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Breaking Barriers:

Facilitating HIV Testing and Disclosure for Children and Adolescents

Indian and Global Scenario

According to the estimates of National AIDS Control Organisation (NACO), 33,000 newborns contract Human Immunodeficiency Virus (HIV) every year from positive mothers. Over 50% of these children die within two years of birth while 80% of them die within five years. Children living with HIV (CLHIV) are susceptible to far greater chances of illness and death, unless they can successfully be provided with treatment just as adults. However, deterioration in health of children is faster compared to adults owing to the fact that a large number of infants succumb to HIV within one year of being infected. Unfortunately, vast majority of children who could benefit from treatment—an estimated 90%—are not receiving it (UNAIDS/WHO, 2006 June, Progress in Scaling Up Access to HIV Treatment in Low and Middle-Income Countries). Worldwide,

everyday there are an estimated 1500 new infections in children less than 15 years of age, more than 90% of them occurring in the developing world and mostly through parent-to-child transmission. Global trends suggest that infants living with HIV frequently present with clinical symptoms in the first year of life. By one year of age, an estimated one-third of HIV positive infants will have died, and about half by two years of age. If a CLHIV is only identified clinically once he/she is ill, it may be too late for Anti-Retroviral Treatment (ART) to be effective. The fact remains that more often than not, HIV in children is diagnosed quite late. Delay in testing children for HIV prevents them from timely medical care and treatment.

Challenges to Testing of Children

There are many significant challenges in testing children for

HIV. Non-availability of Polymerase Chain Reaction (PCR) test and other specialised techniques in testing children below 18 months is a major deterrent. The stigma surrounding HIV/AIDS plays a big role in children's parents/caregivers' unwillingness to take them for an HIV test, even if they know that there is a risk. For a mother who has not yet been tested for HIV, an HIV positive test result of her child is likely to disclose her own status to herself as well, and the fear of finding this prevents her from seeking testing of the child. Notwithstanding this, more often, a child is tested for HIV only after the mother has been tested before and in some stray cases the other way round.

Inaccessibility of healthcare centres that provide testing is another problem. A mother may have to travel long distances to reach the nearest health service that can test

her child. High travel costs and time incurred in such situations may pose a challenge for parents in testing of their children. Also, the timings of Integrated Counselling and Testing Centre (ICTC), quality of services and receptivity of the staff are additional problems faced.

Challenges to Disclosure of HIV Status to Children

Once tested positive, disclosure of HIV status to the child also poses a significant challenge. Many psychosocial barriers that inhibit disclosure to children include – negative emotions that the child may undergo, child's age and consequent inability to comprehend the situation, parents' inability to answer the question about the child's survival duration, hurdles in future prospects like marriage and employment opportunities, fear of stigma and discrimination, social and economic insecurities, parental guilt, and parents' denial of or difficulty in confronting their own illness. It is not easy to explain or impart coping skills to children in dealing with the various manifestations of stigma, adherence to life long treatment, battling the illness, and end-of-life issues.

Age Group-wise Barriers

Testing and disclosure pose various challenges differently to different age groups of children. Testing for children in 0-6 age group is more technology driven (DNA-PCR for

children between 0-18 months) and the test is crucial in reducing the mortality and morbidity among children in this age group. In this case, further challenges arise out of insensitivity to children's needs at ICTC, issue of confidentiality and the fears emanating from this which prevent parents from getting their children tested. For those among 7-14 age group, insensitivity of ICTC staff and lack of confidentiality is a constant challenge. Issues of appropriate disclosure, psychosocial problems, and a child's difficulties in coping with such situations, appear in this age group. In dealing with adolescents (15-18 years), lack of access to testing centres and that of right information by the centre are the emerging issues. They are often deprived of timely and reliable information about needful testing, disclosure, nutrition, and treatment that largely shape an adolescent's response to his/her health.

Additionally, as true for both the other age groups, confidentiality and sensitivity are no less problematic areas as this specific age group is

tormented by multiple pressures of growing at various levels.

Field Reality

The CHAHA programme¹ is working closely with different stakeholders and Government Ministries to find ways to help keep children with their parents or extended families. A network of significant number of Outreach Workers (ORWs) identifies affected children and their families and apart from providing direct services and linkages, motivates them to get their children tested. Testing the child for HIV is the most crucial step in linking them to medical and non-medical services to ensure quality of life and longevity. The dedicated counsellors within CHAHA in all intervention sites make efforts in addressing psychosocial issues which also include the possible consequences of disclosure.

