Chain Reaction (PCR), Deoxy-Ribonucleic Acid (DNA) – that can confirm the HIV status of children below 18 months as well. The health care providers do not discuss about the alternative methods with parents since they believe that it is meaningless to discuss about a method or technique that cannot be made available to patients.

The general community especially in the rural areas is not completely aware that ART is now available and is being provided free of cost at the government facilities. This can be attributed to the fact that there is a lack of child-focussed IEC on paediatric

HIV and AIDS and ART. The existing IEC material developed on HIV and AIDS is too generic and adult-centric.

The existing focus of service delivery remains on sexual transmission and not on parent-to-child transmission, so adults are still the main target for ART delivery. This unidirectional focus has resulted in lack of awareness among the parents about the potential risk of transmission from HIV positive mother to the child. The study clearly brings out that there is inadequate awareness about the available PPTCT services which has resulted in failure of adoption and utilisation of preventive strategies for transmission of HIV from mother to the baby. As mentioned by an HIV positive male -

*“Mujhe nahi pata tha ki PPTCT centre mein ART ki dawaiyan milti hain....agar mujhe pehle pata hota...to mein apne bache ko bacha sakta tha.....”* (I didn't know that ART or paediatric ART is available in PPTCT centre, if I had known I would have been able to save my child).

Lack of education and awareness about the services and significance of treatment for the CLHIV has resulted in inability of the parents or children to understand the implications of HIV and AIDS. As highlighted by an outreach worker - *“Karigumbada HIV positive oiba mama mapasingna, karigumba machasu HIV positive oiramlabadi kari thoklagaba kanduna machgi test toubu kibasu yao-wee”* (Sometimes the HIV positive parents are afraid of conducting HIV test for their children, due to the inbuilt fear of the consequences).

They also fail to comprehend the benefits of ART for CLHIV through a proper treatment adherence and continuous health monitoring. To make matters worse, there is widespread ignorance that even without treatment, the quality of life and longevity of CLHIV is assured. Such beliefs emanating from ignorance adversely impact access to ART centres. Access to ART centres is not seen here in terms of first time visits. The fact is that even if families and children access ART at these centres, such beliefs come in the way of regularly accessing ART centres for periodic health monitoring and regular treatment regimen.

*“Mujhe nahi pata tha ki PPTCT centre mein ART ki dawaiyan milti hain....agar mujhe pehle pata hota...to mein apne bache ko bacha sakta tha...(I didn't know that ART or paediatric ART is available in PPTCT centre, if I had known I would have been able to save my child).”*

- HIV positive male, Sangli

Further interviews and discussions highlighted that there is inadequate awareness among the community members about the community care centres and the existing service availability in these centres. As a result parents resort to treatment by a private practitioner inexperienced in paediatric HIV, a faith healer or some local quack. This is a vicious cycle in which the parents and caregivers get entangled.

Limited integration of RCH with HIV and AIDS control programme also results in lack of awareness amongst the grass root workers who are the only direct contact between the health care services and service users and are actively linked with mother and child health issues in the field.

*“Humein ART ke vishay mein zyada jankaari nahi hai”* (We don not have much knowledge about ART) they further added that *“Hum keval HIV positive mahilayon ko samay nahi de sakte... humein aur bhi kaam hain.. aur bhi mahilaon ko dekhna hota hai”* (We can't just give all our time to HIV positive women as we have other duties and other women to look after as well) - as was remarked by Health Care Workers (HCW) and Anganwadi Workers during discussions with them.

The elected leaders of the three-tier Panchayati Raj Institutions (PRI) at village, block and district level are ignorant about the issues of HIV and AIDS at the local level, leave alone issues of paediatric HIV. They are, therefore, also unsure of their role in relation to issues of HIV in an atmosphere surcharged by widespread stigma and discrimination. The *Gram Sabha*, comprising all adults above 18 years of age, is widely understood as 'village parliament'. It is an important deliberative body at the village level that sets the agenda for village development and social justice to all in a *panchayat*. However, due to lack of proper mobilisation of *Gram Sabhas*, its socio-political agenda of development and social justice to the marginalised and vulnerable does not do enough on HIV including that of access to treatment for children. Some general community men expressed - "...HIV gidamak khungi khulaka, cillage chiefna kari toubage haibadudi eikhoi khangde..." (We do not know what the village chief is doing for/on HIV).

In the absence of any meaningful contribution by the state government for CLHIV by way of adequate educational, travel and nutritional support or special incentives to stimulate proper treatment adherence by the CLHIV and their families, the issues around paediatric HIV and paediatric ART continue to be lower down on the health agenda.

Summing it all, poverty, illiteracy and ignorance coupled with lack of political stewardship at various levels become the contributory factors for non-reporting and non-adherence.

