

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

**A Report on Operations Research
conducted in Maharashtra and Manipur**

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India HIV/AIDS Alliance, New Delhi
December 2009

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For more details, please write to:

India HIV/AIDS Alliance

Third Floor, Kushal House

39 Nehru Place

New Delhi -110019, India.

Tel: +91 11 41633081

Fax: +91 11 41633085

Email: panand@allianceindia.org

Web site: www.aidsalliance.org

Setu, Virtual Resource Centre-www.aidsallianceindia.net

About India HIV/AIDS Alliance

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

AIDS	:	Acquired Immuno Deficiency Syndrome
ANC	:	Ante Natal Care
ANM	:	Auxillary Nurse Midwife
ARV	:	Antiretroviral
ART	:	Anti Retroviral Treatment
AWW	:	Anganwadi Workers
CAA	:	Children Affected with HIV and AIDS
CBO	:	Community Based Organisation
CCC	:	Community Care Centre
CDMO	:	Chief District Medical Officer
CDPO	:	Child Development Programme Officer
CLHIV	:	Children Living with HIV and AIDS
CHC	:	Community Health Centre
CMO	:	Chief Medical Officer
CSO	:	Civil Society Organisation
DGO	:	Diploma in Gynaecology & Obstetrics
DIC	:	Drop-in Centre
DNA	:	Deoxy- Ribonucleic Acid
DOTS	:	Direct Observation Treatment Short course
DPT	:	Diphtheria Tetanus whole cell Pertussis Vaccine
EBC	:	Exposed Baby Care
EDI	:	Entrepreneurship Development Institute
ELISA	:	Enzyme-Linked Immuno Sorbent Assay
EID	:	Early Infant Diagnosis
FBO	:	Faith Based Organisation
FDC	:	Fixed Dose Combination
FGD	:	Focus Group Discussion
GFATM	:	Global Fund to Fight against AIDS, Tuberculosis and Malaria
HCBCS	:	Home and Community Based Care and Support
HCW	:	Health Care Workers
HIV	:	Human Immuno Deficiency Virus
HoD	:	Head of Department
ICDS	:	Integrated Child Development schemes
ICTC	:	Integrated Counselling and Testing Centre
IDI	:	In-Depth Interview
IDU	:	Intravenous Drug Users
IEC	:	Information Education and Communication
IGP	:	Income Generation Programme

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

The major issue brought out by the study related to an all-pervasive stigma and the resultant discrimination at all levels in urban areas not only within the family and community but also in schools 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.

It has been observed that the intensity of stigma in urban areas is somewhat low as compared to rural areas. It is known that urban centres are marked by certain characteristics of impersonal ties, secondary relationships and higher mobility. These facts of urban life provide a degree of anonymity in interpersonal relationships, thus affecting the level, nature and intensity of stigma in urban areas.

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

It is, therefore important to understand the difference between not just urban and rural areas but also that urban areas are not a homogenous whole. Large cities and smaller towns display a vastly different character in stigmatising HIV and propagating or practicing discrimination.

The psychological impact of stigma affects children in more complex ways than adults. CLHIV in slums, low income and squatter settlements also grapple with virulent stigma and discrimination as soon as their sero-positive status gets disclosed.

It has been observed that stigma related to HIV perpetuates due to lack of awareness. A focused and multi-pronged effort is, therefore, needed to address issues like illiteracy, lack of awareness and limited access to Information Education and Communication (IEC) programmes. Lack of awareness about paediatric ART services in the urban population needs to be addressed by creating enabling conditions for wider participation of a range of stakeholders – municipal representatives, religious and spiritual leaders, teachers, families and even children themselves. This could be further supplemented and complemented by an urban and child-focused IEC strategy and media planning to bridge the knowledge gaps on the availability of paediatric ART.

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 an alternative for dealing with this situation. Linkages with rehabilitative services and some Income Generation Programmes (IGP) especially designed for the urban population could be a big encouragement.

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. The urban 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 reaching 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 at present. 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.

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. Although around 58 percent of the People Living with HIV (PLHIV) dwell in rural areas¹; 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 PLHIV².

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 in Urban India

Knowledge of AIDS among men, as well as women, increases sharply with education. Most of the people living in urban India have better awareness about HIV and AIDS than their counterparts in the rural areas. Moreover, gender differences are also apparent with regard to knowledge about HIV and AIDS. Men are more likely than women to know how HIV is transmitted and how it can be prevented. In urban areas, approximately 95 percent of men and 80 percent of the women respectively have heard about AIDS. Around 85 percent of men and 56 percent of women respectively know that consistent use of condom can reduce the risk of HIV and AIDS.

WHO reported in 2005 that approximately 42 percent of the PLHIV were dwelling in urban areas in India. UNAIDS estimated more than 1,70,000 children under 15 years living with HIV and AIDS, while NACO reported in September, 2008 that in the urban areas, an average of 5.75 percent of the total PLHIV treated in ART centres were in the paediatric age group. This report also highlighted that among Children Living with HIV (CLHIV), the female gender predominantly reported to the ART centres.

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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

¹WHO report, 2005.

²HIV Sentinel Surveillance and HIV Estimation Report NACO, 2007.

high at 1.59 percent. The HIV prevalence at antenatal clinics in Manipur has exceeded 1 percent in recent years³.

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 whole⁴.

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%)⁵.

Vulnerability of Children to HIV and AIDS

According to AIDS Epidemic Update, December 2009, released by UNAIDS, there were 33.4 million PLHIV and 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 age⁶.

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 system⁷.

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.

³HIV Sentinel Surveillance and HIV Estimation Report NACO, 2007.

⁴ibid.

⁵ibid.

⁶AIDS Epidemic Update, UNAIDS, December 2009.

⁷Manual 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.

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 cases¹. 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.

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.

¹CMIS 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 transmission². 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 India³.

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, is implementing CHAHA in line with the strategic priorities of the National AIDS Control Programme Phase III.

²Times of India, 1st October 2009.

³Annual 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.

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.

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.

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.

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 Urban 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.

District Profile: Imphal West and Mumbai Suburban

The study was conducted in two high prevalence states of India - Maharashtra and Manipur. As the focus of this research was urban, one district each was selected for study from these states - Mumbai Suburban in Maharashtra and Imphal West in Manipur.

General Indicators

The urban population of India constitutes 285 million people and is estimated to reach 534 million by 2026. Approximately 28 percent of the population in India resides in urban areas¹. Percentage decadal growth in urban areas was 31.2 percent *vis-à-vis* 17.9 percent in rural areas between 1991 and 2001. As a result of this, more than 30 percent of the Indian populace lives in urban areas and contributes to over 90 percent of the Gross Domestic Product (GDP).

Mumbai Suburban district spreads over an area of 369 sq. km and is one of the most densely populated districts of India². Mumbai suburban district is further classified into the Eastern and Western Suburbs. The district covers 14 municipal wards of Bombay Municipal Corporation. The district along with Mumbai City district makes up the metropolis of Mumbai.