Although field realities reveal that some efforts are being made to locally deal with the vexed issues surrounding testing and disclosure, however, problems run deep and wide.

SHAHID is a six year old boy from Andhra Pradesh and his parents are HIV positive.

He has three sisters; the eldest one is married. His father Muhammad Aariz, a tailor by profession, tested positive in 2005 in a government hospital. Prior to this, he spent around Rs. 40,000 on tests and check-ups. Later his wife was also tested positive.

He is currently on ART, and spends Rs. 50 every time he goes for ART. He feels that facilities in the hospital are not adequate as he has to purchase medicines for Opportunistic Infections from outside.

Since Aariz and his wife were accompanied by their eldest daughter and her husband for testing, both of them know about their HIV status. The other children including Shahid, have no idea about it. None of the children have been tested as the mother fears they may be positive too and it will be difficult for her to accept it. The father, though, has an intention of getting them tested.

¹ As a civil society Principle Recipient, India HIV/AIDS Alliance, along with a consortium of 9 Sub-Recipient organisations implements CHAHA, the expanded child-centred home and community-based care and support programme in line with the strategic priorities of NACP-III, with funding support from the Round 6 of Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM). The programme is being implemented in the states of Andhra Pradesh, Tamil Nadu, Maharashtra, and Manipur.

Community voices from CHAHA confirm that parents hesitate in getting their children tested simply because of the fear of the children's status turning out to be positive. Dealing with the emotional issues of adolescents poses a new set of challenges. Most often, children are not aware of the status of their parents. Sometimes, children suspect some health issues with parents but are confused and frustrated. In some cases, they feel betrayed as they think the parents do not trust them. Children, being unaware of the cause, feel rejected when relatives and neighbours discriminate against them. Parents fear, or more often, are at a loss to understand as to how to disclose the status to their children. To complicate things further, help is not available for children to cope with the information when their status or their parents' status is disclosed to them.

It is understood that the challenges pertaining to testing and disclosure for children and adolescents, will have implications in terms of improving the health seeking behaviour of families. CHAHA seeks to create a conducive, non-stigmatised and supportive environment for children and families. However, issues related to testing and disclosure, if not adequately addressed will lead to undoing of some of the efforts being made under the programme, especially in relation to support being provided towards their psychosocial well-being. It is also known that CHAHA seeks to deliver direct and indirect services to children and families in home and community settings. Therefore, wider community problems emanating from testing and disclosure can and do

lead to reduced receptivity of parents/caregivers (in the case of younger children) and adolescents, to receive or access services from civil society organisations (CSOs) as well as from the government.

Study Description

An Operations Research was conducted by India HIV/AIDS Alliance (or, Alliance India) to understand the current barriers and challenges of testing and disclosure for children and adolescents, with the underlying objective of providing possible short to medium term solutions, thereby strengthening the CHAHA programme as well as others working to provide child-centric care and support. This was to make synergistic links between practice and policy. The study was conducted in Hyderabad, Nalgonda and Krishna districts in Andhra Pradesh, and Bishnupur, Chandel and Imphal East in Manipur.

The research was exploratory in nature, and used a mix of qualitative and quantitative methods, with a tilt towards the former. Key Informant Interview (KII), In-Depth Interview (IDI), Focus Group Discussion (FGD) and case study analysis were the qualitative tools used. The age groups covered for the study were 0-6, 7-14 and 15-18 years, with equal representation of both males and females. The key respondents were: (i) parents of children in 0-6 and 7-14 age groups who have been referred for HIV testing; and (ii) adolescent boys and girls in 15-18 age group. Community representatives like CLHIV network



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The key findings of the Operations Research highlighted several issues, particularly in relation to disclosure of HIV status to children and adolescents, while HIV testing did not appear to be a problem with any specific bearings on the age of the children to be tested. In fact, it was observed that in the majority of cases, testing was conducted without any problem. The issue of testing has to be considered more from the point of better service delivery that can be accessed by all and provide the required advocacy and counselling, specific to families with children from different age groups. One overwhelming challenge for communities and CSOs is to design care and support interventions that include effective ways to address the issues, largely psychological and social, related to disclosure which affect the lives of children living with and affected by HIV and their families.

members, village school teachers, religious leaders and village leaders, and service providers such as ICTC staff, field health functionaries, ORWs and non-governmental organisation (NGO) representatives, were also part of the respondents. A total sample size of 223 in Andhra Pradesh and 230 in Manipur were interviewed using the survey method as a quantitative tool. In both the states together, a total of 42 FGDs, 42 IDIs, 6 KIIs and 18 case studies were conducted.

