

## EXECUTIVE SUMMARY

HIV/AIDS has emerged as probably the most complex socio-economic health problem across the globe over last two decades with its peaks in 1990's. The overall number of people living with HIV has increased as a result of ongoing new infections and also the improvement in longevity due to beneficial impact of ART. However the global percentage of people living with HIV appears to be stabilizing since year 2000 though the stabilization of global epidemic is taking place at an unacceptably high level with about estimated 33 million people living globally with HIV in 2007. The annual number of new infections has declined from 3 million in 2001 to 2.7 million in 2007.

Out of these, children under age 15 who got infected with HIV in, 2007 were estimated to be 370,000. Though the annual number of new HIV infections among the children worldwide has declined due to the expansion of PPTCT program, the number of children below 15 years has increased from 1.6 million (2001) to 2 million (2007).

In India the HIV sentinel survey (2007) has portrayed a concentrated epidemic in India with a high prevalence amongst the high risk groups and low prevalence in antenatal attendees. In fact, except for Andhra Pradesh which has 1% prevalence rate, all other states have recorded less than one percent prevalence in ANC attendees. It is estimated that there are 2.31 million people living with HIV /AIDS in India in 2007 with estimated adult HIV prevalence of 0.34% (0.25% -0.43%).

To control the emerging situation ART have been made available for almost a decade. However its use has been irregular, erratic and not based on any structured pattern. As a result the ARV treatment could reach a very few beneficiaries thus denying in the global community benefit which could be drawn through a systematic approach. Keeping this view, WHO declared "lack of access of Antiretroviral treatment for HIV/AIDS" a global public health emergency in September, 2003. An emergency plan popularly known as "3 by 5 initiative" was launched with an aim to cover 3 million people by the end of 2005 as to meet the MDG's.

The Government of India launched free ART program on 1st April 2004. The program has been scaled up in a phased manner and it has been planned that free ART will be provided to 200,000 patients by 2011 in 250 centers across the country. Though the program was launched in 2004 it largely remained confined to the adult PLHA's with very little pediatric focus. The Indian pediatric AIDS initiative was launched in November 2006 after it was realized that there is a great disparity between the number of children suffering with HIV/AIDS and the number receiving ART.

The objective was to maximize the access to ART to the pediatric age group, which remain limited so far. As on September 2008, only 12116 pediatric cases were on ART out of total 177808 cases. A cumulative number of pediatric cases ever started on ART was 15714 (6.17%)

out of total number of 245515. With total cumulative pediatric patients registered in HIV care being 42106, only 37% of the total registered pediatric cases could access ART in the country (NACO 2008). Keeping the above factors in view and to strengthen care and support services for children affected and infected with HIV/AIDS, CHAHA Project was launched under the Global Fund Round by NACO. As per the strategic direction (SD-4) of CHAHA project (Information system and Operational Research) a study on "Identifying barriers to sustainable access of children to ART centers and seeking solutions to address these barriers" has been taken up by India HIV/AIDS Alliance. Astron Hospital and Healthcare Consultants are honoured to be the part of the study, which has been specifically designed to study the barriers to access ART centers by CLHAs both in urban and rural context. The state of Maharashtra and Manipur were selected to include cross section of socio- cultural and economic diversity. In each state one urban district and one rural district was picked up so that a highly representative cross data from these divergent populations could be taken to reach conclusive information, which can become representative of these states. The present report deals with the issues brought out in the urban sector and for that purpose Mumbai District in Maharashtra and Imphal West District in Manipur were taken up for study.

The study strategy was decided by a core team of experts from Maulana Azad Medical College, New Delhi, Ram Manohar Lohia Hospital, New Delhi and Astron in consultation with experts from India HIV/AIDS Alliance. An extensive training of the research team on the research tools and methodologies was conducted before initiation of the field study. The study has been conducted through facility and community level survey covering beneficiaries (CLHAs, HIV positive women and Men and CAAs) and other stakeholders. In- depth interviews and FGDs were conducted with target respondents and stakeholders to collect the required information for further analysis keeping in view the main objective of this study. Keeping this objective as the main focus, the facilities, line staff and some of the stake holders were interviewed through structured schedules to know their views about possible barriers based upon their experiences and interaction with the beneficiaries.