Imphal district spreads over an area of 558 sq. km³. Imphal West district falls in the Manipur valley region. It is a tiny plain at the centre of Manipur surrounded by plains of other districts. Imphal city, the state capital is the nodal functional centre of this district.

Demographic Indicators

Table 1: Comparative population of the study sites

Comparative Population	Maharashtra	Manipur
Total Population	9,67,52,247	22,94,000
	Dist. Mumbai Suburban	Dist. Imphal West
Total	86,40,419	4,44,382
Males	47,41,720	2,21,781
Females	38,98,699	2,22,601
Children (0-14 years)	23,53,900	1,28,958

(Source: Census of India 2001 online data)

¹United Nations report 2005.

²Census of India 2001.

³ibid.

Population wise, Mumbai Suburban is one of the largest districts in the country. The current population of the district is 86.40 lakh. Mumbai has a population density of 21,880 per sq. km. Population density of Imphal district is 847 per sq. km and has a total population of 4.44 lakh, which is quite low as compared to Mumbai Suburban. Decadal growth of Imphal West district is 19.34 percent while that of Mumbai Suburban is 27.20 percent⁴.

The census report shows that the population of Mumbai Suburban is nearly 20 times more than that of Imphal West. Approximately 20 percent of the total population in Manipur dwells in Imphal West district⁵.

Economic Status

Per capita income of the people in Mumbai Suburban is Rs. 48,954, which is more than six times of their counterparts in Imphal West⁶. The comparative per capita income shows a wide difference between the two urban centres. Although per capita income in Mumbai is high as compared to Imphal, it is to be noted that the cost of living in metropolitan cities is high and as a result, the number of families falling in low economic strata is fairly large.

A high percentage of Below Poverty Line (BPL) families in Imphal West indulge in high risk activities. In addition, there is low literacy level and lack of awareness about existing healthcare services which reflects in low health seeking behaviour in the district.

ART Status in Mumbai Suburban and Imphal West

As per NACO 2008 report on ART⁷, number of PLHIV and CLHIV registered and their treatment adherence in Mumbai Suburban and Imphal West districts is given in the following table:

Table 3: NACO report on ART services in the project districts

ART Services	Mumbai Suburban					Imphal West				
	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	1,157	52	35	87	1,244	47	2	2	4	51
Cumulative number of persons ever registered in HIV care by end of September 08	32,310	1,095	879	1,974	34,284	3,476	228	222	450	3,926

Table contd...

⁴Census of India 2001.

⁵ibid.

⁶ibid.

⁷CMIS Report on District ART Data - National AIDS Control Organisation- September 2008.

ART Services	Mumbai Suburban					Imphal West				
	Adult	Paediatric (M)	Paediatric (F)	Paediatric (Total)	Total (Adult + Paediatric)	Adult	Paediatric (M)	Paediatric (F)	Paediatric (Total)	Total (Adult + Paediatric)
Cumulative number of patients ever started on ART	15,117	509	376	885	16,002	1,949	53	57	110	2,059
Cumulative number of patients who ever died	1,112	49	25	74	1,186	159	3	2	5	164
Cumulative number of patients "transferred out"	947	27	29	56	1,003	217	4	5	9	226
Number of all patients whose treatment status is stopped treatment	140	0	1	1	141	7	1	1	2	9
Cumulative number of patients who are lost to follow-up (LFU)	1,046	27	24	51	1,097	132	2	4	6	138
Total number of patients who missed treatment	48	4	1	5	53	85	3	4	7	92

(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.¹
2. Districts identified by CHAHA programme.
3. Availability of target groups as prescribed in the sample size as per NACO ART data 2008² and CHAHA monthly and quarterly reports³.
4. Availability of facilities catering to the target group in the identified states.

Sampling Design

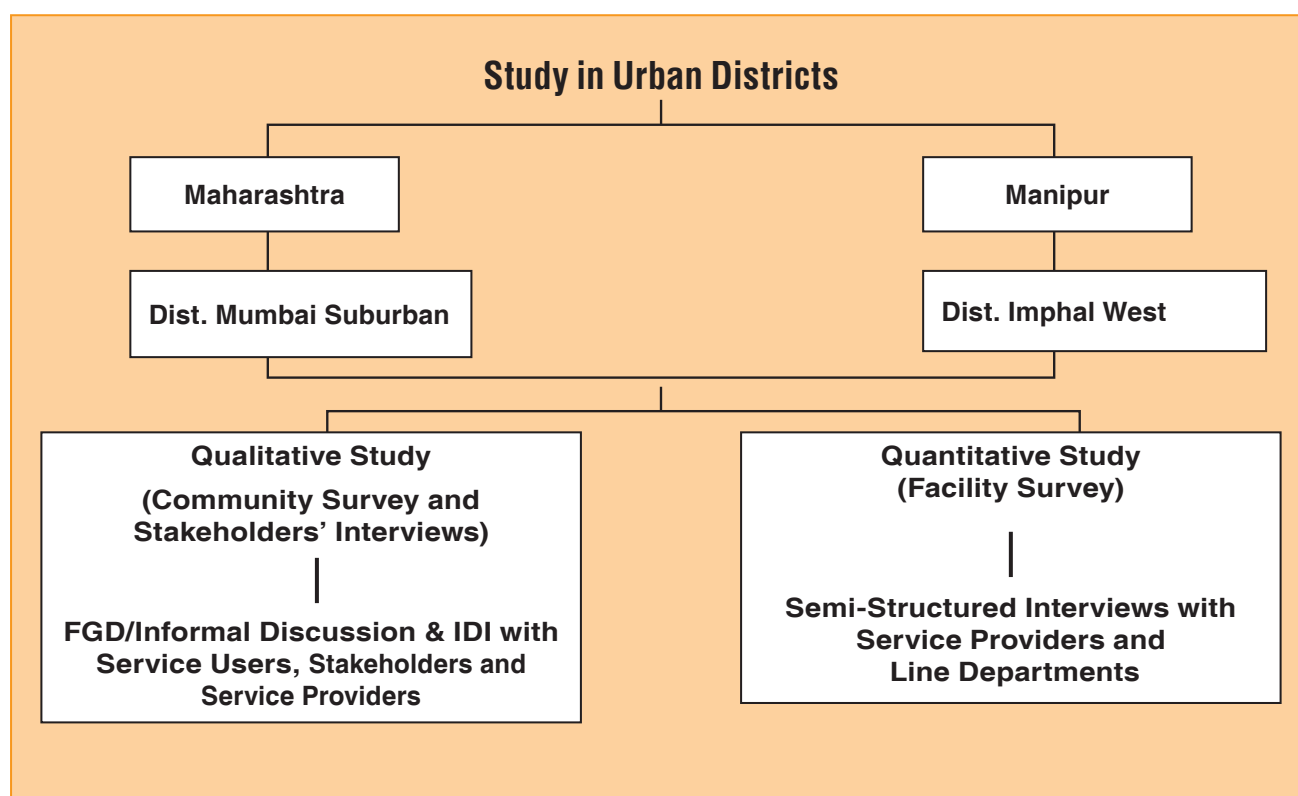
Keeping in view the specific focus of the study and its time line, Stratified Random Sampling Technique was used. Adequate urban sample size was planned in the designated districts that cater to a significant urban population in Mumbai Suburban and Imphal West, to capture the issues.