## Issues of Capacity and Accountability at ART Centres

There is shortage of staff at ART centres when seen in relation to the large population being served by these centres. There is one government ART centre, each in Sangli and Ukhrul to cater to people from a large rural geography of the district. In order to manage a sizable patient load, enough quality time to children and parents is not provided at the health facilities. A CLHIV pointed out - "*Civil Haspatal mein bahut dhakke khae...kisi ne admit nahi kiya DILASA walon ne madat ki....phir ilaaz shuru karwaya....*" (I suffered a lot in the Civil Hospital moving here and there but they did not admit me.....then through help from Dilasa (NGO) my treatment was started).

*There is shortage of staff at ART centres when seen in relation to the large population being served by these centres.*

Also due to the non-availability of paediatricians in the ART centres, the children are usually treated by the Medical Officer/In-charge of the ART centres who are unable to provide the required care. This demotivates the parents who hesitate to bring the child to the ART centre regularly.

The present staffing pattern which is seen as inadequate hinders the identification, follow-up process of HIV positive mothers and exposed children or proper counselling services for the WLHIV and the CLHIV.

*"Kewal DILASA ke log hi hume saari juaankari aur maddad karte hain, sarkar ki aur se kisi bhi prakaar ki koi maddad nahi hai"* (It is only the DILASA people who help us out in all the things. Other than this there is no support from the government or any other agency for financial, travel, treatment and psychosocial support).

The existing personnel in ART centres comprising Medical Officers (MO), Counsellors, laboratory technicians, nurses and even the paediatricians (wherever

available) are not trained on paediatric counselling which creates a communication gap between the providers and the CLHIV. Inability of the providers to converse in a language that can be easily understood by the child is a big challenge for the counsellor. They therefore opt to counsel the parents in place of the child. This leaves many unanswered questions in the mind of young CLHIV and ultimately inhibits their access to ART services. A CLHIV clearly mentioned that - *“...zyadatar doctor bachon ko counsel nahi karte hain, wo kewal parents se hi baat karte hain..”* (Mostly the doctors counsel our parents, they only talk to our parents).

The community had certain reservations about some of the doctors who are engaged in dual medical practice of working in government hospitals and also doing private practice. The community expressed fears that this may lead to malpractices, issues of transparency, accountability and a conflict of interest. It is also seen as a discouraging factor by people accessing treatment services.

It is noted by the community that some doctors choose to commute daily from their place of residence in a distant town to the place of posting in another district town. This leads to their reporting late at their station of duty. Parents and children have to often wait for long hours.

Some of the CLHIV revealed that -

*“Kabhi doctor hota hai.. kabhi nahi”* (Sometimes doctors are present and sometimes not).

*“Doctors hamse achche se baat karte hain lekin zyadatar hote hi nahin hain”* (Doctors treat us nicely but the problem is that most of the times they are not available).

*“ Kabhi doctor hota hai.. kabhi nahi (Sometimes doctors are present and sometimes not). ”*

- a CLHIV group

This is inconvenient to parents and children who travel long distances under trying circumstances and are perennially worried about their travel back to their distant villages. The community believes that some of these ART centres in remote district towns need to be monitored well to enhance patient confidence in the services offered in these centres.

A major issue of concern is the lack of uniformity of training among the service providers implementing overlapping programmes (PPTCT/VCTC/paediatric ART) and the need of creating uniform modules based on the graded level of knowledge to be imparted to specific group of professionals.

Inadequate availability of staff with unplanned and inefficient administrative procedures in the government centres contribute towards inadequate maintenance of the equipment resulting in long waiting period of up to 15-20 days for an ultrasound as part of pre-ART investigations and delayed initiation of ART. CD4 machines operate only thrice a week in Ukhrul.

*“CD4 su hapta amada ahumlak khak sijinei, ningthoukabane, yumasakeisane aduga eeraine. Atei matamdadi CD4 countsu toude. Aduna nong fathok thengba yaoradi CD4 test toudana halakpasu yao-ee”* (CD4 machine operates only thrice a week – Monday, Wednesday and Friday. If we are late, we have to go back without CD4 test and then visit the centre all over again).

These machines are sometimes out of order on designated days in both Sangli and Ukhrul. In such situations, the CLHIV and their accompanying caregivers have

to go back without CD4 test and then revisit the centre resulting in financial and physical burden. The non-availability of DNA-PCR testing facility in the ART centre for testing of children below 18 months contributes to a high number of loss to follow up exposed infants.

All these factors result in creating long break between the first reporting at the ART centre and the initiation of treatment thus hindering adherence of children and their families to the ART centre. At some centres it takes at least 15 days between the maiden visit to the ART centre to actually starting ART. This avoidable long time taken to complete the long procedural formalities deters the CLHIV and families to access the treatment services.

