

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 2.1 million (2001) to 2.7 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 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 ARV 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 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 6 by NACO. As per the strategic direction (SD-4) of CHAHA project (Information system and Operational Research) a study on identifying barriers has been taken up by India HIV-AIDS Alliance. Astron Hospital and Healthcare Consultants are honored 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 rural sector and for that purpose Sangli District in Maharashtra and Ukhrul 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 to collect the required information for further analysis keeping in view the main objective of this study which is to determine the barriers towards access to pediatric ART. 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 rural scenario.

In the rural community, stigma and resulting discrimination at all levels came up as the major issue. Stigmatous attitude is observed within the family, community, friends, school and even amongst health care service providers. This kind of discriminatory attitude discourages young children and their parents to access the ART Centers. In many cases this leads to non disclosure of the HIV positive status of the child and thus keeping the child away from any kind of interventions. A focussed effort is needed to create awareness at all levels to address to these

issues in rural scenario as illiteracy, lack of awareness and limited access to all IEC programmes become associated barriers. Community leaders like PRI members, religious gurus, teachers and even children themselves can become biggest change agents if sensitised properly to the cause. The rural and child focussed IEC strategy and media planning could be other factors which need to be addressed. This would also help in over coming the gross lack of awareness about paediatric ARV services in the rural population. In fact a vast majority of rural population is unaware of availability of such and of the fact that such services are being provided free of charge by the Government Centers. 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 which ART centre may not be providing for. In addition logistical problems and costs complicate the matter. Most of the rural folks are daily wagers and have to loose their daily earnings to access these services, so it becomes a dual issue of loss of earnings and expenses on accessing ART. This results in to reluctance and avoidance in getting regular treatment for children. Innovative methods to bring ART to doorsteps through creation of Link Centers or making ART and testing facilities available through Community Care Centers could help. Linkages with rehabilitative services and some IGP activities specially designed for the rural folks could be a big encouragement.

The factors mentioned above have a common base in the number and location of ART Centers, which are really far and few. With one centre in each district and that too located in the district headquarters, some of the villagers have to travel long distances to access them. In many cases it takes 3 – 7 hours of travel on foot and bus before they can reach the centre. This physical harassment to already sick people creates a need to have an adult attendant every time they have to go for ART, which further increases the cost of availing services. Poor and erratic bus services coupled with bad condition of roads and hilly terrain add on to their difficulties. This makes the rural population prone to missing on ART or they end up approaching some quack, faith healer or a local physician, who may initiate an unscientific or non standardised protocol, which offers an erratic solution to the problem. The local physician does not refer the patient further due to his selfish interest. This creates a complex situation that prevents these CLHAs to reach ART Centers.

With the ART Centers being so few, their catchment areas are very vast, sometimes covering places up to 150 Kilometers from the centre. This results in to overcrowding and resulting management issues. Most of the Centers are understaffed when compared with the patient load. The specialist services are not available. The timings are not properly followed and hygienic conditions below standards. There are no proper waiting areas or separate queues for children. 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 coming from villages get totally lost in the crowds in the big hospitals in which the ART Centers are presently located with poor directions and some times get demotivated, particularly, if they are not able to get required services even after going through so much of harassment and expense. Creation of more strategically located ART Centers and paying special attention to infrastructural needs of existing Centers to make them patient friendly with special attention to paediatric services can be of great help. Advocacy with the state governments for making adequate provisions of transport based on 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 and counseling skills 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, NRHM, RCH, PPTCT, VCTC, CCC, TB and ART Centers need to function hand in glove to reach the common objectives embedded in their programmes. 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 in the rural scenario, 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.

Thus, high levels of illiteracy, lack of awareness, lack of financial resources and low income generating opportunities, high level of stigma and discrimination resulting from social beliefs, low health seeking behaviour compounded by long distances from ART centre, an unfavorable transport system with high traveling time and cost involved to reach ART centre and indifferent attitude of the care providers, community and peers tends to keep PLHA's and CHLA's away from the ART centers. Many other non patient friendly factors add to the problem. An innovative

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.