It should be noted here that these centres, particularly Imphal West also extends to some rural population as well.

¹Classification 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).

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

³SR quarterly report 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

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 selected sample size and respondents for Mumbai Suburban and Imphal West are given in the following table:

Table 4 : Sample size in selected districts

Qualitative	FGDs / Informal Discussions and IDIs		Number of Groups	
		Sub groups (Target)	Mumbai District	Imphal West District
		Community Voices		
		PLHIV groups	4	4
		CLHIV groups	2	4
		General community (Men) groups	2	2
		General community (Women) groups	2	2
		General community Children Affected with AIDS (CAA)/ children in general) groups	2	2
		SHGs/CBOs	2	2
		TOTAL	14	16
		Service Providers	No. of Interviewees	
		Health Staff (Auxilliary Nurse Midwife(ANM)/Accredited Social Health Activist (ASHA)/Anganwadi Worker (AWW)	20	20
		NGOs (SR, SSR)	3	3
		TOTAL	23	23
		Community Voices	No. of Respondents	
		HIV positive women/parents/care givers	18	18
		HIV positive children	18	18
		TOTAL	36	36

Table contd...

Quantitative	Semi Structured Interviews	Facility Survey (Service Providers and Line Departments)	Number Covered	
		ART SACS	2	1
		IEC SACS	1	1
		Chief District Medical Officers (CDMO)	1	0
		Chief Medical Officers (CMO)	1	1
		Private Doctors	5	5
		In-charge District TB Control Programme	1	1
		Child Development Programme Officers (CDPO)	1	1
		Director Education/Zonal Education Officer	1	1
		Teachers preferably involved in School AIDS Education Programme (SAEP)	3	3
		District Nodal Officer	1	1
		In-charge Rehabilitation Programmes	1	1
		State IEC Bureau	1	1
		Municipal Members	1	1
		TOTAL	20	18
		ART Clinics 2 for Mumbai 1 for Imphal West	No. of Respondents	
		Medical Officer ART	2	1
		Counsellor	2	1
		NGO member	2	1
		Pharmacist	2	1
		Paediatrician	2	1
		TOTAL	10	5
		PPTCT Centres 2 for Mumbai 2 for Imphal West (PPTCT Centre-1) (ICTC Centre-1)	No. of Respondents	
		In-charge PPTCT	2	2
		Counsellor	2	2
		Lab Technician	2	2
		Nurse (Labour Room)	2	1
		TOTAL	8	7

Table contd...

Quantitative	Semi Structured Interviews	VCTC 2 for Mumbai 2 for Imphal West (VCTC-1) (ICTC-1)	No. of Respondents	
		Counsellor	2	2
		In-charge VCTC	2	2
		Lab Technician	2	2
		TOTAL	6	6
		CCC (2 for Mumbai and Imphal West each) DIC (2 for Mumbai and Imphal West each)	No. of Respondents	
		In-charge	4	4
		Doctor	4	4
		Counsellor	4	4
		Total	12	12
		Additional Counsellors	5	5
		Additional Gynaecologists	5	5
		Additional Lab Technicians	5	5
		Additional Paediatricians	5	5
		Total	20	20
		Total Urban Sample	149	143

Both in Mumbai Suburban and Imphal West, two facilities each of PPTCT, VCTC, ICTC, ART, CCC and DIC to a maximum of 10 facilities per district were covered. The sample size for the community and stakeholders was largely dependent on the availability of respondents especially WLHIV, CLHIV and PLHIV groups, willingness of the respondents to participate in the study and subsequent discussions with the SR and the SSR.

It was also decided that in case of shortfall in sample size, it will be covered from an urban area within the respective state where CHAHA is operational. As the adequate number of sample proposed in the study was not available in Mumbai, the deficient sample was taken from Sangli Municipal Area.

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

The barriers faced by urban 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 urban India. Some of the apparent barriers that emerged as a result of the study are described below:

Stigma and Discrimination

Stigma and resulting discrimination does exist in all areas, rural and urban, but it has been observed that the intensity of stigma in the urban areas is somewhat low as compared to rural areas. Urban centres are marked by certain specific characteristics such as impersonal ties, secondary relationships, higher mobility and migration within a defined urban setting that provide a degree of anonymity affecting the levels, nature and intensity of stigma existing in the urban sectors of India.

For a variety of reasons, the differential between stigma experienced in large metropolitan areas like Mumbai and that in a medium size town like Imphal is also expressed in terms of characteristics of urban life. Small and medium size towns in many ways have rural-like characteristics e.g. face-to-face relationships, close inter-personal ties and limited mobility often described as 'peri-urban'. There exists a differential in the level and intensity of stigma in different urban areas as well.

It is known that CLHIV in slums, low income and squatter settlements also grapple with virulent stigma and discrimination as soon as their sero-positive status gets disclosed. In fact, the psychological impact of stigma affects children in more complex ways than their parents. CLHIV and their parents are subjected to various forms of humiliation, ridicule and even isolation. An HIV positive women shared her experience thus -

“Meri padosan kehti hai chal chal door baith....kutton ki tarah bartav kartey hai.” (My neighbour tells me to go and sit away from her. She treats me like a dog).

Stigma in urban areas gets manifested in various forms of social isolation such as denial of admission in schools, segregation within the classrooms and other social spaces or playgroups in school, contemptuous attitude of teachers and fellow students. It is this fear of social isolation that parents feel compelled to hide the status of their HIV positive children.

As shared by an HIV positive child during FGD - *“My friends never share their plate and spoon with me. Once I was drinking water in the school. The glass which I used was thrown away into the dust bin. After this incident, I felt very sad and humiliated. On reaching back home I shared everything with my mother, who told me never*

In fact, the psychological impact of stigma affects children in more complex ways than their parents. CLHIV and their parents are subjected to various forms of humiliation, ridicule and even isolation.

to be pessimistic and also advised me to never disclose my HIV positive status to other people”.

Parents who have an HIV positive child prefer not to disclose his/her status lest it may be detrimental to the future of other siblings. This concern is even more pronounced if the parents have a growing up daughter who has to be married off in foreseeable future. These social pressures emanating from stigma and discrimination thwart any effort by parents in accessing treatment for their HIV positive child in the family. As mentioned by an HIV positive male -

“Eichanupi chaoraklabanina eihkoi positive oire kaina haibase talakle” (Our daughter is grown up, so we do not want to disclose our status as HIV positive since this will have a negative repercussion on the future of our daughter).