With inadequately staffed centres, systems and processes that are confusing, and lack of coordination between the referring centres and the government ART centres, the drop-out cases are very difficult to follow-up. The counsellors usually have no time to follow-up with children who have missed ART because they have to manage the new cases in ART centre. They do not have access to adequate means of communication or resources to reach the drop-outs in the villages that are located in the interiors of the predominantly rural districts.

## Lack of Coordination and Collaborative Efforts between Agencies

A major barrier highlighted by the programme Implementers at various levels was the lack of convergence between related programmes like ICDS, RCH and TB with PPTCT, paediatric HIV/AIDS and ART programmes. This has led to the emergence of various stand-alone programmes within the same health care system that provide isolated services to the common target groups.

*A major barrier highlighted by the programme Implementers at various levels was the lack of convergence between related programmes like ICDS, RCH and TB with PPTCT, paediatric HIV/AIDS and ART programmes.*

Consequently, there is a significant level of gap in awareness levels of the ICDS, RCH and NRHM workers. The most distinct example is the lack of integration of existing Maternal and Child Health (MCH) services with the PPTCT and paediatric HIV and AIDS services at the district level leading to low awareness among the existing grassroot health functionaries about HIV and AIDS and paediatric issues. This results in lack of information among the community about the availability of paediatric HIV and AIDS services. This is also coupled with a lack of delegation of authority to the programme implementers in the field to adopt innovative, locally appropriate mechanisms for identification of exposed children and effective follow up of the drop-outs.

The lack of coordination is not only discernible at the programmatic level but also between different departments within the same facility, for example, medicine, Obstetrics and Gynaecology (OBG), paediatrics and ART centres etc.

The mechanisms of joint collaborative activities with HIV-TB have also not been worked out nor has there been adequate of funds from the states for carrying out the activities for sustained joint activities. The roles and responsibilities of different stakeholders involved in joint activities needs to be clarified. Some officials stated

that there are no official records of children with TB-HIV co-infection available as the reporting formats do not ask for it and also that there are gaps in support activities like linking nutrition and palliative care services with TB-HIV.

An important area of concern which has a strong influence on the access of children to ART is the lack of understanding among school teachers on paediatric HIV and AIDS issues. Thus far their rapport in communities has not been utilised to facilitate awareness on paediatric HIV and AIDS, identification and follow up of CLHIV and HIV positive mothers and availability of treatment services in centres catering to rural population.

Non-involvement of the private sector in ART service delivery and stringent rules for their inclusion in the delivery of these services is another deterrent for the children and the private sector providers.

Lack of coordination and effective linkages with the local civil society organisations, CCC, PLHIV networks implementing government HIV and AIDS programmes on PPTCT and paediatric HIV and AIDS is another factor which leads to non-synergistic programme activities due to which the beneficiaries do not get proper attention and care.

*An important area of concern which has a strong influence on the access of children to ART is the lack of understanding among school teachers on paediatric HIV and AIDS issues.*