Though a wide range of issues were brought out but there appear to be some commonalities which constitute the basis for many other barriers to emerge. Based on the issues, the suggestions from various stake holders and beneficiaries have been recorded and analyzed so that these could constitute the basis for evidence based, strategic and child focus interventions to minimize the barriers to access pediatric ART services in urban scenario.

Stigma and resulting discrimination remains a major issue in all societies though the stigmatous attitude in urban society is much less as compared to rural areas. Still stigma remains an important factor impacting the over all interaction of CLHAs and PLHAs within the family, community, friends, school and even amongst health care service providers. In view of better educational and information empowerment of urbanised society, self stigma has been observed as the biggest contributing factor rather than real stigma which HIV positives have to face in rural sectors. In many cases this self stigma and apprehensions of resulting

discrimination (which in reality may be minimal or non-existent) leads to non-disclosure of the HIV positive status of the child and thus keeping the child away from any kind of interventions. A focused effort is needed to overcome this issue at all levels so that IEC programmes address this barrier in the urbanised population. Community leaders like MLAs, members of the Municipal Corporations, religious gurus, teachers and even children themselves can become biggest change agents if sensitised properly to the cause. Urban child-focused IEC strategy and media planning which at present is missing could be another factor that needs to be addressed. It has been observed that in spite of many campaigns a vast majority of urban population is still unaware of availability of paediatric ART services and of the fact that such services are being provided free of charge by the Government Centers. The power and popularity of electronic media and innovative technologies like video games, cartoon books, video spots and radio jingles on popular channels frequently visited by adolescents and children and other similar media can be great sources of information to urban children. Integrating school teachers and authorities with the ART program can help breaking many barriers.

The access to ART Centers gets constrained in a large way due to many socio-economic factors. Though the argument that the ART services are provided free, holds good but the fact is that the

family has to spend large amounts of money on travel, testing facilities and for treatment of Opportunistic Infections, for those which ART centre may not be providing for. In addition logistical problems and high cost of living in the urban areas complicate the matter. Though job opportunities in the urban areas are better, still economic constraints play a major role because of the fact that PLHAs tend to lose their jobs, the moment the employers come to know about their positive status. Innovative methods to bring ART to doorsteps through creation of more Link Centers in all the urban areas or making ART and testing facilities available through alternate sources of service delivery points, Community Care Centers and Drop-in centers could also help. Linkages with rehabilitative services and some IGP activities specially designed for the urban folks could be a big encouragement. Also the existing support provided to the CLHAs and their families through the donor agencies need to be sustained, adequate and cover a larger target so that all infected and affected children could be covered under the care and support program which at present is only restricted to the provision of a limited support to a specific target in specific areas leading to demotivation of those who are not able to benefit from this. This needs for an advocacy with the donors, NACO and respective SACS.

The factors mentioned above have a common base in the number and location of ART Centers, which are really far and few and located only in the major hospitals, some of the children and care givers have to travel long distances to access them. In many cases it takes few hours of travel on bus and/or local trains before they can reach the centre, due to overcrowding on the roads because of long traffic jams during peak hours. Even though link ART centers are available in a few urban areas but the initial work up of the patients is being done in the main centers for which they have anyway go to these centers. This physical harassment to the already sick children creates a need to have an adult attendant every time they have to go for ART, which further increases the cost of availing services. The travel in crowded buses and local trains is a

night mare by itself and many parents/care givers get discouraged because of this. Taxies are too expensive and many people with limited means can not afford the same. The single or double orphans have peculiar problems of finding an attendant, who can afford time and money and is ready to go through the ordeal to take them to ART centres and have the patience to get them treated on regular basis after taking time out of their usually busy urban routine. This creates a complex situation that prevents these CLHAs to reach ART Centers.