The perceived fear of getting a raw deal at the hands of extended family, in the neighbourhood and in institutional spaces has an obstructive effect on disclosure of status. The fear of disclosure is also largely due to self-stigma experienced in urban areas. A general community person added -

“HIV badhit aadmi apni bimari ke bare mein kisi se nahi batate, agar bataenge to log bhedbhav karenge.. unki naukari bhi choot jati hai” (HIV positive people do not disclose their HIV status fearing non acceptance by the society and the fear of losing their job).

The high level of self-generated stigma in urban areas is perceptibly pronounced in comparison to rural areas. In anticipation of contemptuous and scathing community response to disclosure of status, parents shy away from getting their children tested resulting in delay in the initiation of ART.

The high level of self-generated stigma in urban areas is perceptibly pronounced in comparison to rural areas. In anticipation of contemptuous and scathing community response to disclosure of status, parents shy away from getting their children tested resulting in delay in the initiation of ART. Many a times, parents prefer not to disclose the status to their HIV positive child for the fear of scorn that the child may have to face along with serious psychological and behavioural problems.

In order to keep away from the intrusive enquiries of relatives and neighbours pertaining to taking of regular medication, frequenting ART centres and other health facilities for OI, many parents prefer to take the child to an ART centre located far away, so that anonymity can be maintained. For similar reasons, medicines for OI are sometimes not purchased from a local chemist shop.

Stigma and discrimination at health care facilities in large cities is less as compared to smaller urban centres but it exists and gets reflected in myriad ways. An attitude of indifference and callousness towards parents and children is evident in the behaviour and utterances of health care providers which has serious undertones in discouraging the children and parents to access ART centres. More often, the patient load and staffing

constraints at ART centres are found to be the reasons for apathy and cynicism shown by some health care professionals. This leads to reluctance among people in reporting to ART centres, thus causing delay in initiation of treatment and also its adherence on a regular basis of children and even adults. Inadequate staff/HIV specialists attending to CLHIV/PLHIV in an ART centre at a given time is a cause of concern. As mentioned by a CLHIV -

“Ayamba matamda doctordi lei, adubu patient masing yamna yambanina yamna kuina ngaibagi awabadi thoina theng-nei. Doctor masing khara hengatlaadi nungaini”. (Doctor is there but the problem is that there are so many patients so it is difficult

for the doctor to give adequate attention to all patients. It will be good if the number of doctors is increased).

Many a times, stigma also affects the psyche of doctors who treat HIV positive children or adults. Some of them do not prefer to be identified as HIV specialists due to the fear that it may impede their professional growth and status.

Economic Constraints : Impoverished families, diminishing incomes and mobility

The stark realities of urban poverty in India are too well known to be over emphasised. Urban poverty in India remains high; over 80 million poor people live in the cities and towns of India¹. As the urban population in the country is growing, so is urban poverty. In a large number of states, poverty in urban areas has increased significantly, even much above that in some of the rural areas.

It is known that a significantly large proportion of CLHIV who are accessing ART centres, come from poor families, generally below poverty line. As clearly mentioned by a PLHIV woman -

“I faced many financial difficulties for buying second line ARV drugs, with the cost of school education of three children. Sometimes I have to sleep on an empty stomach”.

The parents, being poor are unable to pay the transport expenses for going to ART centres. Since most children cannot travel alone and have to be accompanied by a caregiver, twice the amount has to be spent on travel which makes it even more difficult for resource constrained families to take their children regularly for treatment. A CLHIV said that -

“Peisa letrabanina khongna chatle aduna hallakpadadi pura chokthare” (As we do not have enough money, we go by foot to the ART centre and on reaching home we get exhausted).

Given the low and often diminishing incomes, families are unable to provide proper nutrition to the child. Hence, the general health and immunity of the child does not show apparent improvement and disheartens the parents who feel that ART is doing no good to the child. This real or perceived situation frequently results in the families abruptly discontinuing ART to the child. As mentioned by a CAA -

“Peisa leidana eikhoi chara henbasu yao-ee, eemadi hidak leibasus ngamde, ART centeda chatpasu ngamde” (Due to financial problems we are starving and our mother cannot even buy medicines nor go to the ART Centre).

In many situations, a visit to the ART centre also means missing a day's earning for the parents or caregivers who are daily wage earners. This loss of income is perpetuated by travel and food-related expenses and has to be understood in the context of a situation where one or both parents are PLHIV. Absence from work on account of their own ill health adds to the struggle in eking out a living. Added to this is the high cost of living in urban centres and treatment costs for Opportunistic Infections (OI), as some of the medicines are sometimes not available in the hospitals.

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¹National Sample Survey Organisation's survey report as quoted in UNDP India: Urban Poverty Report, 2009.

An HIV positive person stated during FGD - “...Main painting ka kam karta hun, main apni ek din ki bhi pagar chhod kar nahi aa sakta.” (I am a painter by profession. I cannot afford to miss my one day wage for coming to the ART centre).

Similarly a CAA also mentioned - “...Hamari maa ghar chalati hai..., jab behen ke sath jaana padta hai ART ke liye...poora din lagata hai aur sham ko khane ko nahi hota” (Our mother is the only earning member in the house and when she goes with my sister to the ART centre, the entire day is spent in that. As a result, there is no food to eat in the evening).

It is not difficult to comprehend that access to ART centres for treatment of CLHIV becomes harder for an urban poor family when they have to forsake other significant needs in a child's life e.g., education. Although cessation of education cannot just be attributed to poverty but also the health of the child and/or the caregivers, but in a large number of cases it is both. It is important to understand that the economic costs of HIV to the family have negative implications such as the impoverishment of families, discontinuation of education or the lack of adequate nutrition. During the study, children not going to school cited economic constraints, poor health condition and discrimination as the reasons for cessation of education. This points to the fact that the child may face challenges to attend school and thus requires support from others to resume education at school.

“Once I went to my relative's home for some purpose. There I was hugging our relative's child but the uncle there told me not to hug the child as my father and mother had died of HIV and TB. From that day I thought I would never to go to their house again. I cried a lot and remembered my parents.”

- A CLHIV

Also, economic constraints faced by child-headed families and children who have lost both parents due to serious disruption in family income and the existential challenges of making ends meet, is a deterrent to CLHIV in accessing ART services. In a condition of deep financial distress, some of these children become dependent on relatives or care givers.

During in-depth interviews conducted with a sample of HIV positive children, it was found that more than one-third had lost both parents, generally referred to as double orphans, with a higher percentage found in Imphal West (39%) as compared to Mumbai (25%). They were either living with other family members or caregivers. In 68 percent of the cases, their father had passed away and 35 percent of the CLHIV interviewed had lost their mother. One of the female respondents from Imphal West was living all alone and without any caregiver.

More often, the lack of caregivers' support to orphan children makes them further vulnerable to HIV. As a CLHIV shared her woe -

“I don't have parents and I was living with my aunt. My aunt did not treat me well so I was sent to hostel by my grand mother. I got sick in hostel with high fever and weakness, so I was brought back to the house by my sister. During my checkup, I was tested for HIV and was detected positive. Now my aunt does not allow me to go to the doctor.”