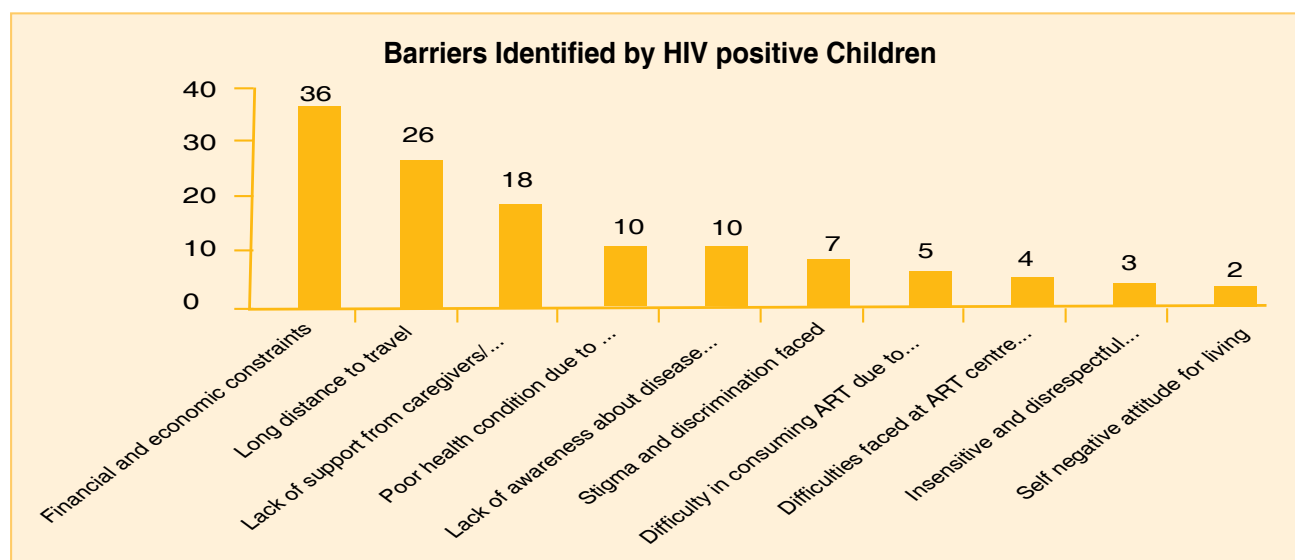
## Barriers Identified by CLHIV

Among the series of barriers identified by HIV positive children, majority of the respondents across the board identified financial constraints as the main barrier that hampers access to ART services by children and families. Long distances coupled with lack of availability of adequate transport mechanisms to reach ART centres was also pointed out by a significantly large number of respondents. It is understood that illiteracy is a prime reason for low levels of health awareness in general and lack of knowledge about HIV and AIDS in particular, as opined by many HIV positive children interviewed.

Taste of medicines is also seen by some children and parents as a factor that hampers treatment adherence. Some children find the taste of medicines bitter and unpalatable. As a CLHIV mentioned-“*Aushadi kadwi lakti hai to kuch backhoe ne aushadi chodd di...*” (Drugs are bitter in taste so some children discontinued the medicine).

Lack of support from the caregivers was another point highlighted by the children. The main reason was helplessness on the part of caregivers and parents emanating from their rural social milieu, physical and financial constraints. Stigma and discrimination faced by CLHIV within the society and by service providers is a prime reason that thwarts access to ART centres, though not a relatively large number of sample respondents (i.e HIV positive children) openly expressed this factor. Closely associated to stigma and discrimination is the negative feeling about self-worth that some of the respondents pointed out. Other barriers mentioned by the CLHIV were difficulties faced at ART centres in terms of infrastructure, service orientation and responsiveness, even if they take the initiative to reach these centres.

These apparently are some of the major barriers coming in the way of sustained access to ART services in rural India.

**Graph 2 : Barriers identified by CLHIV**

## Case Study

### Prayers for Good Health

***“I don’t know how things will improve, what I can do is to pray to God, and one day the Lord will surely help us and make our wishes come true.”***

Her name is Pinky (name changed), and she is from Poi. She is 11 years old. She has been living with HIV since childhood. She does not know when she was tested positive, but she thinks she must have been tested in Ukhrul District Hospital as it is the only place in Ukhrul where HIV testing facilities are available. She is the only child of her parents. She does not remember her parents as they died when she was very young. She lives with her maternal grandparents. She has been taking ARV for the last three years or more from the District Hospital. She takes the medicine twice a day, morning and evening after meals. Every month she goes with her grandmother to the ART centre, it takes them an hour to reach the town and it is tiresome for her to travel by bus on such bad roads in a hilly terrain. But she considers herself to be lucky comparing herself to those children who are coming from far off villages like Kamjong, Namrei etc. who are travelling for 3-4 hours or more by bus. “Can you imagine how difficult it is for them?”- she says.

Sometimes the doctor is there in the hospital and sometimes not. When he is not there they meet the counsellor or the pharmacist in the hospital. Mostly they talk with her grandma, though sometimes they do tell her to have the medicines daily on time, and also to have proper meals, and attend school regularly. The centre is too small, and there is no proper place to sit except for few benches which are occupied by other patients all the time.

In school, many of her friends do not want to sit or play with her. So, most of the time she sits on the last bench. She does not tell about the behaviour of her classmates to her teachers, as she thinks that if she complains to the teachers, her class mates will even stop talking to her. The same things happen in the community also as many of her class mates are also from the same locality. But at home it is better as she has other children to play with, like her cousins whose behaviour towards her is relatively better. She believes in God and has faith that God will do something for her one day. Every time she goes to the Church she always prays to the Lord that no other child becomes HIV positive and also that all children remain healthy. Even though she prays a lot, she still does not feel well and does not know why it is so? She feels people in the school and locality should be more supportive and caring towards PLHIV/CLHIV and their families, considering the problem that they face. NGO workers do visit her at home, and also give her family some food and sometimes note books and pens also. But it will be great if they also come to the school and meet her teachers and other students and take sessions on HIV and AIDS.

# Recommendations

The issues relating to access of CLHIV and their families to government ART centres or NACO approved private centres are in many ways complex and face a number of barriers. While some of these emanate from socio-cultural or economic factors, others are structural and institutional. In formulating recommendations, the challenge was to put forward ideas that are pragmatic enough to be implemented.