Recommen

Actions for Testing of Children and Adolescents

Modify healthcare service delivery

- Expand the number of testing centres and days of functioning to facilitate timely testing of children. The number of ICTCs in each district can be worked out based on its population and size.
- Fill gaps in infrastructure, equipment and human resource at ICTC, especially in places such as the hilly district of Chandel in Manipur.
- Work out feasible and flexible timings of testing centres for parents and children (many respondents strongly favoured the idea of increasing the number of days that the testing centres function to at least five days a week).
- Monitor the scheduled timings of the ICTC staff in terms of presence and punctuality.



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Improve diagnostic services for children below 18 months

- Create awareness about the DNA-PCR technique to generate informed demand from communities and healthcare providers.
- Alternatively, adopt the DBS method (Dried Blood Sample) for children to enable Early

Identification and Diagnosis (EID).

Action for Disclosure to Children and Adolescents

Capacity building and training

- Scale up knowledge and capacity building at different levels—parents, healthcare providers, counsellors and outreach workers from NGOs; develop training tools with guidelines for each, with practical guidance notes on disclosure to children.
- Train counsellors in appropriate ways of counselling about disclosure to help parents handle the process of disclosure, about the right way and time to disclose, and how to deal with issues arising out of the process.
- Train counsellors in child-centric counselling as a specialised counselling technique.
- Strengthen the knowledge of counsellors and healthcare

Recommendations

providers on issues related to sex and sexuality and sexual and reproductive health, to deal with young adolescents, especially young girls.

- Include various aspects of disclosure while designing trainings for counsellors and ORW in care and support programmes.

Actions for both, Testing of and Disclosure to Children and Adolescents

Establish improved and focused counselling services

- Use services of professionally skilled counsellors to address the barriers of testing and disclosure to children and adolescents.
- Re-allocate budget in commensuration with qualifications and experience of professionally skilled counsellors for improved counselling services.
- Use child-centred counselling technique including play

therapy, storytelling, drama, dance/movement, drawing and art that could help not only the process of disclosure to children, but also enable them to express emotions and overcome fears during and after the process of disclosure.

- Regularly organise refresher training courses for counsellors in tune with the needs of different age groups of children. The trainings should include elements such as – assessing maturity level of children to understand the benefits and risks of testing and for providing consent, how to inform a child of his/her HIV status, talking to children about death and bereavement, helping children cope with emotions and challenges when they know their parents' HIV status, and helping them make choices and decisions that will prolong and improve the quality of their life.
- Scale up youth-friendly testing and counselling facilities, and integrate with adolescent reproductive health programmes.

- Develop systematic plan to aid parents in disclosure, including post-disclosure issues. Counselling modules for parents should include – coming to terms with guilt, overcoming fear, and dealing with issues during and after the process of disclosure.

- Focus on positive attitude and positive living for parents and children. Firstly, to help parents overcome the fear of death and condition of their children thereafter. Secondly, to prevent children from acquiring negative attitude during/after the process of disclosure.

Strengthen IEC coverage

- Create awareness through IEC materials
- Strengthen its coverage to intervention areas
- Facilitate its special observation time periodically
- Intensify its use by ORWs, counsellors and in support groups and training sessions.

Understanding Barriers and Challenges to HIV Testing and Disclosure for Children and Adolescents

Key Findings

Factors Preventing HIV Testing

Fear of stigma and discrimination

- Lurking fear of associated stigma
- Incidences of discrimination in neighbourhood
- Probability of hurdles in marriage especially for girl children

Financial constraints

- Fear of wage loss
- Travel to testing centre
- Time and opportunity cost incurred

Fear of disclosure in the locality

Issues of maintaining confidentiality and the fears emanating from this deter few parents of children in 0-6 age group, from taking their children for testing

Lack of awareness about HIV and AIDS

- Lack of awareness on the part of parents makes it difficult for them to explain to their children in 7-14 age group (almost all children were not told the reason for taking them for an HIV test)
- Lack of awareness on the part of healthcare providers