Grandparents as caregivers also have their limitations on account of age-related morbidity. In the midst of many stories of strong and determined relatives/family members who have served the interests of children well after both parents of a child have passed away, children many a times experience neglect or apathy from other relatives members. As shared by a CLHIV -

“Once I went to my relative's home for some purpose. There I was hugging our relative's child but the uncle there told me not to hug the child as my father and mother had died of HIV and TB. From that day I thought I would never to go to their house again. I cried a lot and remembered my parents.”

The oft-cited reasons are poor means, ignorance, anticipated financial implications of long-term care giving or a combination of all these factors. In the given situation, some relatives perceive accessing treatment at ART centres a waste of time and an unnecessary financial burden. This is also to be seen in the backdrop of some caregivers' strong notion that the child's life is cut short anyway and that early death is imminent.

It is known that most of the urban slum dwellers are a mobile population. Since the relative permanency of these families in one place is not assured, effective treatment and follow-up is not possible.

The children of migrant labourers face unique problems. When their parents test positive and fall sick, they sometime prefer going back to villages, where access to ART for the child or the parents becomes even more difficult. In some other cases, when one or both parents of a migrant family die in a town or city, the orphan child is taken back to the village by other village natives or relatives; most of the times ignorant of the fact that treatment of the child should not be discontinued.

Accessing treatment in district headquarters from a distant area poses another set of problems that needs no elaboration. Therefore, despite the availability of free ART at government centres, the transport cost, loss of daily wages and treatment of OI become the main reasons for the CLHIV and families not being able to access and adhere to ART.

Infrastructural Issues

There is a wide variation of demand and supply in the ART delivery system as the number of facilities providing ART is low vis-à-vis the patient load. These centres are located either in medical colleges or tertiary and secondary care hospitals and being less in number, cater to a wide catchment area and a large number of patients. In Mumbai, some major ART centres do have Link Centres which are strategically located. In some of the Link ART centres surveyed, children collect their monthly provision of ART but for prognostic testing like CD4 count and other required investigations, they have to visit the main ART centres. This is also true for those children who have yet to be registered into the ART programme.

Given these limitations on access to prognostics and treatment, children and caregivers have to cover long distances most of the time, only to encounter long queues at the ART centres. Even adults find it difficult to reach these centres as they along with their children have to spend one complete day for visiting the ART centres.

Imphal is a medium size town categorised as *Nagarpalika Parishad* (Municipal Council). In Imphal, as in many other such towns, the distances are not much as compared to large metropolitan cities but a non-existent or weak public transport system in such mid-sized towns is a reality. In the absence of a public transport system in Manipur, the private transport system tends to overcharge fare, as demand-supply gap is wide. A different situation in Mumbai poses another dimension to the transportation problem. Though the connectivity is good, long distances coupled with heavy rush and overcrowding in the public transport system like buses and local trains proves to be the undoing. Given the tariff, local taxi services are out of reach for many children and their families.

“Pehle bus mein do ghanta khada hoke aspatal pahunchne ka.. fir kabhi is line main kabhi us line... halat kharab ho jata hai.. sham tak itna kamzori lagta hai”
(First I have to stand in bus for two hours to reach the hospital, then stand in different queues in the hospital for ART. Doing this my conditions gets so bad that by evening I feel very weak).

-An HIV positive woman

After managing to reach the ART centre, even the adults generally feel lost in the big medical college campus or hi-end tertiary care hospitals. They also find it difficult to reach the ART centre which is generally located in a small corner of the hospital campus. The poor or non-existent signages only help to make things difficult for children and caregivers. Adding to the complication is that many of them are unlettered people. Sometimes they also have to line up in separate queues more than once to avail of different services within the same centre like registration, counselling, consultation, ARV drugs, laboratory etc. As strongly voiced by an HIV positive woman during FGD -

“Pehle bus mein do ghanta khada hoke aspatal pahunchne ka.. fir kabhi is line main kabhi us line... halat kharab ho jata hai.. sham tak itna kamzori lagta hai” (First I have to stand in bus for two hours to reach the hospital, then stand in different queues in the hospital for ART. Doing this my conditions gets so bad that by evening I feel very weak).

This issue of inadequate access to ART centre is much more pronounced in Imphal West as there is only one ART centre that serves a large urban population and also adjoining peri-urban areas, villages and towns. In addition, Manipur is affected by insurgency and other issues of internal security which makes it really hard to reach the ART centres.

Lack of Support from Parents and Care Givers

Parents and caregivers play a vital role in ensuring continuous treatment support by escorting the children to ART centres. There are elaborate procedures and formalities which need to be completed for the initiation of ART at the Centre which include registration, consultation, counselling, testing, follow-up and collection of medicine. It is presently difficult for children to manage these complexities on their own. Any reluctance or inability on the part of parents and caregivers, therefore, seriously impedes access of children to ART centres. As put forward by an HIV positive woman -

“Marna to hai hi, Kya fayada aushadhi lekar” (the child is going to die anyway, then why to take care and spend money)

Similarly an outreach worker shared the attitude of HIV positive parents thus - *“Baad mein le lenge, abhi theek hai”* (We'll take medicines later... right now we are fine).

In many cases, parents lack awareness about the symptoms and seriousness of the disease. They usually do not understand the complexity of the condition as the child appears to be apparently healthy and therefore they try to delay treatment until the child falls seriously ill. This practice of denial in accepting HIV positive status of the child becomes the biggest barrier. This denial emerges from the fact that some parents themselves do not want to accept their status and therefore the need for treatment. In such situations, it is extremely difficult to convince parents to bring the child for testing or treatment.

The parents are also subject to myths and misconceptions, false advertisements, rumours and hopes from the quacks and faith healers, which distract them from securing the main line of treatment for their children. At times, they also get scared by the side effects which they themselves underwent on initiating ART. The cumulative effect of all these apprehensions make the parents feel that their healthy-looking child will face more harm than good by taking ART. Hence they get discouraged to bring the child to the ART centre.

There are also situations where the parents themselves are too unwell to take the child to the centre. As revealed by father of an HIV positive child -

“Mera swasthya achha nahi hai aur upar se local train mein bahut bhid hoti hai aur mein bus aur taxi nahi le sakta kyunki mere paas paisa nahi hai” (My own health is not good so I can not travel in the overcrowded local trains and I also cannot travel by bus or taxi as I do not have money to afford that).

Another facet is evident in case of estranged or broken families. Women Living with HIV (WLHIV) are sometimes thrown out of their house along with their children. These women have little or no means to support the treatment of their children. The same causative factors are also largely true for women who are widowed. It is known that women in most communities confine themselves to the household and do not have the experience of interacting in public spaces. Therefore when the women are faced with the responsibility of facilitating treatment access for CLHIV, they exhibit a lot of apprehension and are often gripped by an ‘unknown fear’.