A major effort through the study was to record, understand and analyse the community voices not just in terms of understanding the issues but also to dig out solutions based on local knowledge and experiences of the community. The study also purported to capture the ideas and perspectives of other stakeholders in what is perceived by them as practical solutions. At this juncture, programme planners, implementers and the advocates of policy change need to carefully analyse the feasibility, expediency and benefits of each of the suggestions in specific contexts as mentioned below:

## Communication Strategy to Fight Against Stigma and Discrimination

The study findings have confirmed that one of the biggest barrier in accessing treatment services is stigma and discrimination that takes several complex forms especially in rural settings and its consequences are too costly to ignore. Dealing with stigma, therefore, requires a multi-pronged response that would have to be an intensive-extensive exercise.

### Clinicians to Provide Care for Children with HIV: a Global Review

Even where appropriate HIV diagnostic testing is available and drugs for treatment of HIV infection and prophylaxis for HIV-associated infections are accessible, **lack of personnel trained in treatment of children** with HIV severely limits access to treatment for large numbers of children. In many areas of the world, medical care is provided by physicians, nurses, and other clinicians with training and experience in the management of adult, but not paediatric patients. Even the best Programmes for training health care professionals in the principles of HIV care for children offer **little practical exposure to treating paediatric patients, which is time- and resource-intensive**. Some Programmes send health care professionals from resource-rich areas of the world to resource-limited areas to train local practitioners (e.g. Medecins Sans Frontieres, the Baylor Paediatric AIDS Corps, the Clinton Foundation, the Children's HIV Association of UK and Ireland, UK/Kwazulu-Natal, the South Africa Collaboration). Additional efforts are needed to expand the availability of clinicians who are skilled in paediatric HIV **care in resource-limited areas of the world**, including integrating paediatric HIV care into existing comprehensive child health Programmes, expanding local networks of experienced health care professionals, and linking local clinicians with local, regional, and international experts.

*Source: Progress on Global Access to HIV ART. A report on "3 by 5 and beyond", March 2006, WHO-UNAIDS*

Awareness about paediatric diagnosis, care and treatment services are a weak link in the national IEC strategies. That is why, intensified child focused IEC programmes especially designed for the rural areas can be an effective tool to disseminate correct information about the epidemic and wipe out all existing myths and misconceptions that permeate the rural landscape. These IEC programmes should also take into account the age, gender and other defining identities for greater impact. This should then be disseminated through mass media, mid-media and other locally appropriate forms.

As stated by an HIV positive woman - "*Hum HIV positive logon ko pyar nahin milta. Meri samajh mein logon ki jaankari badhani chahiye*"... (we, the HIV positive are not shown care and love by the people. In my opinion, awareness levels of the community are required to be improved).

## Strengthening Local Response against Stigma and Discrimination

While NACP III provides a strong support to a national response, it must subsume an equally strong local response since many of the local issues and problems are best dealt locally. A result-oriented implementation of communication strategy will mean building wider support within the community through greater participation and mobilisation of all stakeholders – village elders, local opinion/political leaders, media, trade unions, religious and spiritual leaders, members of positive networks

at block and district level, women Self Help Groups (SHG) and women collectives, youth clubs and other civil society forums. As mentioned by a group of general community men during FGD -

“*Mayamgidamak HIV gi awareness toina tourabadi, tathi ta-woina tou-wee haribisai hanthagani... (If there is HIV awareness programme for all, the discrimination that we heard about will be reduced).*”

- a general community man,  
Ukhrul

“*...Peisaga mari leinaba matengdi eikhoisu thoidokna pangba ngamgadaba mande, adubu achumba HIVgi matangda mayamda haiba aduga kadawaida karamba hospitalda khudong chaba fangbage haidudi mayamda haiba ngamgani. Adubu eikhoibusu takpiba tambibadi tangai fade...*” (We don’t think we will be able to extend support related to finance/money, but we can tell people about the places/hospital where facilities for ART are available. However, we need to be taught about it).

Members of the village *panchayats* and other local bodies can be effectively involved in disseminating correct information through key messages and in eliciting a strong local response. Similarly, a wider coalition of NGOs, Voluntary Organisations (VO) and Civil Society Organisations (CSO) can be created to counter the tide of societal stigma. A general community man mentioned - “*...Mayamgidamak HIV gi awareness toina tourabadi, tathi ta-woina tou-wee haribisai hanthagani...*” (If there is HIV awareness programme for all, the discrimination that we heard about will be reduced).

## Expanding Testing and Treatment Footprints to Tackle Infrastructural Issues

A major barrier highlighted by both the rural community and service providers is the long distance to be travelled to reach ART centres mostly located in urban areas. Increasing the number of ART centres or Link ART centres (LAC) at various strategic locations especially in the outlying areas having poor connectivity to the rest of the village can solve this problem to a great extent.