In the urban areas even if the ART centers are available (eg Mumbai), still the children find it difficult to access services due to the high patient load and vast catchment area to which an individual center caters to. This results in overcrowding and resulting management issues.

Though the ART Centers in the urban areas are adequately staffed as per the authorised manpower, but have important issues in their empowerment to deal with the paediatric patients. The specialist paediatric services are generally not available at the centre and children needing such services are required to go to the paediatric departments of the parent hospitals thus causing harassment to CLHAs which acts as big demotivator. The child has to further bear the brunt of the ego problems of the implementers, planners and administrative heads. Even at the centres, there are no proper waiting areas or separate queues for children and the hygienic conditions remain pathetic. There are no child centered activities at the centre which could keep the CLHAs occupied till they are waiting to avail the facilities. To complicate the matter further, the patients are required to visit multiple locations in the hospital for different services like registration, counseling, testing, drug dispensing and consultation of doctor in the ART center. The children and parents/caregivers get totally lost in the crowds in the big hospitals in which the ART Centers are presently located with poor directions and this demotivates them some times. The centres should be revamped to make them patient friendly with special attention to paediatric services. Advocacy with the state governments for making adequate provisions of transport to the convenience of the children and their care givers and parents is required. Even within the hospitals lack of integration within various departments and specialists acts as a big deterrent. This issue needs to be addressed as HIV/AIDS programme needs an ownership from all stake holders and service providers and it should not be seen just as a NACO or SACS activity. A better mechanism for monitoring of the ART Centers and related departments is needed to maximize their reach to the community in an efficient and synergistic manner.

The attitude and capability of health care providers has a lot to do with success of ART Centers. They need to ensure that there is no stigmatous or discriminatory act perceived from their services. It has been observed that child focus is almost missing as the services are largely adult centric at present. Training of doctors, paramedics and particularly counselors in pediatric orientation, communication and counseling skills in addition to training them on dealing with children especially adolescents who are already under the stress of their growing up issues and also are being raised in an urban environment where they are exposed to a lot of luring and vulnerable activities, is a definite need if pediatric ART is to be encouraged.

The policy makers too need to ensure that there is an integration of all programmes and services which impact deliverance of HIV/AIDS related activities. Thus EDUCATION, ICDS, RCH, PPTCT, VCTC, CCC, TB and ART Centers need to function hand in glove to reach the common objectives embedded in their programs. As a part of this activity, the existing grass root workforce (ANMs/

AWWs) available under the Government machinery needs to be adequately utilized. The individualistic approach tends to create more confusion, more so in the minds of field level workers and NGOs active at the ground level. These grass root workers and NGOs constitute the nucleus for success because of their better reach to the community, better understanding of local issues and better level of rapport and communication so needs to be empowered for an effective output of the program. A formal involvement of the private sector in the pediatric HIV program will improve the required coverage and delivery of standardized treatment which at present is erratic and self prescribed regimens. Also the service providers providing alternate system of medicine which also diverts a lot of these patients due to their ignorance needs to be sensitized for referral to appropriate centers.

*Thus, the urban population, though relatively literate, still lack adequate information thus making them prone to stigma and discrimination with reluctance to declare their HIV positive status because of a self created stigmatous attitude. Inadequate financial resources coupled with long distances from ART centre, crowded transport system with high traveling time and costs involved to reach ART centre and indifferent attitude of the care providers, community and peers tends to keep PLHA's and CLHA's away from the ART centers. With hardly any effort in enabling the ART staff on child focused management strategies, the CLHAs get disillusioned and discouraged to visit the ART centre on regular basis. An innovative, evidence based, practical, time bound action plan is required to be devised to address these issues to overcome the barriers to access of children to ART services even in the urban environment.*