Gender perspectives with regard to CLHIV not attending schools was also revealed during the course of the study, when it was found that more CLHIV girls are disallowed from attending schools than boys. This brings forth the societal discrimination towards infected female children and requires an extensive change in the mindset of community against gender discrimination of girls living with HIV.

“Mera swasthya achha nahi hai aur upar se local train mein bahut bhid hoti hai aur mein bus aur taxi nahi le sakta kyunki mere paas paisa nahi hai (My own health is not good so I can not travel in the overcrowded local trains and I also cannot travel by bus or taxi as I do not have money to afford that).”

-Father of an HIV positive child

Lack of Awareness about Paediatric AIDS and ART

There is a lack of awareness in poor urban settlements about paediatric AIDS and availability of paediatric ART services because the initial focus was on adult-centric treatment. Although paediatric ART started in 2006, people in poor urban localities are still not aware that ART is 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 material on paediatric AIDS and ART. The existing IEC material is too generic and adult-centric.

Illiteracy coupled with lack of awareness about the existing services and significance of treatment for the children has resulted in inability of some parents or children to understand the implications of HIV and AIDS. They fail to comprehend the benefits of ART for their children through a proper treatment adherence and continuous health monitoring which may have a positive impact on the quality and longevity of their children.

The research also highlights 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, a faith healer or some local quack.

Lack of integration of RCH with HIV and AIDS control programme also results in lack of awareness amongst the grass root workers (AWWs) 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. As mentioned by a Health Care Workers -

“HIV positive test touraga positive oiba angansingu makha kari chat-thabage haibadudi eidi khangde, hidak tharamganina doctorna” (I do not know what is done after a child is found HIV positive. May be the doctor is putting them on medication).

“HIVgi hidak chang naina chabra chdabra, hospitalda chatpra chttabra haibadudi eikhoidi toude, madudi NGO kangbuna ayamba toubane.” (If the medicine for HIV is being taken or not, whether they are going to hospital or not, we do not deal with all this. It is done by NGO people) - as pointed out by some of the healthcare workers.

“HIV positive test touraga positive oiba angansingu makha kari chat-thabage haibadudi eidi khangde, hidak tharamganina doctorna. (I do not know what is done after a child is found HIV positive. May be the doctor is putting them on medication).”

- A Health Care Worker

Most of the elected councillors in smaller Urban Local Bodies (ULB) are generally not well informed about the issues of HIV and AIDS at the ward or municipality level, leave alone issues of paediatric HIV. They are, therefore, also not sure of their specific roles in relation to issues of HIV in an atmosphere of ignorance and general apathy. Some larger municipal bodies do have HIV programmes but issues of treatment for CLHIV are still not well understood by all elected leaders.

Unlike rural areas that have *gram sabhas* comprising all residents who are 18 years and above, ULBs do not have formal structures that are equivalent to *gram sabhas*. Even if there are *mohalla samitis* or some citizen collectives, these are informal in nature and not backed by any legal authority to pass any enforceable resolutions in the interest of larger public good, especially those of the poor, vulnerable and disadvantaged sections of society. Issues relating to HIV hardly find any place in these collectives except some occasional and casual mention.

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

“No care and support for my children is being provided by the government. No regular support in terms of nutrition or financial is coming from the government on a regular basis.” - remarked an HIV positive mother in Imphal.

Summing it all, high levels of poverty, illiteracy and ignorance coupled with lack of political leadership at various levels become the causative factors for non-reporting and non-adherence to ART in urban areas.

Deficient Capacities at ART Centres

There is a lack of adequate provision of paediatric medical care of children at the ART centres. In addition, there is a great need for improved dissemination and promotion of available paediatric ART guidelines and a greater emphasis on paediatric counselling during the ART trainings. This will lead to better trained resources on paediatric ART. As reported by an HIV positive child -

“Moina ayamba matamda ema hoi baba hoiga oina yari sanei aduga eikhoidadi hakselgi oiba wari amata sabide...” (Mostly the counsellor and doctor counsel our parents. No one tells us about health and nutrition).

Paediatricians are usually not deputed in most of the centres with the result that these services are provided either by referring the children to the paediatric department in the paediatric OPD or they are managed by medical officers who are not trained on paediatric ART services. In other cases, the specialists come to the ART centre only on specific days leading to delay in the treatment of children. This de-motivates the parents even when their clear preference is for government ART centres.

While the study findings reveal that a substantially large number (91.2%) of children reported having ever been counselled, several questions were raised about the quality, appropriateness and methods of counselling provided to children. The existing personnel in the ART centres are neither trained in paediatric counselling nor they can converse in a manner that can be easily understood by the children simply because there has not been adequate focus on skill building on paediatric counselling. They, therefore, opt to counsel the parents or adult caregivers in place of the child. As mentioned by a CLHIV group -

“Makhoina aphaba chinjak chanaba hidak chang naina chanba hairakhi adubu ayamba waridi eikhoi baba amadi emahoiga oina sanakhre...” (They talk about good food, and taking medicine on time and everyday, but most of the time they talk to our parents).

In some instances children are not counselled individually but in common groups of adults and children. Most children and adolescents find it extremely embarrassing to talk about certain personal and often traumatic experiences in front of adults and children who may be strangers. This makes some children pull out from active counselling and eventually retreat from all treatment processes.

According to the administrative procedures, detailed documentation and reports of the children and families on ART are needed with their addresses. Many a times, information is not recorded or provided properly which later acts as a barrier in follow-up of drop-outs.

“Moina ayamba matamda ema hoi baba hoiga oina yari sanei aduga eikhoidadi hakselgi oiba wari amata sabide...” (Mostly the counsellor and doctor counsel our parents. No one tells us about health and nutrition).

- An HIV positive child

Coordination, Collaboration and Convergence

A major barrier highlighted by the policy implementers and line departments was the lack of convergence between different programmes like TB, PPTCT, paediatric AIDS and ART. There is inadequate coordination between PPTCT and ART centres both at the level of the health care providers (gynaecologists, paediatricians and In-charge ART) and activities (referrals from the PPTCT centres, follow-up of the HIV positive drop-outs, follow-up of the exposed children and referrals from ART centre to paediatric OPD or wards) which leads to delayed identification of exposed children and follow-up for adherence. This has led to the emergence of various vertical stand alone programmes within the same health care system; thus providing isolated services to the common target groups within the same area and communities.

A large number of HIV exposed children are lost to follow-up for HIV testing during the 18 month long follow-up period due to lack of awareness among the parents about transmission risk, inadequate counselling by the counsellors in the PPTCT centres, lack of follow-up by the counsellors and paediatrician and non availability of PCR/DNA testing services.

A major barrier highlighted by the policy implementers and line departments was the lack of convergence between different programmes like TB, PPTCT, paediatric AIDS and ART.