In situations where new ART centres cannot be opened but the potential load is high, it is advisable to establish Link ART centres which can serve as satellite centres to the main ART centres. These LACs supported with adequate staff could be established at the sub-district level so that services are easily accessible and within the reach of those who are unable to reach the main centres due to various reasons.

Ideal sites for the LAC could be the Community Care Centres (CCC) which are far more proximate to a large cross-section of peri-urban and rural population making them relatively more accessible. These Link Centres should be made self-sufficient and provide all essential services like, PPTCT centres for ANC, HIV testing, follow-ups, counselling, CD4 tests and delivery kits for emergency deliveries along with a paediatric unit for child counselling. In such a decentralised model of services, the ideals of Early Infant Diagnosis (EID) and Exposed Baby Care (EBC) would become a reality.

These centres should be entrusted to provide two-way linkages with district hospitals so that ICTC/VCTC could refer the HIV positive cases directly to the CCC. This will help in reducing the drop-out rates and also sharing the high load presently experienced at the government facilities.

For facilitating access of children to ART, a recurrent voice was that the Direct Observation Treatment Short course (DOTS) model should be applied to the ART programme for providing a well coordinated and strengthened ART services up to sub district level.

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## **Broadening the Response through Public Private Partnership (PPP)**

Involvement of the private sector should be encouraged through a well planned and cost effective PPP model where government could provide infrastructure and human resource, while the techno-managerial aspects of running such centres can be the mandate of the private sector. This new mode of working will allow for leveraging complimentary capacities and competencies which is so vital to the complex issues of treatment for CLHIV. If select private centres meeting the government's eligibility criteria are designated as ART/Link Centres/PPTCT and VCTC, the burgeoning load at some of the government-run centres in high-prevalent districts will be reduced considerably. This will help augment quality and efficiency of services at government centres and will result in early detection and treatment of the exposed children and reduction in drop-outs of pregnant WLHIV.

## **Expanding the Scope of Care and Support Services**

Looking at the level of poverty in India, it is imperative to create enabling conditions that can help CLHIV and families to access government treatment services. Travel allowances or free bus passes and even doing away with the registration fee of Rs. five per patient at the ART centre can be one such small step that would help BPL families to access treatment.

All said and done, a comprehensive care and support programme, having a minimum number of services coordinated at the district level, in areas like education, health,

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- a PLHIV group, Ukhrul

nutrition, psychosocial support besides protection, legal and alternative care can be planned in a strategic manner. To start with, some of the most under-developed districts falling in high prevalence states should be chosen to deliver a care and support programme that seeks to bring in its fold those at the margins of economy.

While a package of direct care and support services to CLHIV and families in severe economic distress is a *sine qua non* in short to medium term, NACO and SACS should move towards a framework for sustainable income and livelihood options for such families. As mentioned by a PLHIV group - “...chanabaga aduga gari bharagakhakna problemsi fahanba ngamloi, income generation programmesig darker oi...” (additional nutritional and travel support only cannot solve the problem. There is an urgent need for IGP).

SACS can organise special cohort for imparting entrepreneurial skills that have the potential for income generation or employment. This can be done by engaging Entrepreneurship Development Institutes (EDI) at the state level and building partnership with large corporate houses.

## Expanding Scope and Substance of Diagnostic and Treatment Services

The progression of NACP III in India has reached a critical phase. Early Infant Diagnosis (EID) and Exposed Baby Care (EBC) are significant areas of work that need to complement the gains made so far under NACP III in respect of children. NACO should consider developing guidelines, training manuals and Standard Operating Procedures (SOP) on EID and EBC. To enable this, PPTCT and paediatric ART services should be integrated. This is needed to sensitise women and their families during the antenatal period for a sustained follow-up for early detection of HIV status of the child and also to motivate partners to bring WLHIV to ART centre periodically.

It is an opportune time that critically important diagnostic services like Polymerase Chain Reaction (PCR), Deoxy- Ribonucleic Acid (DNA) and Viral Load tests are made available at district level free of cost to all children so as to reduce the time period of follow-up of children up to 18 months. This will help in reducing the drop-out rates.

It is a common refrain that all medicines required for effective management of OI are not available in government hospitals. This is perhaps an area where NACO and SACS will need to put in systems and processes in place to ensure an improved supply chain. Related to this is also the question of provisioning of paediatric second line ARV drugs.

HIV-TB co-ordination also needs to be strengthened by sensitising policy makers for an effective and sustained coordination between the programmes at the vertical and horizontal levels. Simple, cost effective and sustained mechanisms need to be developed where ART can be provided along with the DOTS programme. This will make ART services more accessible for the children and their parents. Also health care providers i.e. medical officers, counsellors and DOTS providers need to be trained on the follow-up of children with HIV-TB, in addition to the follow-up of

adults which they are already performing. There should be a follow-up of children for OI by the counsellors so that early identification of CLHIV can be done through the data so generated.