Low motivation level

- Parents' inability to overcome shock/grief of their own positive status
- Fear of their children testing positive and callousness in approach
- Financial expenses involved
- Disillusionment

Attitudinal issues of service providers

- Unfriendly hospital environment and procedures
- Discrimination by service providers
- Overburden of work on counsellors
- Lack of specialised trainings for counsellors

Issues Related to Disclosure

Challenges and dilemmas

- Children in 0-6 age group are too young to comprehend
- Guilt and mental turmoil for parents
- Dilemma, at the first place, to decide whether to disclose or not, and the right age of disclosure
- Parents' inability to deal with issues arising during and after the process of disclosure
- Lack of counselling and guidance by ICTC on disclosure

Channels of disclosure

- As informed by most, the order of preference for channels of disclosure are – parents, NGO, and ICTC staff
- Parents are best placed than others to assess the opportune time, psychological status, and temperament of their children
- NGO staff are seen as trustworthy and the communities look forward to their support
- Lack of focus on post-test counselling, especially about disclosure of status, makes a significant difference in the way children come to know about their own and/or their parents' HIV status
- Overhearing and suspicion in some cases

Immediate psychosocial effect of disclosure

- Pain: for parents' health condition, parents' limitation to earn, children's need to take up economic activity, limitations in social life
- Fear: strong warning from parents to keep the information confidential, fear of hostility from society
- Worry: financial insecurity, sustainability after parents' loss, losing rented house, denial in marital alliance especially for girls
- Helplessness: parents' health condition and the extreme thought of their death, taking up family responsibilities, discontinuation in education to earn a livelihood

Key Messages

- Testing and disclosure are closely correlated – the inability or unwillingness to confront the issue of the parents' own HIV status with his or her children is an important barrier to children's testing. Such correlation would have strong implications for counselling policies and merit confirmation on a larger scale.
- Counselling services within the continuum of care and support to children and families need to be strengthened to respond to the challenges of testing and disclosure; clear and unambiguous guidelines supported by improved training of counsellors is important.
- Government's HIV testing facilities hold the key; more testing centres coupled with expanded and flexible timings would help deal with institutional barriers.
- Targeted Information, Education and Communication (IEC) using appropriate mediums for rural and urban audiences that highlights the centrality of testing and disclosure for children is a sine qua non in the fight against HIV.



ANA, 11, and her mother tested positive in 2003. Her mother was not surprised about the result as her husband took drugs and had died due to prolonged illness. But she felt sorry for her daughter. Both are on ART.

Ana's mother has to cover a long distance (from Chandel to Imphal, Manipur) to get medicines for her daughter and spends Rs. 200 each month for the same. Sometimes she has to spend the night at Imphal. For herself, she gets ART from Chandel Hospital.

Ana's mother did not disclose the HIV status to her daughter for the fear of possible negative impact on her. With passage of time, Ana gained awareness about her condition. She was disappointed with her mother for not taking proper care like avoiding breastfeeding after her birth.

Ana's mother wishes a paediatrician is posted at District Hospital, Chandel so that she can get ART for her daughter from there.

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A global partnership:

International HIV/AIDS Alliance

Supporting community action on AIDS in developing countries

About India HIV/AIDS Alliance

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

The vision of the Alliance is of a world in which people do not die of AIDS. This means a world where communities have brought human immunodeficiency virus (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 and support, and treatment services.

Established in 1999, the India HIV/AIDS Alliance (or Alliance India) comprises a Secretariat in New Delhi, five lead partner organisations (the linking organisations within the global Alliance) and their networks of over 100 community-based NGOs and community-based organisations (CBOs) across Andhra Pradesh, Tamil Nadu, Maharashtra and Delhi states, and a state partner in Manipur.

Alliance India has supported over 120 community-based projects through its NGO and CBO partners to prevent HIV, improve access to HIV treatment, care and support, and lessen the impact of HIV by reducing stigma and discrimination, particularly among the most vulnerable and marginalised communities key to the epidemic—Female Sex Workers (FSWs), Men who have Sex with Men (MSM), Injecting Drug Users (IDUs) and adults and children living with and/or affected by HIV.

Funding from the Global Fund to Fight AIDS, Tuberculosis and Malaria (GFATM) was awarded to Alliance India in 2007, whereby the partnership in India has been broadened to include two new project-based lead partner relationships with two external organisations and their networks of implementing NGO partners.

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