There is a significant gap in awareness levels of the ICDS workers, programme planners (e.g. CDPO and AWW), Reproductive and Child Health (RCH) workers (e.g. ANM), National Rural Health Mission (NRHM) workers (e.g. ASHA) and HIV-TB coordination (DOTS providers). 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 paediatric HIV and AIDS and the service availability. 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.

There is a need for improved coordination between State AIDS Control Societies and District Health Departments (DHD). The district health authorities need to be well informed about the implementation of the programme in the district so that the policy and implementation framework are fully known to the health department and there is active involvement of the health department in HIV and AIDS control activities. It was also highlighted that in districts with a high urban population, there is lack of convergence between RCH and HIV and AIDS programmes as compared to those with high rural population where active integration of HIV and AIDS programme with state health programmes is evident with the involvement of all cadre of health care providers.

There is a perceptible lack of effective co-ordination between the HIV-TB programmes both at the level of policy makers and the programme implementers. This leads to lack of identification and diagnosis of children with dual infection and inadequate follow-up. The HIV test on a TB patient cannot be conducted at a TB centre and has to be done only at the VCTC/ICTC. In certain situations, the TB and HIV centres are located in different facilities at a distance from each other. Within the same facility also, both the services are located at different corners so the child has to

shuttle between the counselling, testing, ART and TB sections which may be very exhausting and hence poses a barrier for him/her to come to the centre regularly. As shared by a CAA -

“ART centre si eikhoidagi khara laappee. Amukhakti, eemana ART centeda chatlaba tungda, DOTS centre dasu chatluraga halakpadadi, masa pura chokthei...” (The distance from ART to DOTS centre is quite far. Once my mother had gone to the ART centre and then to the DOTS centre. When she came back home she was so tired and weak that she collapsed).

It has also been reported that mostly, timings of the ART and the DOTS centres are the same. This means that at a given time, the child can either go to the ART centre or to the DOTS centre. Consequently, non-availability of related services under one roof is another major barrier inhibiting children from accessing ART services. Keeping this in mind, there is a need to work towards greater convergence of interrelated services and programmes.

The lack of coordination is not only discernible in inter-agency approach to health services, the intra-agency coordination between different departments within the same facility also needs to be strengthened. For example, between Medicine, Obstetrics and Gynaecology (OBG), paediatrics and ART centres etc.

The centres providing pre-ART investigations are spread in different locations within the same campus housing the ART centre. The testing services for Complete Blood Count (CBC), CD4, Liver Function Tests (LFT), X-rays, Ultrasound and CT scans are located in different buildings housing different departments. The inconvenience of running all over the facilities is discouraging to those who are sick and weak and have yet to initiate ART.

An important area of concern which has a strong influence on the access of children to ART is the lack of involvement of school teachers with paediatric HIV and AIDS programmes. 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 CLHIV.

Barriers identified by CLHIV in accessing ART

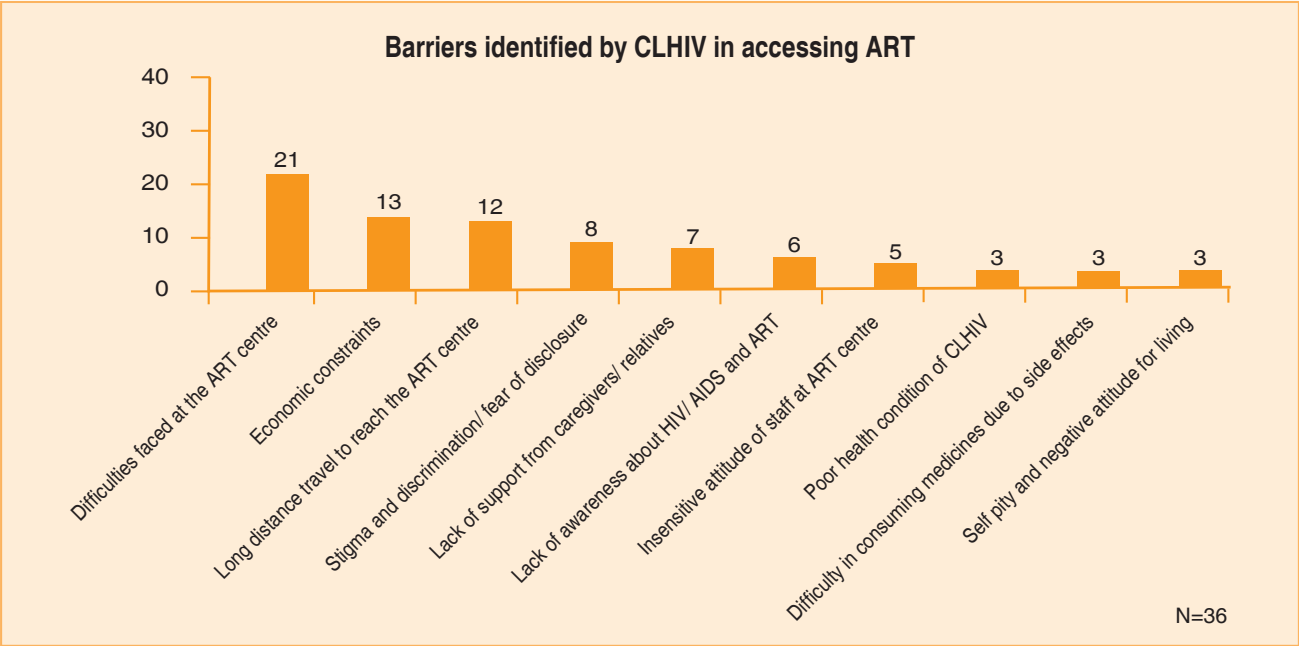
Children have their own perceptions about constraints existing within their social milieu that thwart any step towards their treatment process. Stigma and discrimination no doubt is the most obvious impediment in the road to ART, yet children with their limited vision tend to perceive issues related to financial constraints and infrastructural difficulties as apparent barriers in accessing ART. Travelling long distance to reach the ART centres coupled with difficulties experienced therein, was a major barrier pointed out by most of the children interviewed during the course of the study. Lack of support from the caregivers and parents emanating from their social milieu, poor health and difficulty in consuming medicines were also highlighted as other impediments by these children.

Among the series of significant barriers identified by a sample of HIV positive children interviewed (N=36), the most important barrier pointed out by a majority of respondents (60 percent) was difficulties faced at the ART centres in terms of service orientation and responsiveness. Some of the significant difficulties cited were long

queues, crowded atmosphere, inadequate waiting spaces or seating arrangements and bad smell inside the hospitals.

Children apparently identified unsatisfactory infrastructure at the ART centres related to inadequate availability of medicines and testing equipment. It was also mentioned that hospitals are ill-equipped with provision of drugs or tonics for Opportunistic Infections and other paediatric formulations. Many a times, CD4 tests are postponed due to improper functioning of the testing machines. Apart from this, another major barrier that emerged as a result of the study was biased attitude of service providers and counsellors including lack of confidential conditions during counselling or handing over of medicines. These are some of the dominant factors that discourage children from accessing ART.