## Staffing and Capacity Augmentation

There is a greater need to strengthen all operational facilities to provide a comprehensive package of services that include counselling, HIV testing, PPTCT, ART, follow-up and adherence under one roof to enhance the accessibility of CLHIV and families. However, strengthening the infrastructure would mean little unless issues of staff capacities are dealt with. A CLHIV mentioned - *“hidak loupnam maphamsida doctor amasung staff khara yamna leiradi eikhoina ngairisi kuina ngairaroi...”* (If there are more number of doctors and other hospital staff, we will not have to spend so much time waiting for our turn).

The main issue related to staff capacity is about the minimum qualification and/or training. Even in cases of staff constraints where postgraduate specialists are not available, the Medical Officer posted in the ART centre should preferably be a paediatrician. There is a strong felt need for training of the counsellors on paediatric counselling which is presently seen as grossly inadequate in the ART component.

*“...Angang counselling toubagi fajana training fanglaba mee leifam thok-ee.....”* (there is need for people who are well trained on paediatric counselling) - as mentioned by a Health Care Worker.

In fact, the entire staff in the ART centres i.e. lab technicians, pharmacists, nurses, medical officers including paediatricians need to strengthen their skills on paediatric counselling. There is also a need for regular and frequent refresher trainings/workshops/courses so as to keep them updated with the latest best practices.

A major issue of concern is the lack of uniformity of training among the service providers implementing overlapping programmes (PPTCT/VCTC/paediatric ART) and the need of creating uniform modules based on the graded level of knowledge to be imparted to specific group of professionals. Training modules must be so amended as to reflect the greater need for paediatric counselling in view of strong stigma and discrimination experienced by children. Moreover, given the petty corruption at the ART centres, there should be a community feedback and redress mechanism at an appropriate level.

Integration on paediatric ART and PPTCT is seen as a valuable proposition. However, for the integration to yield desirable results, capacity building of the gynaecologists both in the government and private sector would be important so that all HIV positive women approaching them for PPTCT services could be provided the required services or linked up with service delivery points. To ensure follow-up of uniform treatment protocols, all private sector providers practicing ART (paediatricians, general practitioners etc) should be trained on all aspects of mother and child issues especially paediatric ART, child counselling, national guidelines and treatment protocols so that standardised treatment is followed across the country. This would

*“hidak loupnam maphamsida doctor amasung staff khara yamna leiradi eikhoina ngairisi kuina ngairaroi... (If there are more number of doctors and other hospital staff, we will not have to spend so much time waiting for our turn).”*

-a CLHIV, Ukhrul

be of benefit to the CLHIV; in the event of migration there would be no change in protocol and consequently reduced risk of drug resistance to the children.

As part of the integration efforts, there is a need for advocacy with ICDS, RCH and NRHM Programmes for integrating PPTCT, paediatric HIV and AIDS and ART. Capacity building of existing grass root workers like ANM, AWW, ASHA will be an effective step towards the same as this resource will prove to be cost effective and efficient due to their prior involvement with the similar target group, area, issues and also cater to women coming for ANC to the centres and those at home. This exercise will improve identification of pregnant WLHIV and exposed children, referral and follow-up of those on treatment and will also dilute the stigmatising attitude of the community and care providers towards the CLHIV and the family. To help strengthen referrals to ART centres, training of all staff in the Primary Health Centres (PHC) and Community Health Centres (CHC) needs to be done. All CLHIV must have priority access to nutrition at the anganwadi centres.

Besides AWWs and ASHAs, there is a need of periodic training sessions for *Dais* who are an active resource in the villages, so that HIV positive women delivering at homes could be provided with the required prevention, care and support services through timely referrals.

## Improving Service Orientation and Responsiveness at ART Centres

Community voices indicate that there is an urgent need of streamlining the systems and processes existing in ART centres. The long queues for each service viz., registration, meeting with MO, counselling and ARV dispensing should be shortened by a direct referral of the children from the counselling section to ART dispensing section. Else, one day should be exclusively marked as children OPD day so that they can get exclusive attention.

*Community voices indicate that there is an urgent need of streamlining the systems and processes existing in ART centres.*

Considering the CLHIV load at these centres, additional drug dispensing counters with specially earmarked counter for CLHIV can be provisioned. Rest and recreation are two important criteria in improving services at ART centres. Rest-cum-recreation rooms for CLHIV would be a strong pull for children who are weak, debilitated and/or sick. As desired by an HIV positive child -

*“Paba yaba nungaiba comic ka leiradi aduga TV ga leiradi yamna ngungaigan”* (It will be nice if there are comics and TV room in the ART centre).

School going children and sole bread earners in poor families have a special need. A strong community articulation suggests that introduction of flexi timings in ART centres will help them avoid frequent absence from work and schools. Opening of ART centres on Sundays also would be an additional facility. At least one day in a week should be exclusively fixed for OPD for Children at the ART centres to avoid hassles and the tiresome procedure of children standing in long queues.

Most of those who access government or government-approved ART services are either illiterate or have only functional literacy. Therefore, all ART centres must have vernacular signage along with a standardised pictorial description of various services

or service points. These should be placed at all vantage points in the hospitals for guiding the children and their parents to the ART centres.

Improvement in systems and processes in ART centres has to be dynamic in nature. All child-focused services must be subjected to an independent evaluation periodically and a dynamic accreditation of all such services will be the long-term answer to issues of quality, service orientation and greater responsiveness.

## Renewed Focus on Advocacy

There is a greater need for a renewed thrust on advocacy at different levels. State governments need to mainstream HIV and AIDS programmes and actively work towards integration of PPTCT, paediatric HIV and AIDS within the RCH and MCH programmes which will further lead to improved identification and treatment of CLHIV and their families in the state. Strategic positions in programmatic management within the related programmes should be filled with public health professionals who have adequate exposure in RCH, HIV and AIDS programmes for framing effective policies and implementation of programmes. Policy makers at all levels within the related programmes should have a practical outlook while making policies for HIV and AIDS programmes so that they are able to appreciate the difficulties faced by the healthcare providers while dealing with the service users. All these changes would require influencing the decision makers at appropriate levels.

Within CHAHA, children are provided support and services for nutrition, travel to ART centres, OI medication (e.g. co-trimoxazole prophylaxis), paediatric counselling and monitoring of treatment follow-up. However, in view of the increasing support needs of the families, it is important to work more closely with the government at all levels to enable the children and families to have greater access to government programmes and services. There is a need for initiating policies for the implementation of the School AIDS Education Programme (SAEP). Paediatric issues and HIV and AIDS should be an essential component of the same. Also, intensive programmes on adolescent issues coupled with life skill education, reproductive health, HIV and AIDS, treatment, care and support for CLHIV need to be planned by the District Education Department (DED) and AIDS control societies in schools to build up a peer support for children infected and affected with HIV and AIDS.

*State governments need to mainstream HIV and AIDS programmes and actively work towards integration of PPTCT, paediatric HIV and AIDS within the RCH and MCH programmes which will further lead to improved identification and treatment of CLHIV and their families in the state.*

## CHAPTER 8

# Conclusion

When the global impact of HIV and AIDS was first felt, its effect on the future generations was probably not understood well. However, the last two decades have shown that an increased number of children are being detected positive. This situation has surfaced as a serious challenge for health policy planners and implementers alike.

The '3 by 5' initiative launched by WHO in September 2003 was adopted by Government of India to launch free ART programme on 1st April 2004, but with limited paediatric focus. In India, children getting ART was much lower than the number affected by HIV and AIDS.

*The need is to strengthen linkages and referrals so that these entitlements reach CLHIV and their families.*

The study has brought out that stigma and resultant discrimination needs serious attention. Use of appropriate communication strategies and building a wider support base of community leaders would go a long way in dealing with stigma rooted in ignorance, myths and misconceptions.

It is time that the health policy planners focus on the structural constraints, work towards decentralisation of services and improve the responsiveness of all testing, diagnostic and treatment centres. The issues of horizontal coordination and integration, with other health programmes, as well as staffing, training and widening the scope of treatment services should be taken up simultaneously.

In a liberalised and globalised economy where market is playing an important role in all spheres of human life, it is prudent to engage market institutions with health delivery systems where state can act as regulator. Market along with civil society can help the state deliver goods and services in a partnership mode. This will help in ensuring quality, reach and service orientation of paediatric HIV diagnostic and treatment services. In addition, efforts should be made for greater accountability and responsiveness of government testing and treatment facilities.

India is committed to the ideals of reaching out to the last person and family in socio-economic distress. Both the union and state governments have formulated schemes to either enhance livelihood options of the poor or build social security nets for special groups. The need is to strengthen linkages and referrals so that these entitlements reach CLHIV and their families. This can be done by building a larger civil society coalition with government agencies.

Civil society has played a strong role in prevention, care and support services. It has been at the forefront of developing and implementing innovative home and community-based care and support programmes through a vibrant and effective outreach and community-centred model. Its efforts have raised the bar for any future care and support model that seeks to reach out to CLHIV and their families and to promote strong linkages and referrals. The government can help upscale and promote further civil society action in this area of work with a predominantly rural, urban and peri-urban focus.

In essence, it is imperative that the efforts in the field of paediatric HIV must gain a central place as we move into a crucial phase of NACP III.

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