Graph: Barriers identified by CLHIV



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, the 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 eliminate Stigma and Discrimination

The study findings have confirmed that the biggest barrier in accessing treatment services is stigma and discrimination that takes several complex forms 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.

Awareness about paediatric diagnostics, care and treatment services being a weak link in the national IEC strategies, an intensified child-focussed appropriate IEC programme should be designed for urban and peri-urban areas by taking 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.

A result-oriented implementation of communication strategy will mean building wider support within the community through greater participation of all stakeholders.

A result-oriented implementation of communication strategy will mean building wider support within the community through greater participation of all stakeholders – political leaders, businessmen, professionals, media, trade unions, religious and spiritual leaders, members of positive networks at block and district level, women self help groups and women collectives, youth clubs and other civil society forums.

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.

“... IGP na chingba HIV positive oiba missing-gee makhoigi eemung manung-gee leiba darker oi...” (There is a need of IGP for PLHIV and their families).

-Self Help Group, Imphal West

Urban Local Bodies (ULB) are the third tier of governance and like their rural counterparts (known as *panchayats*), have representatives directly elected for five years. These ULB are of three types – *town panchayats*, *municipal councils* and *municipal corporations*. Urban poverty alleviation, public health, social development and safeguarding the interests of weaker sections of urban society are some of the essential functions that they perform. Therefore, the capacity enhancement and carving out an appropriate role for municipal leaders and a more central role of District Planning Committees would help build a wider coalition in urban centres to deal with issues of stigma and discrimination and also ensure economic self sufficiency of CLHIV and their families. As suggested by a Self Help Group from Imphal West-

“... IGP na chingba HIV positive oiba missing-gee makhoigi eemung manung-gee leiba darker oi...” (There is a need of IGP for PLHIV and their families).

It is known that urban centres have various interest groups, associations, professional bodies and citizen collectives. These groups can also help in the fight against stigma and discrimination. Similarly, a wider coalition of Non-Government Organisations (NGOs), Voluntary Organisations (VOs) and Civil Society Organisations (CSO) can be created to counter the tide of societal stigma.

Tackling Infrastructural Issues

Since urbanisation in India is happening at a fast pace, prognostic and treatment services require a stronger urban-centric response in terms of decentralised services and support. With growing urbanisation, increasing the size and scope of prognostic and treatment facilities becomes a necessity.

One of the major barriers highlighted by both the community and service providers is the long distance to be travelled to reach the ART centres. As suggested by respondents from SHG in Imphal West -

“...HIV khaki nate, hospitalda chatke hairadi, rikshaw tonglaga chatpa tabani, busti imphal manungi anakpa mafamsingi chenbadi natabanina, mi-kharadi gari mathaang mathaang tonglaga chatpasu yaoribani. Aduda matam lina mangba jatni. Bus service sina khara fadana imphal manungi oiba hospitalsing youba sarkargibu oiro lanaibu oiro bus chenba ngamladi fani...” (It is not only the HIV positive people but other people also who go by rickshaw, as there is no public bus service within Imphal for commuting to nearby places. One has to catch one vehicle after another for reaching one's destination. Therefore, it will be good if there are bus services either operated by government or private agency within Imphal for travelling to different places, especially to the hospital).

Increasing the number of ART centres or Link ART centres (LAC) at various strategic locations across large metropolitan cities especially in the outlying areas having poor connectivity to the rest of the city can solve this problem to a great extent. In situations where new ART centres can not be opened but the potential load is high, it is advisable to establish LAC which can serve as satellite centres to the main ART centres. These LAC supported with adequate staff could be established at the sub district level in small and medium size towns 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 in providing all essential services like PPTCT for ANC, HIV testing, follow-ups, counselling, CD4 tests and delivery kits for emergency deliveries etc. 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 may refer the infected cases directly to the CCC. This will help in reducing the drop-out rate and also sharing the high load presently experienced at the government facilities.

Effecting Public Private Partnership (PPP)

A well planned and cost effective PPP model can serve as an essential tool to broaden the response and also reduce the load of government health facilities at the districts and sub district levels. This means involvement of the private sector in such a manner wherein 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.

Comprehensive Care and Support Services

The socio-economic conditions of CLHIV and their families residing especially in urban slums and peri-urban areas calls for creating enabling conditions that can help them access government treatment services easily. Travel allowances or free bus passes and even doing away with the registration fee of Rs. 5 per patient at the ART centre can be one such small step that would help BPL families to access treatment.

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

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

Expanding Scope 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 with respect to 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 families to bring WLHIV to ART centre periodically.

It is an opportune time that critically important diagnostic services like DNA, PCR 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.

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.

It is a common critique at local level 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 systems and processes in place in order to ensure an improved supply chain. Related to this is 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 to 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 co-infection, in addition to the follow-up of adults. Counsellors should follow-up children on OI so that when records are generated on treatment of children for OI, early identification of CLHIV can be done through the data so generated.

Staffing and Capacity Augmentation

Strengthening of all operational facilities and providing a comprehensive package of services under one roof is a strong felt need. This includes counselling, HIV testing, PPTCT, ART, follow-up and adherence in the same health facility to enhance the accessibility of CLHIV and families. However, strengthening the infrastructure would mean little unless issues of staff capacities are dealt with.

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. As mentioned by a HCW -

“Angang counselling toubagi fajana training fanglaba mee leifam thok-ee...” (There is need for people who are well trained on paediatric counselling).

In fact, the entire staff at 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 and courses so as to keep them updated with the latest best practices on paediatric ART.

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.

Integration of 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 be of much benefit to the CLHIV. In the event of migration as well, there would be no change in protocol and consequently reduced risk of drug resistance to the children.

Improving Service Orientation and Responsiveness at ART Centres

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

Additional drug dispensing counters with specific earmarked counters for CLHIV can be provisioned, given the CLHIV load at these centres. Rest and recreation are two important criteria in improving services at ART centres. Rest-cum-recreation rooms for children and their parents would be a strong pull for children who are weak, debilitated and/or sick.

School going children and sole breadwinners 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 exclusively for children on Sundays would be an additional facility and enable a hassle free access to ART by CLHIV.

School going children and sole breadwinners 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.

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 centres has to be dynamic in nature. All child-focussed 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 children 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 health care providers while dealing with the service users. All these changes would require influencing the decision makers at appropriate levels.

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.

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.

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, paediatric AIDS initiative was launched in November 2006 after it was realised that the number of children getting ART was much lower than the number affected by HIV and AIDS.

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.

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.

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A global partnership:

International HIV/AIDS Alliance

Supporting community action on AIDS in developing countries

For more details, please write to:

India HIV/AIDS Alliance

Third Floor, Kushal House

39 Nehru Place

New Delhi 110019, India

Tel: +91 11 41633081

Fax: +91 11 41633085

E-mail: panand@allianceindia.org

Website: www.aidsalliance.org

SETU, Virtual Resource Centre – www.aidsallianceindia.net